Enhancing Child Development Services for Neurodivergent Children in Waikato:

A Qualitative Study

A thesis

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Abstract

Background: Children with neurodevelopmental disorders often face unmet needs, placing their well-being at risk. Effective healthcare delivery is important to enhance outcomes for these individuals. In New Zealand, limitations in funding and resources, compounded by escalating demand, have led to deficiencies in the provision of Child Development Services (CDS). This has resulted in prolonged waiting lists and children missing out on essential support.

Objective: This project aimed to develop a proposed service delivery model for the Child Development Centre (CDC) in the Waikato district by considering stakeholders' perspectives regarding support for neurodivergent children and ways to adapt service delivery to ensure improved health and social outcomes.

Participants: Stakeholders from health and education sectors, including CDC service users, clinicians, healthcare managers, education professionals, and policy representatives, were recruited using purposive sampling.

Methods: This qualitative project had two phases: The first involved 41 semi-structured interviews inspired by grounded theory principles to uncover current perspectives and improvement ideas. The second phase, guided by co-design principles, featured two focus groups to formulate a service delivery model grounded in participant insights and literature.

Findings: Findings revealed concerns about inadequate support, delayed CDC services, pathway navigation challenges, and inadequate infrastructure. Participants emphasised the need for improved collaboration, increased therapeutic support, age-spanning support, and a community-focused CDC integrated with schools. Findings are visually summarised in a proposed service delivery model.

Conclusion: Enhancing experiences and outcomes for neurodivergent children requires collaborative, integrated efforts across sectors. The proposed service delivery model serves as a tool for guiding systemic changes and policy development.

Keywords: Child Development Services, neurodevelopmental disorders, child disability, service delivery, multi-agency collaboration

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Glossary of Māori words and Abbreviations

Māori words

Aotearoa	New Zealand
Haere mai	Welcome
Hei matau	Fishhook
Kāhui Ako	Community of Learning
Kaitiaki	'Guardian' - Provider of Māori cultural support at Te Whatu Ora Waikato
Kapa haka	A group which performs traditional Māori dancing and chanting
Kura Kaupapa	A primary school where teaching is based on Māori language and culture
Mahi	Work, job, employment
Mana	Prestige, authority, control, power, influence, status, spiritual power
Māori	Indigenous people of New Zealand
Marae	Traditional Māori campus of related areas and buildings
Ngaa Ringa Awhina	Single point of entry for child and adolescent mental health services
Oranga Tamariki	Ministry for Children
Tamariki	Children
Takiwātanga	Term used to represent autism in te reo Māori
Te reo Māori	The Māori language
Te Tiriti o Waitangi	The Treaty of Waitangi
Te Whatu Ora	Health New Zealand - the weaving of wellness
Waka	Canoe, vessel, conveyance
Whakawhanaungatanga	Process of establishing relationships, relating well to others
Whakama	Shame or embarrassment
Whaikaha	Ministry of Disabled People
Whānau	Extended family group

Abbreviations

ACC	Accident Compensation Corporation
ADHD	Attention-deficit/hyperactivity disorder
ASD	Autism spectrum disorder
CAMHS	Child and Adolescent Mental Health Services
CDC	Child Development Centre
CDS	Child Development Services
CGT	Constructivist grounded theory
CHIRP	Child Health Integrated Response Pathway
DCD	Developmental coordination disorder
DHB	District Health Board
DSL	Disability Support Link (needs assessment and service coordination in Waikato)
DSM-V	Diagnostic and Statistical Manual of Mental Disorders (5th edition)
EGL	Enabling Good Lives
ERO	Education Review Office
FASD	Foetal alcohol spectrum disorder
GDD	Global developmental delay
ICAMHS	Infant, Child, and Adolescent Mental Health Services
ID	Intellectual disability
IHC	Group of charities who advocate for the rights, inclusion, and welfare of all people with intellectual disabilities
ILE	Innovative Learning Environment
LSC	Learning Support Coordinator
MOE	Ministry of Education
MOH	Ministry of Health
NZEI	New Zealand Educational Institute (union)
ORS	Ongoing Resourcing Scheme
OT	Occupational therapist
P4C	Partnering for Change (service delivery model)
RTLB	Resource Teachers: Learning and Behaviour
SENCO	Special Education Needs Coordinator
SLD	Specific learning disorder
SLT	Speech and language therapist
VNT	Visiting neurodevelopmental therapist

Chapter 1: Introduction

Imagine a future where New Zealand is a society that embraces inclusivity for disabled individuals, providing them with an equitable chance to pursue their dreams and ambitions. Disabled people would be able to say they live in a society that highly values their lives and continually enhances their full participation. This is the vision of the New Zealand Disability Strategy (Office for Disability Issues, 2016). Neurodevelopmental disorders, many of which are commonly recognised as disabilities, are estimated to affect 3-10% of New Zealand preschool-aged children and worldwide trends suggest that the prevalence of these disorders is rising (Centers for Disease Control and Prevention, 2023, April 04; Cutfield et al., 2019; G. Russell et al., 2022; Zablotsky et al., 2019). Neurodivergent children often experience challenges associated with impairments of social, personal, cognitive, and/or occupational functioning which require the input of services and allied health professionals to support them in meeting their goals and living their best lives (American Psychiatric Association, 2013). The increased demand for support for neurodivergent children coupled with limitations in funding and resources have contributed to inadequacies in the provision of Child Development Services (CDS) in New Zealand. These include service rationing, extensive waiting periods for service users, and unfortunate situations where some children are unable to receive the necessary support to reach their fullest potential (Claridge, 2023). Therefore, it is necessary to investigate alternative approaches to providing CDS in New Zealand to promote better health and social outcomes for neurodivergent children and their families.

Neurodevelopmental disorders encompass a diverse group of conditions that have historically been conceptualised through the perspective that there is only one correct or typical form of neurocognitive functioning and any deviation from this standard is deemed as a deficiency or disorder (Neurodivergent Counselling Services, n.d.; Walker, 2021). Aligned with the ecological systems theory perspective, advocated by Bronfenbrenner and other psychologists (Shelton, 2018), there is a growing trend to move away from the deficit-oriented approach of the medical model. Consequently, the terminology used to describe neurodevelopmental disorders is constantly evolving and is currently shifting towards the concept of the ‘neurodiversity paradigm’ (Walker, 2021). Within this paradigm, the term ‘neurodivergence’ is applied to characterise individuals whose brain functioning deviates from the expected norm. This shift in terminology reflects a broader recognition and acceptance of the diverse range of neurological profiles that exist within the population (Neurodivergent Counselling Services, n.d.).

The extensive impact of neurodivergence on the individual and their family is widely recognised. It is estimated that up to 50% of people with neurodevelopmental disorders will have at least one additional co-occurring disorder (Williams & Lind, 2013). The presence of co-occurring conditions can present additional obstacles to healthcare and education systems and these individuals are at risk for more severe symptoms and poorer outcomes compared to those who have only one diagnosis (Fleming et al., 2020; Thapar et al., 2017; Tonnsen et al., 2016; Totsika et al., 2011). Some challenges associated with neurodevelopmental disorders can persist throughout life and impact learning abilities in both academic and professional settings (American Psychiatric Association, 2013; Anderson et al., 2014; Faraone et al., 2006; Howlin et al., 2004; Magiati et al., 2014; Simon et al., 2009). Furthermore, the ability of neurodivergent individuals to live independently as adults may vary greatly with some individuals required to reside in supported living arrangements (Anderson et al., 2014; Lee et al., 2020).

Neurodivergent children are more likely to experience unmet needs and face more obstacles in participating in activities compared to their non-disabled peers, which can negatively affect their overall well-being (Department of the Prime Minister and Cabinet, 2019a; Te Ihuwaka - Education Evaluation Centre, 2022). Compared to non-disabled peers, disabled children are more likely to want to avoid attending school due to their inability to participate in certain activities, are less likely to engage in social activities at school, and are more susceptible to being targets of bullying (Te Ihuwaka - Education Evaluation Centre, 2022). The impact of neurodivergence on equity in opportunities and resources is an important issue in New Zealand, especially when considering the differences in health outcomes for the Māori community (Craig et al., 2007; Tobias et al., 2009). Māori children experience poorer health outcomes than non-Māori children (Mills et al., 2012) and it has been recognised that to better meet the healthcare needs of neurodivergent Māori children, advancements need to occur in the development of culturally responsive services and assessments that align with Māori cultural values and practices (Bevan-Brown, 2004; Robson & Harris, 2007).

To adequately support neurodivergent children, it is important to find effective ways to provide services and support. Bringing together different systems related to a child’s development, like healthcare and education, can help identify and address their needs. This collaboration can lead to better health outcomes, lower costs, and empower those important in the child’s life to support their well-being (Council on Children with Disabilities, 2005). However, there are limitations and factors that can enable or impede the delivery of multi-agency collaboration in practice (Power et al., 2013; Sloper, 2004). There are ongoing efforts to establish multi-agency approaches to support neurodivergent children that account for identified barriers and facilitators (Arora & Bohnenkamp, 2016; CanChild, 2015; Phoenix et al., 2021; Power et al., 2016).

The literature discusses various collaborative approaches which are currently being implemented. Some key examples include assigning a key worker to support families in navigating complex systems (Bruder et al., 2005; Drennan et al., 2005), an interagency partnership model where a mobile healthcare team provides support in education settings (Bagnato et al., 2004), a collaborative care model that integrates general and behavioural medical practices (American Psychiatric Association and Academy of Psychosomatic Medicine, 2016; Lyon et al., 2016), and a population-based service delivery model which was developed to provide rehabilitation support in schools for children with special needs (CanChild, 2015).

Supporting the needs of neurodivergent children is a complex and widespread challenge on a global scale. The task of devising effective and economical approaches that offer these children the essential services and support they require is an ongoing and evolving process (CanChild, 2015; Council on Children with Disabilities, 2005; Drennan et al., 2005; Lyon et al., 2016; Phoenix et al., 2021). The implementation of collaborative efforts between various agencies such as healthcare and education is presented as a potential solution (Mirfin-Veitch et al., 2020; Power & Bradley-Klug, 2013; Sloper, 1999), however, there is limited research on the consistency, generalisability, and long-term outcomes of models aiming to improve collaboration between child healthcare and education (CanChild, 2015; Michel et al., 2018; Phoenix et al., 2021; Power et al., 2013; Talbott et al., 2021).

The context of this project is set within the unique setting of New Zealand. Within New Zealand, Child Development Services (CDS) are delivered nationally through 31 contracted providers. These services comprise of allied health professionals who provide support for children who face additional challenges in achieving expected developmental milestones, including children who have or are suspected of having, some of the conditions that sit within the neurodevelopmental disorder diagnostic category (Claridge, 2023; Whaikaha, n.d.). Throughout New Zealand, CDS are currently unable to meet the community demand to access allied health support for children and the need to modernise CDS and develop a nationally consistent service model is paramount (Claridge, 2023). The significance of the improvements required to modernise the national delivery of CDS is beyond the scope of the current research, therefore a case study approach is applied in the context of the Child Development Centre (CDC) which is the primary provider of CDS for the Waikato region (Waikato District Health Board, n.d.).

Given that school is a frequently attended environment for children, it is important to understand neurodivergence in the context of the education setting and the impact this can have on the child. In New Zealand, the Ministry of Education (MOE) is the government's lead advisor on the education system, shaping the direction for education agencies and providers, and contributing to the government's goals for education (Ministry of Education, 2021, February 12). The MOE offers various forms of specialised support to schools, such as Resource Teachers: Learning and Behaviour (RTLB) who can assist with learning support (Ministry of Education, 2022, October 13), the School High Health Needs Fund (SHHNF) which helps children with significant health conditions (Ministry of Education, 2021, July 19), and the Ongoing Resourcing Scheme (ORS) which provides specialist support for students with a high level of long-term learning needs (Ministry of Education, 2021, March 30). Although there are several learning support schemes available for children requiring extra educational assistance, a significant number of neurodivergent children do not meet the eligibility criteria, despite their potential to greatly benefit from such support (Ministry of Education, 2019; Mirfin-Veitch et al., 2020; NZEI Te Riu Roa, 2018).

Overall, the current level of support provided for neurodivergent children in New Zealand falls short of adequately addressing the growing need for support in both home and education environments (Claridge, 2023; Mirfin-Veitch et al., 2020). There is a noticeable absence of research on the viewpoints of stakeholders involved in the care of these children regarding the availability and quality of support. Furthermore, there is a lack of research aimed at enhancing the provision of services tailored to the unique requirements of neurodivergent children in New Zealand.

I have both personal and professional motivations for being involved in the current project. I have a longstanding passion for supporting children to achieve their best outcomes, particularly children who are from disadvantaged backgrounds. As an occupational therapist with a clinical background, I value the importance of providing client-centred services that consider the holistic needs of the client and their families. Through my work in healthcare and involvement in diagnosing neurodivergent children, I have developed increased empathy for service users navigating complex healthcare systems and the challenges they face in accessing necessary care. Having observed and heard numerous experiences of families on their diagnostic journeys, I feel strongly about the need to find ways to improve the access to and provision of care for neurodivergent children.

The literature indicates a need to further explore whether collaborative approaches involving multiple agencies are a feasible solution to better support the needs of neurodivergent children or if alternative innovative approaches are proposed. To ensure the development of effective solutions that are applicable in real-life situations and can sufficiently cater to the specific needs of neurodivergent children and their families there is a need to explore the viewpoints of various stakeholders who have various levels of connection to these children.

To address the identified service and research gaps, the current project adopts principles of grounded theory and co-design to develop a proposed service delivery model encompassing an enhanced provision of CDC services. To inform the development of a model that is grounded in stakeholder insights and existing literature, the project seeks to understand the current perspectives of stakeholders regarding the access to and provision of support for neurodivergent children and how the delivery of CDC services could be enhanced to ensure improved health and social outcomes for neurodivergent children. To achieve this, the project is carried out in two phases with the outcomes of the first phase informing the content of the second phase. The first phase involves the completion of semi-structured interviews with key stakeholders to identify current perspectives regarding the access to and provision of support for neurodivergent children and ideas around how service provision of CDS could be enhanced. The second phase consists of two focus groups where the findings generated from the stakeholder interviews and evidence arising from the literature are presented, enabling the focus group participants to inform the development of a service delivery model.

The proposed service delivery model serves as a valuable tool that can be used to support policy processes and decision-making for the design of evidence-based initiatives to improve service delivery and provide consistent care for neurodivergent children and children experiencing developmental differences throughout the entirety of New Zealand.

The overall structure of this thesis is presented as eight chapters. The current and first chapter introduces the context of this thesis, highlights the importance of the current project, provides a brief review of the literature, presents the need for the current research, and summarises the project’s overarching aim.

Chapter two provides a literature review that explores and presents academic publishing and grey literature including government policies and documents. It explains the search process and defines key terms. The literature review is divided into two main parts. The first part discusses explanations of neurodevelopmental disorders and neurodivergence, different theoretical perspectives, and the impacts of neurodivergence. The second part focuses on literature relating to collaborative approaches to supporting neurodivergent children. The chapter discusses the need for enhancing services for neurodivergent children in the context of New Zealand and concludes with the research aims and questions.

Chapter three provides an overview of the research philosophy, design, and strategy, focusing on grounded theory and co-design principles. The chapter also explores the researcher's role and reflexive processes.

Chapter four presents the method for the first phase of the project. This includes a breakdown of the participants representing a range of stakeholder groups including CDC service users, CDC clinicians, frontline education professionals, Te Whatu Ora Waikato managers, principals and deputy principals, and nationwide policy representatives. The chapter discusses the application of principles of grounded theory and the use of semi-structured interviews as the method of data collection. The use of the data collected from the interviews to conduct data analysis is explained.

In chapter five, the results from the first phase of the project are shared. The findings are first presented in relation to each individual participant group and are then presented regarding the findings that were generated across the dataset as a whole.

Chapter six provides an overview of the methods utilised in the second phase of the project. These methods involve the use of focus groups, which are guided by principles of co-design. The chapter also discusses the recruitment of participants and provides details on the processes of data collection and analysis.

Chapter seven presents the results of the second phase of the project, which is divided into the findings from two different focus groups. The chapter concludes with an overview of the overall outcomes from the focus group data, which includes the development and presentation of a proposed service delivery model.

The final chapter of the thesis provides a summary of the main findings and discusses how they relate to existing literature. The findings are discussed and presented in relation to the research questions. The chapter and overall thesis concludes with a discussion on the implications of the findings, the limitations of the project, and suggestions for future research.

Chapter 2: Literature Review

This chapter presents various sources of academic publishing and grey literature, including government policies and documents, related to neurodivergence and service delivery. The search process and definitions for key terms will be outlined. The literature review is divided into two sections, with the first discussing the definitions and descriptions associated with neurodevelopmental disorders and neurodivergence, theoretical perspectives, and the impacts of neurodivergence. The second section focuses on collaborative approaches as a way of meeting the needs of neurodivergent children and their families. This includes consideration of barriers and facilitators of multi-agency collaboration. Examples of collaborative multi-agency approaches for supporting neurodivergent children will be presented. The chapter will also highlight the need for improved services for neurodivergent children in the context of New Zealand and the rationale for the need for the current project. To conclude the chapter, the research objectives and questions will be stated.

2.1 Search Process

To gather information for this project, an electronic literature search using various databases related to healthcare, allied health, mental health, neurodevelopmental disorders, child development, paediatrics, and education was conducted. Some key databases accessed included Cochrane Library, EBSCOhost CINAHL® Ultimate, PsycINFO, Web of Science, PubMed and PubMed Central, ERIC, and Scopus. Searches were also conducted within the WorldCat catalogue. The Connected Papers website was used as a tool to seek additional relevant papers (Connected Papers, n.d.). This integrative literature review draws upon a range of both academic and grey literature, such as governmental reports and policies, including those associated with the Ministries of Health, Education, and Social Development. The study's intersecting components encompass a wide range of existing literature; therefore, in light of its broad scope, the review focuses primarily on literature relevant to the healthcare sector, ensuring a focused exploration of neurodivergence and service delivery through a health-oriented lens.

2.2 Definition of Terms

Allied health: The allied health workforce in New Zealand consists of health professionals who do not belong to the medical, dental, or nursing professions. There are at least 43 professions categorised as allied health (Ministry of Health, 2023, August 16). The allied health professions most relevant to the current project include occupational therapists (OT), psychologists, social workers, physiotherapists, visiting neurodevelopmental therapists (VNT), and speech and language therapists (SLT).

Neurodevelopmental disorders: Neurodevelopmental disorders are multifaceted conditions characterised by impairments in cognition, communication, behaviour and/or motor skills resulting from abnormal brain development (American Psychiatric Association, 2013). The primary neurodevelopmental disorders relevant to the current project include intellectual disability (ID), global developmental delay (GDD), autism spectrum disorder (ASD), attention deficit/hyperactivity disorder (ADHD), specific learning disorder (SLD), and developmental coordination disorder (DCD). Neurodevelopmental disorders will be discussed in further detail within Part 1 of the literature review.

School-age: In New Zealand, education is mandatory for children between the ages of 6 and 16. While most schools allow children to start at the age of 5, some schools prefer to start them as a group at the beginning of each term. Most students continue their education until they are approximately 17 years old. Pre-school age typically refers to children aged 3-5 years. Primary education captures children around the ages of 5-12 years and secondary education includes youth around 13-17 years (Ministry of Education, 2023, September 20). In the context of the current project, ‘school-age’ is used to refer to primary school-aged children.

Stakeholders: This refers to people, groups, or communities who are directly involved or affected by a project, research, or policy and have a vested interest in its process and results (Deverka et al., 2012). The specific stakeholders involved in the current project include CDC service users, CDC clinicians, frontline education professionals, Te Whatu Ora Waikato managers, principals and deputy principals, and nationwide policy representatives from the Ministry of Disabled People (Whaikaha) and the Ministry of Education.

Te Whatu Ora: Te Whatu Ora (Health New Zealand) leads the day-to-day running of the health system across New Zealand, with functions delivered at local, district, regional and national levels. Te Whatu Ora was established in July 2022 to deliver a consistent approach to healthcare across the country. Before the transition to Te Whatu Ora, the health and disability system within New Zealand was managed and delivered by 20 District Health Boards (DHB) representing different regions throughout the country (Te Whatu Ora Health New Zealand, 2023, September 22). While Te Whatu Ora operates as a nationwide healthcare system, it is also possible to specify the region by adding it to the title, for instance, ‘Te Whatu Ora Waikato’.

Therapeutic support: Therapeutic support encompasses a diverse array of therapies intended to enhance functional abilities and promote independence. These supportive measures are designed to aid individuals in various aspects of their daily lives, such as engaging in self-care (bathing, toileting, grooming), navigating their surroundings, socialising, building relationships, and participating in community activities (NDSP plan managers, 2023, January 31).

2.2.1 Contextual Terminology within the Current Project

In reading this thesis, it is important to consider the context behind some of the terminology that the participants and I refer to. In simplistic terms, it is easiest to think of CDS as the provider of ‘child development’ and ‘child disability’ services, however, many participants refer to CDC and/or CDS within this project as ‘child health’ because of the commissioning within the Ministry of Health at the commencement of the current project. It is important to acknowledge that ‘child health’ also holds a different meaning. Some participants use the term ‘child health’ (paediatrics) to more accurately represent ‘child and youth health service specifications’ which encompasses paediatric and primary health care services for children, including children who are medically unwell or present with medical or surgical-related conditions, such as heart conditions, cancer, or asthma (Ministry of Health, 2014; Te Whatu Ora, 2023, April 03). Within the current project, participants also mention ‘child mental health’ which refers to child and adolescent mental health services (CAMHS). Child and adolescent mental health services are for children and adolescents with or suspected of having a mental health and/or alcohol and other drug disorder, which may include conditions such as depression and anxiety and is often the context applied to discussion regarding ADHD.

2.3 Literature Review Part 1: Defining Neurodivergence and Exploring its Impact

The early years of a child’s life are important for their life-long health and development (Levitt & Eagleson, 2018; McDonald & Thorne-Lyman, 2017; Stiles & Jernigan, 2010). The study of child development is dedicated to exploring constancy and change from conception through adolescence. Development is typically separated into four major interacting domains: physical, behavioural, social and emotional, and cognitive. A range of age periods are usually applied when discussing child development: the prenatal period (conception to birth); infancy and toddlerhood (0-2 years); early childhood (2-6 years); middle childhood (6-11 years); and adolescence (11-18 years) (Berk, 2013).

As children grow, they gain more advanced functioning through mastery of new skills. Developmental milestones are a set of age-specific behaviours, skills, or abilities that most children are able to achieve at a certain age range. While some variation is to be expected among individuals, the acquisition of developmental milestones is used as a guideline to assist in observing and monitoring child development (Centers for Disease Control and Prevention, 2021, January 22). If an infant or child does not appear to be reaching, or is significantly delayed in meeting developmental milestones, further assessment may be appropriate (Aylward, 2020; Centers for Disease Control and Prevention, 2021, January 22; Daniel et al., 2009).

A child's attainment of developmental milestones may be affected by the interaction of biological and environmental factors (Empson, 2015). Atypical development is a term used to describe scenarios when development does not follow or is markedly different from the usual pattern (Malim & Birch, 1998). Factors influencing atypical development may include genetics, circumstances during pregnancy, the presence of a specific diagnosis or medical factors, and/or limited opportunity or exposure to helpful resources (Empson, 2015). Early identification of atypical development is beneficial to allow for early intervention, thus minimising the impact of the developmental concern on the child's overall skill development (Daniel et al., 2009). Neurodevelopmental disorders are a group of conditions that are associated with differences in development (American Psychiatric Association, 2013).

2.3.1 Neurodevelopmental Disorders

The term 'neurodevelopmental disorders' refers to a group of conditions, which are marked by impairments of social, personal, cognitive, and/or occupational functioning. Such developmental deficits are usually first identified in early childhood, often before the child starts primary school. Deficits associated with neurodevelopmental disorders range from learning difficulties or control of executive functions to extensive impairments of social skills or intelligence. Such disorders may be mild and manageable with behavioural and educational interventions, or they may be more severe with the affected child and family requiring higher levels of support (American Psychiatric Association, 2013). Neurodevelopmental disorders result in significant personal, physical, psychological, social, and economic costs for individuals, their families and the healthcare system (O'Neill, n.d.; Rogge & Janssen, 2019). Within the American Psychiatric Association’s (2013) Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-V), the neurodevelopmental disorder classification comprises of a range of overarching conditions that incorporate related conditions (see Figure 1).

The neurodevelopmental disorders associated with disability commissioning and commonly assessed for at CDC include ID, GDD, ASD, and DCD. It is unclear why other conditions that are categorised within the neurodevelopmental disorders classification are not considered disabilities and therefore do not receive support or funding within the disability sector. While CDC does not directly assess for ADHD and SLD, CDC clinicians take into consideration whether symptoms associated with these conditions may be contributing to a child's ongoing challenges. These factors are taken into account during the formulation of the diagnostic process and appropriate referrals or recommendations for further evaluation or support are made if necessary.

Due to a limited number of published papers regarding the prevalence of neurodevelopmental disorders in New Zealand children, the specific prevalence is unclear, however from the data that is available, it is estimated that 3-10% of New Zealand preschool-aged children are affected by neurodevelopmental disorders (Cutfield et al., 2019). The estimated rate of neurodevelopmental disorders in preschoolers in New Zealand appears similar to the rate in the United States, which is estimated to be between 10-15% (Bloom et al., 2011). The neurodevelopmental disorders most relevant to CDC will be briefly described.

Intellectual Disabilities. The intellectual disabilities classification consists of ID, GDD, and unspecified intellectual disability. Intellectual disability is described as a disorder with deficits in cognitive abilities, including reasoning, problem-solving, planning, abstract thinking, judgement, academic learning, and experiential learning. Intellectual disability also consists of limitations in adaptive functioning, impacting levels of personal independence in day-to-day tasks. Global developmental delay is a diagnosis applied to children under the age of 5 years who present with delays in their achievement of cognitive milestones. Unspecified ID is applied in exceptional circumstances for individuals over 5 years old whose ID is unable to be assessed due to sensory or physical impairments (American Psychiatric Association, 2013). Within New Zealand, 2% of the population is known to have an ID with males (3%) more likely than females (1%) (Stats NZ, 2014, June 17).

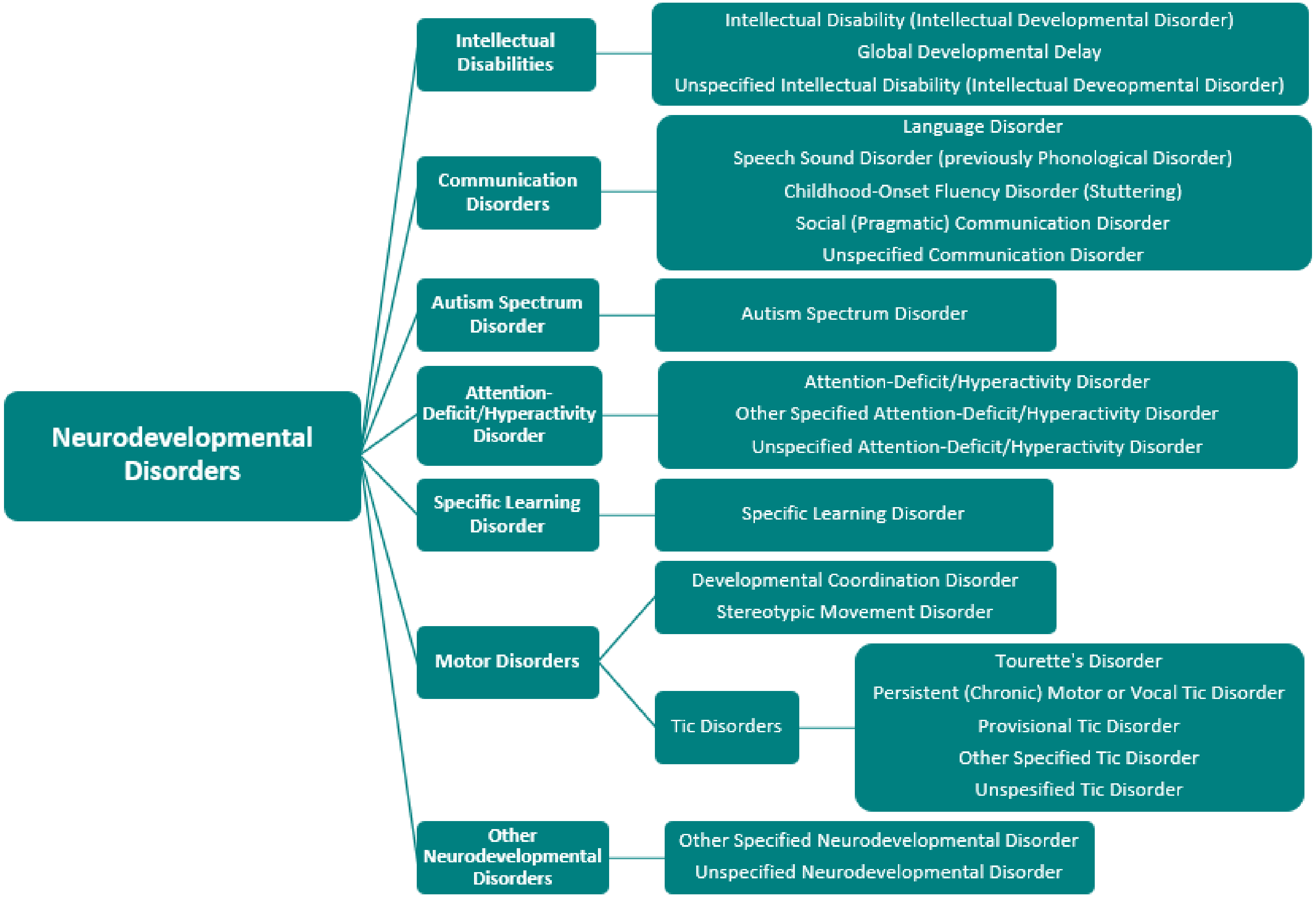
Autism Spectrum Disorder. Autism is a spectrum disorder meaning some individuals are significantly more affected than others. For example, some individuals may not use spoken language, whilst others have exceptional spoken language abilities. Autism spectrum disorder is characterised by two core domains including persistent deficits in social communication and social interaction across contexts, and the presence of restricted and repetitive patterns of behaviour, interests, or activities (American Psychiatric Association, 2013). Within New Zealand, in 2020, 2.9% of boys aged 2-14 years and 1.5% of girls were diagnosed with ASD (Figure NZ Trust, 2020b, November 19). Overall, it is estimated that more than 40,000 New Zealanders are affected by ASD (Ministries of Health and Education, 2016b). Autism spectrum disorder is typically more prevalent in males compared to females with males diagnosed four times more often than females (American Psychiatric Association, 2013). According to American data, the rate of ASD has risen significantly from an estimated one in 150 children in 2002 to one in 36 children in 2020 (Centers for Disease Control and Prevention, 2023, April 04). Similarly, research from the United Kingdom indicates a 787% increase in autism diagnoses between 1998 and 2018 (G. Russell et al., 2022). The explanations behind the increased prevalence of ASD can be variable, however, common hypotheses include expanded diagnostic criteria and assessment (Croen et al., 2002; Fombonne, 2005; Fombonne, 2008; Honda et al., 2005; Waldman et al., 2008), increased awareness of ASD (Ouellette-Kuntz et al., 2007; Wing & Potter, 2002), and diagnosis at an earlier age (Wazana et al., 2007).

Motor Disorders. Within the motor disorders classification, DCD is a condition assessed for at CDC. Developmental coordination disorder, also often referred to as dyspraxia, is characterised by a delay in the development of motor skills, or challenges coordinating movements, resulting in difficulties performing everyday tasks. Developmental coordination disorder is thought to affect around 6% of children aged 5-11 years, with males more often affected than females (Farmer et al., 2017).

Attention Deficit/Hyperactivity Disorder. Attention deficit/hyperactivity disorder is characterised by a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with day-to-day adaptive functioning or development. The condition impacts an individual’s memory, concentration, planning and organisation skills, and ability to regulate behaviours (American Psychiatric Association, 2013). In 2020, ADHD was diagnosed in New Zealand in 4.2% of boys aged 2-14 years and 0.5% of girls (Figure NZ Trust, 2020a, November 19). There are inconsistencies across New Zealand regions regarding how ADHD is assessed for and supported (Bradley, 2021, December 06). From a diagnostic perspective, ADHD is classified as a neurodevelopmental disorder (American Psychiatric Association, 2013), however, despite this, diagnosis and intervention for ADHD are more commonly accessed via CAMHS involving the input of a psychiatrist (Bradley, 2021, December 06) as opposed to the input from a child development team and/or a paediatrician.

Figure 1

American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-V) Neurodevelopmental Disorders



Specific Learning Disorder. Specific learning disorder is diagnosed when an individual experiences significant impairment in their ability to perceive or process information proficiently and accurately. Individuals with SLD may have difficulties with listening, thinking, speaking, reading, handwriting, written language and/or maths. Specific learning disorders are typically specified whether they are with impairment in reading (dyslexia), impairment in written expression (dysgraphia), or impairment in mathematics (dyscalculia). The global prevalence of SLD is estimated to be between 5-15% in school-aged children (American Psychiatric Association, 2013). Within New Zealand, formal assessment for SLDs is primarily accessed through private services such as SPELD NZ (SPELD NZ, n.d.) which may cost between NZ$700 and NZ$1500 (Scurr, 2021).

2.3.2 Neurodiversity Terminology

Conditions such as ASD and ADHD, have often been understood through the ‘pathology paradigm’. This particular lens perceives that there is one ‘right’ or ‘normal’ kind of neurocognitive functioning and anything that diverges from the norm is considered a deficit or disorder. Neurodevelopmental disorders are commonly discussed within the context of diagnosis within a medical model where diagnostic criteria focus on identifying the deficits that an individual may present with (Neurodivergent Counselling Services, n.d.).

In recent years, the concept of the ‘neurodiversity paradigm’ has emerged and represents a specific perspective on neurodiversity that highlights neurodiversity as natural and part of human diversity (Walker, 2021). ‘Neurodiversity’ is a broad political, non-scientific term and is not a diagnosis. The term was first coined in 1998 by Australian sociologist Judy Singer, in her Honours thesis (Singer, 2017). When describing neurodiversity, Singer (2020), who has a diagnosis of autism herself, emphasises that each individual’s mind is different, there is endless variability within human cognition, and each individual is neurodiverse as no two people are exactly the same. The concept of neurodiversity recognises that while individuals learn and think differently, these cognitive traits are acknowledged as differences as opposed to deficits (Donaldson et al., 2017; Kapp et al., 2013; Rentenbach et al., 2017; Singer, 2020). Despite the intent for the term to refer to differences between each individual, including both typical and atypical, in many cases neurodiversity has become a term used synonymously to describe those considered to have atypical neurological configuration and/or those with a diagnosis of a neurodevelopmental disorder (Kapp et al., 2013; Rentenbach et al., 2017). Although the term neurodiversity was not intended to be used to specifically describe individuals with neurodevelopmental disorders, by applying the term this way, it has been beneficial for encouraging the perspective that building on children's natural strengths and special interests, rather than focusing on attempting to correct their deficits, is a more effective method of educating individuals with neurodevelopmental disorders (Colombo-Dougovito et al., 2020; Silberman, 2017).

It has been emphasised that a clear understanding of terminology and using the correct terms for their intended purpose is important for effective communication and knowledge transfer (Walker, 2021). The term 'neurodiversity' or 'being neurodiverse' can be considered an umbrella term to describe the variability between people in how our brains process information and therefore experience the world. Two primary categories sit beneath the umbrella of neurodiversity: 'neurotypical' and 'neurodivergent'. Individuals may be considered either neurotypical or neurodivergent but are all neurodiverse. Even within the neurotypical category, neurodiversity still exists as no two neurotypical brains are identical (Grant, 2022).

The term 'neurotypical' refers to individuals whose thought processes and behaviours align with society-defined standards of typical intellectual and cognitive development, and who do not have a diagnosis of a neurodivergent condition (Grant, 2022; Walker, 2021). The origin of the term ‘neurodivergent’ or ‘neurodivergence’ is not clearly identified, with some saying the term was coined by Judy Singer (Cleveland Clinic, 2022, June 02; Gregory & Courtney, 2023, February 27; Resnick, 2023, January 12) and others saying the term was coined by Kassiane Asasumasu, a neurodivergent activist (Adan et al., 2021, September 01; Chapman, 2021, August 18; Neurodivergent Counselling Services, n.d.; Therapist Neurodiversity Collective, 2020; Walker, 2021). Kassiane is reported to have described ‘neurodivergent’ as a brain that diverges from what is considered typical (Neurodivergent Counselling Services, n.d.). Neurodivergence may include genetic/innate and/or acquired conditions. Examples of acquired neurodivergence may present as a result of a brain-altering experience such as a stroke, dementia, traumatic brain injuries, and/or mental health conditions. Innate forms of neurodivergence may include conditions such as ADHD, ASD, ID, Tourette’s disorder, dyspraxia, or SLDs (Grant, 2022).

Increasingly, people in the autism community prefer to use identity-first language such as ‘autistic’ or ‘an autistic person’. This recognises autism as an intrinsic part of their identity. ‘A person on the autism spectrum’ is the preferred person-first language, over other person-first references, and may be applied alongside identity-first language (Bury et al., 2020). For other conditions, person-first language is typically applied, which puts the person before a diagnosis, such as ‘a child who has ADHD’, ‘individuals with ID’, or ‘he has a developmental delay’ (Crocker & Smith, 2019; Foreman, 2005; Mackenzie, 2017). Overall, there continue to be uncertainties and fluctuating changes regarding preferences for the use of person-first or identity-first languages. Person-first language suggests that the label or diagnosis is not a part of the person themselves, as if one could remove or eliminate ASD or ADHD and have a ‘neurotypical’ person left. However, this is not the case for neurodivergent individuals. Their neurological wiring is lifelong and deeply connected to their personality. Even if a person learns coping skills to support some of the challenges they face, they are still considered neurodivergent (Kircher-Morris, 2022).

Many of the conditions within the diagnostic category of neurodevelopmental disorders are recognised as disabilities, therefore the terminology around disability is important to consider. While diverse perspectives on suitable terms for identifying people with disabilities exist, the Ministry of Social Development (2016), recognises the current consensus for language about disability in New Zealand as the identity-first term ‘disabled people’.

To apply neurodiversity-affirming terminology (Kemp, 2023) throughout this thesis, the terms ‘neurodivergent’ or ‘neurodivergence’ will be used in the context of describing those who have, or are suspected of, a diagnosis of a neurodevelopmental disorder. These terms will primarily be used as identity-first language such as ‘neurodivergent child’.

2.3.3 Theoretical Perspectives

The definition of disability varies within literature and services; however, disability is often described as the result of the interaction between a non-inclusive society and individuals with impairments. Disabled people include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may limit their full and active participation in society on an equal basis with others (United Nations Convention on the Rights of Persons with Disabilities, 2006, November 06). Two models that are often used to demonstrate how perspectives about disability have been shaped include the medical model of disability and the social model of disability (Mason, 1992). Both the medical model and social model of disability have strengths and weaknesses when considering ways to improve the lives of disabled people, however, it is becoming increasingly common for other models to be applied that recognise the impact that society has, whilst also acknowledging the impact and experiences of people’s individual impairments.

The Medical Model of Disability. The medical model of disability focuses on the individual impairments and medical conditions that cause disability. It views disability as an inherent problem within the person that needs to be fixed or treated. The goal of this model is to rehabilitate or cure the person so that they can function as much as possible within society's norms (Olkin, 2001). According to Woods and Thomas (2003), medical professionals who apply a medical model approach typically view patients as issues that need solving, neglecting to consider the numerous factors associated with the individual's entire life. The medical model may fail to consider how a person's environment affects their abilities and instead focuses on the individual as the source of the problem. This approach does not address the underlying conditions that may be causing or contributing to their disability. As a result, if the person is unable to be ‘fixed’, they may not be treated as equal to others (Marks, 1997).

In Western society, the medical model perspective has historically been dominant in shaping conceptualisation and views of neurodevelopmental disorders with the connotation that neurodivergent individuals are less than neurotypical individuals. The diagnosis indicates that there is a problem with the way an individual’s mind and body are functioning, which causes them to behave or think differently and abnormally, and this has negative effects on their daily life (Stein et al., 2010). This can also be seen as a deficit model, as the criteria have often been developed from the perspective of what is considered ‘normal’ in society and it focuses on the shortcomings and difficulties associated with a particular condition (Woods & Thomas, 2003). For example, the DSM-V outlines the criteria for ASD and highlights two key areas of deficit: ongoing difficulties in social communication and interaction across different situations, and repetitive and restricted patterns of behaviour, interests, and activities (American Psychiatric Association, 2013). Deficit-focused paradigms and perspectives reinforce negative stereotypes and assumptions about neurodivergent people, viewing them primarily in terms of their perceived weaknesses, limitations, and dysfunctions (Adan et al., 2021).

When a medical model of disability approach is applied within the education setting, the challenges faced by children experiencing disability are perceived to be due to their impairment rather than from inadequacies within the education environment. The focus often becomes on attempting to fix or change the student with a disability to bridge them closer to society's perspective of 'normal', rather than adapting the environment or teaching methods. This approach can contribute to children being excluded from the education environment and/or learning opportunities (MacArthur, 2009).

The Social Model of Disability. The social model of disability offers an alternative perspective to the medical model approach. Disabled people have endured prejudice and discrimination throughout history. There have been periods of extreme discriminatory practices whereby disabled people have been removed from mainstream economic, educational, and social life (Barnes, 1997; Borsay, 2005; Gleeson, 1999; Oliver, 1990). The establishment of the Union of the Physically Impaired Against Segregation (UPIAS) in 1974 influenced objection of historical perspectives on disability, promoting social model thinking (Union of the Physically Impaired Against Segregation, 1976).

The social model of disability highlights the concept that disability is constructed by a society that is preoccupied with 'normality'. Different to the medical model view which perceives disability as a 'problem' that is the responsibility of the person, the social model locates the 'problem' within social attitudes, systems, environments, and practices that act as barriers to full participation. The social model perspective argues that the experience of disability is derived from living in an unjust society that considers some people as atypical and is then unsuccessful in responding to or supporting them (Barnes, 2019; MacArthur, 2009).

The societal perspective that individuals with disabilities are different and therefore unable to fit in with the rest of society, creates numerous barriers for disabled people to fully participate within their communities. Society is often resistant to change and as a result, disabled people are often oppressed and discriminated against (Barnes, 2019; MacArthur, 2009). Social model thinking creates platforms to promote the removal of barriers (Shakespeare, 2013). When social model of disability approaches are applied, attention is shifted away from the functional limitations of disabled individuals and instead focuses on environments, barriers, cultures, and attitudes that disable the individual. The social model argues that it is not the person with an impairment who should have to change to fit societal perspectives about normality. Instead, society should be making changes to eradicate ideas about normal and abnormal, and enhance the inclusiveness of diversity (Barnes, 2019; Shakespeare, 2013).

It can be beneficial to apply the social model of disability within education settings. Supporting disabled individuals, within mainstream classroom contexts, builds a foundation perspective of inclusion and that disability is a part of general human diversity (Ainscow et al., 2006). In addition to recognising how a student's impairment may affect their learning and social interactions, adopting the social model approach encourages teachers to identify obstacles, such as bullying or lack of resources, which hinder learning and participation in school. By acknowledging and addressing these barriers, inclusive education can be fostered through the reduction or elimination of such hindrances (MacArthur, 2009).

Bronfenbrenner’s Ecological Systems Theory. In the 1970s, American developmental psychologist, Urie Bronfenbrenner, theorised about the influence of social environments on human development. Bronfenbrenner's ecological systems theory perceives the development of a child as a complex network of relationships influenced by various levels within the surrounding environment (Berk, 2013). This theory categorises an individual’s environment into five different systems: the microsystem, the mesosystem, the exosystem, the macrosystem, and the chronosystem. Each layer of the environment joins with the others to affect development and when a change in one of the five systems occurs, it has the potential to influence the other systems (Shelton, 2018).

The microsystem is the system closest to the person and the one in which they have direct contact, such as parents, siblings, teachers, and school peers. Relationships in a microsystem are bi-directional whereby the child may be influenced by other people in their environment and is also capable of altering the beliefs and behaviours of others. The interactions that occur within microsystems are often personal and critical for fostering and supporting the child’s development (Shelton, 2018).

The second level of ecological systems theory is the mesosystem which encompasses the connections between the child’s microsystems such as home, school, neighbourhood, or child care setting (Berk, 2013). For example, a child’s academic performance is influenced by parents’ involvement in school life such as attending parent/teacher meetings, as well as the extent to which academic learning is supported within the home environment. A cooperative relationship between parents and teachers is shown to positively impact a child’s development (Gershoff & Aber, 2006).

The exosystem incorporates formal and informal structures that do not directly contain children but affect children’s experiences in immediate settings. Exosystems may include parents’ workplaces, religious institutions, social networks, and social and healthcare services in the community (Berk, 2013). For example, a child may be affected by a parent receiving a promotion at work or losing their job (Coulton et al., 2007). Another exosystem example is mass media as the media is external to the child’s direct experience, however is likely to affect them (McHale et al., 2009).

The macrosystem consists of cultural elements that affect a child’s development including cultural values, beliefs, customs, and laws. The culture that individuals are exposed to may influence their beliefs and perceptions about their experiences. An example of the influence of the macrosystem is that children living in countries affected by war will experience development differently than children in amicable environments (Shelton, 2018).

Bronfenbrenner described the environment as ever-changing, and that over time, significant life events such as the birth of a sibling, starting school, moving locations, or parents’ divorce, contribute towards new conditions that affect development. The chronosystem captures the dimension of time demonstrating the influence of both change and constancy in a child’s environments. Life changes may be enforced on the child such as starting school, or changes may arise from within the child; As they grow older, they have more influence over choosing, altering, and creating many of their own settings and experiences (Shelton, 2018).

Bronfenbrenner's theory stands out for its holistic approach that considers the entire range of systems that affect children's development, as well as the dynamic nature of family dynamics (Shelton, 2018). However, there are also limitations to consider. One limitation is the insufficient research on mesosystems, particularly the interactions between neighbourhoods and a child's family. This contributes to an ongoing lack of clarity regarding the extent of the impact these systems have on child development (Leventhal & Brooks-Gunn, 2000). Another limitation lies in the difficulty of empirically testing the theory. Although studies exploring ecological systems may identify effects, establishing direct causation from these systems to the observed effects is challenging (Tudge et al., 2009).

In acknowledgement of the limitations of Bronfenbrenner's theory, the theory is not used in the current project to directly measure specific outcomes. Instead, its application lies in drawing inspiration from the contribution the theory makes in understanding how a child grows and develops and the impact and interconnectedness between the services and supports surrounding the child. This understanding enables the consideration of the various internal and external factors to a child that may interact with and influence a child's development and well-being.

In consideration of health and development, ecological systems theory provides a holistic perspective emphasising that children are both products and producers of their environments (Skelton & Rosenbaum, 2010). This view acknowledges how a child’s biological attributes interact with various environmental systems to shape their development and a child’s development is determined by the interaction of many processes across time and space (Bronfenbrenner & Ceci, 1994). The environment surrounding an individual plays a significant role in determining their health outcomes, especially for neurodivergent children and children with complex care needs. In this context, their environment includes the family as well as the services and support systems that the child and family have access to (World Health Organization, 2007). By applying an ecological systems theory approach to supporting disabled children, the focus can shift from historical perspectives around ‘fixing’ the disabled person to focusing on approaches that promote function, participation, and engagement in life.

2.3.4 Impacts of Neurodivergence

This section explores some of the wide-ranging effects of neurodivergence including how neurodivergent conditions often coexist with other health conditions, the influence of neurodivergence across the lifespan, the association between neurodivergence and well-being, and consideration of neurodivergence and equity through the lens of the New Zealand context.

Neurodivergence and Comorbidity. It is common for neurodevelopmental disorders to co-occur alongside other neurodevelopmental disorders as well as other medical, physical, or mental health conditions (American Psychiatric Association, 2013). Comorbidity is often defined as the presence of more than one acute or chronic illness or disease occurring in one person at the same time. Multimorbidity consists of the presence of two or more acute or chronic co-occurring illnesses or diseases within one individual (Harrison et al., 2021). The prevalence of comorbid neurodevelopmental disorder diagnoses varies within the literature however it is estimated that up to 50% of individuals diagnosed with a psychiatric or neurodevelopmental disorder experience more than one disorder (Williams & Lind, 2013).

Co-occurring conditions can pose increased challenges for healthcare and education systems. One issue for individuals with multimorbid diagnoses is the disjointed provision of services. It is common for assessment and treatment pathways to concentrate on disorders in isolation (NICE, 2017, December 20, 2019, September 13), and by focusing explicitly on a single disorder, salient features of other disorders may not be acknowledged (Thapar et al., 2017). When conditions are viewed in isolation, yet multimorbidity is present, prognosis and treatment may be inappropriate and ineffective (American Psychiatric Association, 2013; Thapar et al., 2017). For example, the threshold of intervention may be impacted when another condition is present or the effectiveness of a suggested assessment or intervention may be altered in the presence of additional conditions (Thapar et al., 2017). Assessment and intervention pathways may require modifications to best meet the needs of those experiencing multimorbid diagnoses (American Psychiatric Association, 2013). Within the education environment, there are already challenges supporting neurodivergent students due to the extensive variation of needs. Furthermore, when children have co-morbid diagnoses, comprehending and responding to their needs becomes more challenging (Ministry of Education, 2019).

Children with comorbid neurodevelopmental disorder diagnoses tend to experience increased symptom severity as well as poorer outcomes than those with a singular diagnosis (Tonnsen et al., 2016). In their population-based cross-sectional comparison of the behavioural and emotional problems of children and maternal mental health Totsika and colleagues (2011) found that those with a comorbid diagnosis of ASD and ID experience poorer psychosocial and family-related outcomes than those experiencing ID in isolation. Fleming and colleagues (2020) explored the prevalence of neurodevelopmental multimorbidity among Scottish schoolchildren aged 4-19 years in a population-based record linkage cohort study. They concluded that those with multimorbid diagnoses had significantly poorer educational outcomes when compared to peers with one or no conditions. This study also found that multimorbidity was associated with increased absences and exclusion from school, poorer exam attainment, and increased unemployment.

Neurodivergence across the Lifespan. While the symptoms and behaviours associated with neurodevelopmental disorders often change or evolve as a child grows older, some difficulties are chronic and, in some cases, may lead to life-long challenges in learning skills both in schools and in the workplace (American Psychiatric Association, 2013; Anderson et al., 2014; Faraone et al., 2006; Howlin et al., 2004; Magiati et al., 2014; Simon et al., 2009).

The long-term prognosis for autistic individuals has improved over time with advancements in earlier diagnosis and the establishment of effective, evidenced-based treatment plans (Volkmar et al., 2017). Autistic people are now more likely to be able to verbally communicate, read, drive a car, and graduate from school (Lord et al., 2018). However, autistic people are still likely to experience long-term effects such as social isolation, family discord, difficulty forming and maintaining friendships, difficulties relating to and empathising with others, and sleep issues. The ability of autistic people to live independently continues to be impacted, with only a marginal number of autistic adults living in their own homes (Anderson et al., 2014). It continues to be rare for autistic adults to marry or have long-term relationships, or have longstanding reciprocal friendships (Howlin et al., 2013). Those with co-morbidities, such as ID, are likely to experience increased difficulties and require more intensive support (Lord et al., 2018).

The prognosis for ID is dependent on the severity of cognitive impairment as well as the level of support received. Common long-term effects of ID include requiring individualised teaching to be able to learn, needing support with everyday problem solving, development of depressive symptoms, and difficulty establishing interpersonal relationships. When effective supports are in place, individuals with mild ID are likely to be able to live independently, maintain paid employment, and raise a family. Those with severe ID are likely to have more difficulties gaining spoken language, however, can be supported to develop alternative communicative strategies. It is common for adults with severe ID to reside in supported living situations where support workers assist them in doing the tasks they need and want to do in their day (Lee et al., 2020). Individuals with mild ID have an average life expectancy however, for those who experience severe ID, particularly when compounded by comorbidity, life expectancy may be reduced (Sulkes, 2020, May).

Neurodivergence and Well-being. The definition of child well-being varies within literature and is often considered across a range of specific domains such as physical, social and emotional, cognitive, and environmental contexts such as standard of living. Well-being is often associated with feeling good or an inherent positive state (Pollard & Lee, 2003), which in turn, influences mental health (Te Hiringa Mahara - The Mental Health and Wellbeing Commission, 2022). Positive well-being is crucial in facilitating optimal outcomes for child development. Neurodivergent children may experience a variety of unmet needs and children with disabilities and learning needs are at increased risk of several adverse outcomes, both during childhood and as adults (Anderson et al., 2014; Howlin et al., 2013; Lee et al., 2020; Lord et al., 2018). When effective supports are in place, individuals experiencing neurodevelopmental disorders achieve better outcomes (Fleming et al., 2020; Lee et al., 2020).

Within New Zealand, measures of children's well-being revolve around a set of well-being indicators categorised into ten domains. These domains are outlined in the Children and Young People: Indicators of Wellbeing in New Zealand report and encompass health, care and support, education, economic security, safety, civil and political rights, justice, culture and identity, social connectedness, and environment (Ministry of Social Development, 2008). The ‘Children with Disability New Zealand’ charity shares that a good life for disabled children and young individuals involves having access to suitable education, healthcare, and support services, as well as opportunities for social interaction and inclusion in their community. It also includes having their rights and needs acknowledged and being able to live as independently as possible. A supportive and empathetic family and community can also contribute significantly to ensuring a favourable quality of life for disabled children and young individuals (Children with Disability New Zealand, n.d.).

The New Zealand Government has acknowledged the importance of improving the well-being of New Zealand children, particularly for those with ‘greater needs’, with the establishment of the Child and Youth Wellbeing Strategy 2019 (hereafter referred to as the Strategy) (Department of the Prime Minister and Cabinet, 2019a). Although the definition of ‘greater needs’ is not specified, the Strategy mentions that many neurodivergent children experience a variety of unmet needs. Statistics reported within an Education Review Office (ERO)[1] report show that disabled learners face more barriers to participating at school compared to non-disabled peers. Compared to peers without disabilities, disabled learners are more likely to want to avoid attending school due to their inability to participate in certain activities (14% of disabled learners compared to 3% of learners without disabilities), their lack of interest in certain activities (31% of disabled learners compared to 20% of learners without disabilities), and the difficulty of their schoolwork (27% of disabled learners compared to 11% of learners without disabilities). Disabled children are also less likely to become involved with social activities at school such as sports and clubs (25% of disabled learners compared to 43% of learners without disabilities) which can influence their motivation to attend school. Learners with disabilities are more likely to lack the necessary resources for attending school (19%) compared to those without disabilities (11%) and are also reported to experience more bullying (20%) than peers without disabilities (8%). To protect the health and well-being of disabled children who have been bullied, a significant number of caregivers choose to keep their child away from school. This decision has been made by 12% of caregivers for disabled children, while only 3% of caregivers for children without disabilities who have experienced bullying make the same choice (Te Ihuwaka - Education Evaluation Centre, 2022). Factors such as bullying and lack of resources can directly impact the well-being of disabled children and influence their ability to participate, learn, and develop. An initial focus for supporting the well-being of those with greater needs is within the area of supporting learning through the implementation of the Learning Support Action Plan (Department of the Prime Minister and Cabinet, 2019a) which will be discussed in further detail in a later section.

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[1] The Education Review Office (ERO) is the New Zealand government’s external evaluation agency who evaluate and report on the education and care of learners in schools and early childhood services.

Neurodivergence and Equity. The New Zealand Ministry of Health (2019, October 01) explains health equity as "In Aotearoa New Zealand, people have differences in health that are not only avoidable but unfair and unjust. Equity recognises different people with different levels of advantage require different approaches and resources to get equitable health outcomes" (p.1).

Health inequalities within New Zealand are extensively recognised, particularly around Māori health (Craig et al., 2007; Tobias et al., 2009). Māori children experience poorer health outcomes than non-Māori children, across a variety of health indicators, and the inequities in child health result in significant costs for New Zealand society (Mills et al., 2012). Principles within Te Tiriti o Waitangi (the Treaty of Waitangi) establish the foundation for Māori rights to health equity and the New Zealand government acknowledges the need to continue working towards achieving equity for Māori health outcomes (Waitangi Tribunal, 2019).

New Zealand research regarding the health needs of Māori children experiencing developmental delays or ID is limited (Craig et al., 2012), however, it was estimated in 2006 that 2% (n=4,500) of Māori children aged 0-14 years had a global developmental delay or an ID (Statistics New Zealand, 2010). Through a health lens, these children are likely to require routine health care such as immunisation and growth monitoring, and targeting commonly associated medical conditions such as epilepsy, and vision and hearing issues (Rudolph et al., 1996). There may be difficulties meeting these health needs, as the 2011-2013 New Zealand Health Survey states that 27% of Māori children had an unmet need for primary health care. The rates of unmet need for primary health care were around 1.6 times higher for Māori children compared to rates for non-Māori children (Ministry of Health, 2014). From a cultural lens, to support Māori with ID in achieving optimal outcomes, advancements need to occur in the development of Māori specific support services that consider culturally appropriate needs assessments, service coordination, and funding of resources (Robson & Harris, 2007).

Within New Zealand, accurate data on the prevalence of ASD for Māori and non-Māori is scarce (Bowden et al., 2020; Craig et al., 2012), however, the 2018-2019 New Zealand Health Survey suggests the rate of ASD for Māori children (2.7%) may be higher than non-Māori children (2%) (Ministry of Health, 2019). Perspectives and understanding of ASD vary between different cultural groups and research aimed at understanding what ASD means for Māori is emerging (Tupou et al., 2021). Keri Opai, Māori strategic lead at Te Pou (a national workforce centre for mental health, addiction and disability in New Zealand), has aided this understanding by coining the term 'Takiwātanga' to represent autism in te reo Māori. The term is derived from 'tōku/tōna anō takiwā' meaning 'my/his/her own time and space' (Opai, 2017).

In a research report for the Ministry of Education, Bevan-Brown (2004) explored Māori perspectives of ASD by interviewing parents and whānau of autistic Māori children. Seventeen out of 19 participants identified their desire for the inclusion of some cultural content into their children's education and service provision. Concern was raised regarding the limited ASD knowledge of some Māori staff and service providers, and parents voiced their preferences for assessment measures and procedures that were more culturally appropriate. Parents identified numerous barriers they experienced including difficulty accessing services, assessment and procedural challenges, financial strain, personal and family stress, unfavourable attitudes of professionals and society in general, and limited expertise of ASD among professionals resulting in unsuitable, ineffective interventions. Māori children also experienced cultural disadvantage as impairments associated with ASD impacted their ability to participate in cultural activities including staying on the marae, kapa haka, and learning te reo Māori. To ensure autistic Māori children are provided opportunities to achieve optimal outcomes, one key conclusion from the report emphasises the need for the development of more culturally appropriate programmes and services. This can be achieved across health and education settings through the implementation of services that centre on Māori perspectives, enhancing the expertise of personnel in existing Māori services, and augmenting the bicultural knowledge of professionals engaged in mainstream services.

2.4 Literature Review Part 2: Meeting the Needs of Neurodivergent Children through Collaborative Care

To improve the outcomes and overall well-being of neurodivergent children and young individuals, it is important to consider the most effective methods of providing services and support. With reference to Bronfenbrenner’s ecological systems theory, collaboration between different systems that impact a child's development is thought to be beneficial for screening, prevention, and intervention efforts. This can lead to improved health outcomes, reduced healthcare costs, and empowers important individuals in the child's life to support their well-being (Council on Children with Disabilities, 2005). Having coordinated, collaborative care for neurodivergent children is also of significant importance since they frequently experience co-occurring medical and mental health issues that require input from different professionals (Baio, 2014; Cubala-Kucharska, 2010; Salazar et al., 2015; Simonoff et al., 2008). Furthermore, as a result of school inclusion policies, the need for collaboration between education and health agencies has become more prevalent (Arora & Bohnenkamp, 2016; Hillier et al., 2010; Schwab, 2005; Shapiro & Manz, 2004).

Collaboration involves working with others to achieve a common goal (Forman et al., 2018). Multi-agency collaboration is a collaborative effort involving practitioners from multiple agencies who come together to work in partnership, with the shared goal of intervening early to prevent potential issues that may negatively impact children's learning and achievement. This collaborative approach involves the sharing of aims, information, tasks, and responsibilities among the practitioners, as well as the joint planning and delivery of coordinated services that are tailored to address the evolving needs of children and young people. Within the literature, several terms and concepts are often used interchangeably with multi-agency collaboration including inter-agency working, integrated working, multi-professional/multidisciplinary working, joint working, and partnership working (R. Cheminais, 2009). Research reviewing the literature associated with models of service support and responding to the needs of neurodivergent children has highlighted the importance of and the need for considering ways in which schools and healthcare settings can better collaborate to support the complex needs of neurodivergent and disabled children (Mirfin-Veitch et al., 2020; Power & Bradley-Klug, 2013; Sloper, 1999). Special education transformation reports (Bennett & Wynne, 2006) and research applying a learning collaborative methodology to explore the level of awareness among leaders of Canadian provincial/territorial teacher associations regarding inclusive education laws and policies (Thompson et al., 2015) have shown that many educators have expressed concern regarding the lack of collaboration with health professionals and the ability to support children with diverse needs.

The delivery of multi-agency collaboration in practice presents with limitations and enablers. Through consideration of various barriers and facilitators, there are emerging attempts at establishing multi-agency approaches to support neurodivergent children (Arora & Bohnenkamp, 2016; CanChild, 2015; Phoenix et al., 2021; Power et al., 2016).

2.4.1 Barriers to Multi-agency Collaboration

Various barriers that may interfere with the establishment of collaborative practice between multiple agencies, such as child health and education settings, have been identified. Understanding barriers is important in comprehending why services may not already be collaborating effectively and these barriers can be taken into account when considering new approaches for the future (Phoenix et al., 2021).

In their paper which uses ADHD as a case example to describe barriers that may interfere with collaboration across systems of care, Power and colleagues (2013) showed that administrative and fiscal confinements can add pressure on professionals to increase productivity, thus reducing the time available to collaborate with others. In these situations, it can become difficult to coordinate times when health professionals and education staff are both available to liaise for collaboration. Privacy laws across different systems may also present challenges for sharing information between schools and healthcare settings. Sloper (2004) carried out a literature review exploring the facilitators and barriers to multi-agency working and the outcomes for children and families of a more coordinated approach. Aligned with findings also presented by Power and colleagues (2013), Sloper’s review highlighted that differences in expectations, culture, and terminology between health and education professionals can make communication within multi-agency collaboration difficult. The training programmes for healthcare providers and educators differ significantly which is likely to result in differences in theoretical understanding and terminology used (Leslie et al., 2004). Without a common language, these differences can contribute to difficulties in communicating effectively with one another, which may affect the development of rapport with individuals from other systems (Guevara et al., 2005).

Role restriction may contribute towards difficulties in establishing multi-agency collaboration. System-level criteria can result in a rigid definition of scope within professional roles which may inhibit the ability to provide multi-agency approaches for children’s diverse needs (Power et al., 2013). Sloper (2004) highlights several additional obstacles to multi-agency collaboration including confusion about roles and responsibilities, lack of support from upper management, incompatible technology systems, insufficient resources and lack of shared budgets, limited training opportunities, absence of strong leadership, negative stereotypes among professionals and a lack of trust and understanding between individuals and agencies, and frequent staff turnover.

2.4.2 Facilitators of Multi-agency Collaboration

For multi-agency collaboration to be successful, it is beneficial to reduce barriers wherever possible and to ensure concepts known to support successful multi-agency collaboration are considered and applied where feasible (Phoenix et al., 2021). The establishment of various toolkits and guidelines can help support multi-agency collaboration by providing consistent information in one central document (American Academy of Pediatrics, 2011; Power et al., 2013). For example, the New Zealand Autism Spectrum Disorder Guideline, revised by the Ministries of Health and Education (2016a), has been developed to assist health professionals, educators, and consumers in making informed decisions about education and the best care for autistic individuals. The guideline recommends that during diagnosis and initial assessment, services should be coordinated within and across sectors and multi-agency assessments should be provided. The guideline also provides recommendations for the provision of education for autistic individuals. It is recommended for the treatment and management of ASD that professionals, autistic individuals, and whānau work together to evaluate treatment approaches. For ongoing professional learning and development, it is suggested that different professional groups be provided with the opportunity to train together. This approach of joint training is recognised by Sloper (2004) as a facilitator of multi-agency working. Although the guideline helps provide recommendations, it does not provide detailed descriptions regarding how to implement some aspects of the various recommendations, such as how collaboration should occur (Ministries of Health and Education, 2016a).

Application of a care manager approach, involving a key person responsible for the coordination of care such as a practice-based nurse or social worker, can be beneficial for supporting multi-agency collaboration (Power et al., 2013). Guevara and colleagues (2009) adapted a care manager model for pilot use with children with ADHD. Their care manager model included a family-centred management plan outlining intervention goals, monthly review to track progress, family education, primary care provider education, and coordination of care between schools and mental health services. The coordination of care component occurred once a month, via phone or email contact between the care manager, the child's teacher, and a mental health professional. Compared to a control group who did not receive a care manager approach, after 6 to 9 months of intervention, children receiving care manager input experienced fewer symptoms of ADHD and fewer impairments, and families reported higher levels of programme satisfaction.

One way of carrying out an integrated model of care is the co-location of services where the services of relevance are located in the same setting or in nearby offices (Elkin et al., 2017). The school can be a beneficial setting to host multi-agency collaboration because schools have access to nearly the entire population of children and are often readily accessible for families. The school environment is also beneficial for gaining insight into children's functioning in real-world settings and their response to intervention through a real-life application (Power et al., 2013).

The establishment of electronic platforms that allow professionals working across health and school settings to access information concurrently can aid multi-agency collaboration (Power et al., 2013). Some attempts at setting up such programmes have been emerging. Power and colleagues (2016) acknowledged the poor connection between schools and primary mental health care providers, resulting in fragmented and suboptimal care for youth experiencing emotional or behavioural disorders. Their research explored the development and implementation of an electronic health record portal, known as the ADHD care assistant. This electronic system allows primary care providers to share and access information from schools to encourage evidence-based practices in supporting children with behavioural health conditions. The ADHD care assistant is comprised of three main components; an electronic survey tool to gather information from teachers and parents; a module accessible to providers integrated into electronic health records and; a web service that facilitates communication between schools and primary care providers. The researchers found the electronic system to be beneficial for gathering information from parents and teachers which could support decisions regarding a diagnosis of ADHD. Parents were included in shared decision-making, and treatment outcomes were more easily monitored. To further improve and examine the effectiveness of the ADHD care assistant, Michel and colleagues (2018) gathered feedback from parents, teachers, and paediatricians regarding which information they preferred to share, such as treatment goals, symptomology, medication side effects, and educational performance, and adapted the electronic system accordingly. Results showed a willingness of stakeholders to share health information, however, there was less reciprocity to view shared information. The ADHD care assistant is a starting point to increase collaboration between education and health systems, however further research and quality improvements are required to advance the system and determine generalisability beyond the current methods.

Additional factors that contribute to effective collaboration between multiple agencies include having clear and achievable goals that are understood and agreed upon by all involved agencies, clearly defined roles and responsibilities, and a system of accountability. Both senior and frontline staff need to be committed and involved in policy development. Strong leadership is important, as well as sufficient resources, including administrative support and dedicated time for joint activities. Hiring staff with the right skills and approach is important, as is providing appropriate support and supervision. Regular monitoring and evaluation of the service, as well as reviewing policies and procedures, is necessary to adapt to changing circumstances and new knowledge (Sloper, 2004).

2.4.3 Implementation of Multi-agency Collaboration

Although there are various barriers to multi-agency collaboration, the demand for effective partnership continues to be prevalent and ways of implementing multi-agency collaborations regarding child healthcare, including collaborations between health and education services, are beginning to emerge (Power et al., 2013).

The Key Worker Model. One technique that adopts a multi-agency approach to working with children with special needs and is suggestive of some positive outcomes for families is a key worker model. Many terms are often used interchangeably with ‘key worker’, such as ‘care coordinator’, ‘link worker’, ‘guide’, ‘service coordinator’, ‘navigator’, ‘family support worker’, and ‘family liaison worker’. The key worker model is a method of offering support to families by assigning a designated individual to act as a guide and central point of contact. This person helps families coordinate their care across different systems, such as healthcare, education, and social services. The main goal is to enable a needs-led approach and empower parents by providing them with personalised support, resources, and information. This model involves the key worker being consistently available to families and providing assistance in understanding and navigating systems. This may include attending meetings or appointments, interpreting assessment results, and helping parents develop skills to empower themselves. When there is no designated keyworker model in place, professionals who work with the child often end up taking on the role by default which may be beyond their scope of practice. Furthermore, they may not have the necessary skills or capacity to effectively fulfil this role (Bruder et al., 2005; Drennan et al., 2005).

The importance of effective care coordination for families with children who have special care needs is consistently highlighted within the literature. Children with an array of health or developmental issues tend to be under the care of multiple services which can compromise family-focused care (Law et al., 2003). Caregivers frequently experience a lack of information and support to meet the various needs of their child, including developmental guidance, respite care, necessary equipment, and financial aid. Caregivers encounter difficulties in obtaining the necessary information and services, causing heightened stress and detrimental effects on their child's development. This also increases the risk of the child's and family's needs being overlooked or not met due to gaps in the services provided by different agencies. Many caregivers express a desire for a single point of contact and a trusted person to help them navigate and obtain the necessary support (Sloper et al., 2006).

In their 'keeping current' article for the CanChild Centre for Childhood Disability Research, Drennan and colleagues (Drennan et al., 2005) highlight that the effectiveness of key worker models continues to be explored with a range of strengths and limitations currently acknowledged within the literature. As documented in Liabo and colleagues' (2001) book reviewing key worker systems for disabled children, families with key workers reportedly experience better quality of life, improved relationships with services, easier access to services, and reduced stress levels compared to families without key workers. In contrast, while parents with a key worker tend to have a better relationship with professionals, it does not necessarily solve all the problems they face with services, which are often due to collaboration and availability issues (Beresford, 1995). Some key workers also feel frustrated as they are unable to utilise their skills and provide direct care (MacDonald et al., 1994). The concept of key working may appear simple, but putting it into practice may be complex (Sloper & Turner, 1992).

The HealthyCHILD Model. The HealthyCHILD (Collaborative Health Interventions for Learners with Differences) model is an interagency partnership model designed to serve the needs of teachers and caregivers/families for children with developmental, behavioural, and physical healthcare needs. A mobile developmental healthcare team delivers whole-school tiered support to educators, parents, and individual children on-site in education settings to promote children's social-emotional competence and teacher and parent effectiveness (Bagnato et al., 2004). The model is currently being implemented in Pittsburgh, United States, and is reported to support over 150 preschool classrooms, 300 early education professionals, and 3000 children and families in Allegheny County each year by offering onsite education, consultation, technical assistance, and direct service (University of Pittsburgh Office of Child Development, 2022). Although the literature describes the programme (Bagnato et al., 2004), little information appears to be available regarding the longitudinal effectiveness of the programme.

The Collaborative Care Model. The collaborative care model has evolved as a way of integrating the provision of mental health services. This model of practice has been shown to improve patient outcomes as well as reduce barriers to accessing services, expenditure, and stigma associated with mental health. The collaborative care team is overseen by a primary care provider who has access to behavioural healthcare managers and psychiatrists. The behavioural healthcare manager is available to liaise with a consulting psychiatrist and ensures the patient is set up with appropriate treatment pathways at the time, rather than having to await referral or having to access an alternative service for immediate care (American Psychiatric Association and Academy of Psychosomatic Medicine, 2016). Lyon and colleagues (2016) acknowledged the empirical support for implementing a collaborative care model and proposed the exploration of integrating a collaborative care approach with school-based mental health services. The ACCESS (Accessible, Collaborative Care for

Effective School-based Services) project explored the integration of a collaborative care approach with school-based mental health services. In this preliminary model, the collaborative care team is established using existing school staff who engage students and families in intervention. By situating this model within the education sector, accessibility to care can be increased, stigma associated with mental health is likely to be reduced, and the well-being of youth experiencing mental health challenges, such as ADHD, is likely to improve.

Partnering for Change. Partnering for Change (P4C) is an evidence-informed, population-based service delivery model, developed to provide rehabilitation services for children with special needs in school environments. P4C was initiated in Ontario, Canada, as a two-year project focussing on children with DCD, as they were the largest group of children on waitlists for school health support services. The model was developed by researchers at the CanChild Centre for Childhood Disability Research with an initial focus on occupational therapists (OT) partnering with educators to observe, identify, and support children in education settings with motor coordination challenges. P4C consists of four main goals: increase early identification of students with special needs; build capacity of educators and families to understand and manage children's needs; prevent secondary consequences and facilitate self and family management and improve children's ability to participate successfully in school and at home. The P4C acronym not only represents 'Partnering for Change' but also the '4 Cs' that encompass the principles of Partnering for Change; Building Capacity through Collaboration and Coaching in Context (CanChild, 2015).

The partnership for carrying out P4C includes educators, families, children, and therapists. The P4C model reflects the collaboration required between the different stakeholders to create environments that will enable successful participation for all students. Beginning with a foundation that focuses on relationship building and sharing of knowledge, the stakeholders collaboratively design environments that facilitate skill development for children of varying abilities, differentiate instructions for children experiencing challenges, and accommodate for children who need to participate in an alternative way (CanChild, 2015). Similar to the learning support tiered model (Mirfin-Veitch et al., 2020) in New Zealand which will be discussed in further detail in a later section, the P4C model uses a needs-based tiered approach where all students are supported through class-wide health promotion and learning (universal design for learning). Students who require further support are assisted through targeted services, small group intervention, and more individualised or specialised programmes are put in place for children who continue to have difficulties after trialling the lower levels of tiered input (CanChild, 2015).

P4C offers an alternative to a referral-based model, where children are identified as requiring further input and referred to other services. The referral-based model is shown to have many deficits including long waitlists, inequities in access, poor coordination of services, and limited opportunities to develop educator capacity (Deloitte & Touche LLP, 2010; Dunford & Richards, 2003; ISD Scotland, 2012). P4C applies a population-based approach where the whole school is the target of intervention, allowing therapists to reach a vast number of children. Within the P4C model, collaboration and intervention are carried out in the education setting which aids therapists' integration into the school setting, allows for services to be provided in context and in a timely manner, and therapists can support educators through knowledge translation (Campbell et al., 2012; Missiuna et al., 2015).

The P4C project emphasises the success possible when researchers, healthcare, and education systems collaborate together, allowing research to be applied to practice. The P4C project found that educators' capacity was built, children who needed support were identified and responded to earlier, and children with a variety of diverse needs were able to be supported. Although P4C was initially designed to support children with DCD, focussing on fine and gross motor skill development, the model has helped identify and provide skill development beyond this, such as organisation, social interaction, and self-regulation skills, to support all children’s engagement in school occupations. P4C facilitates equitable opportunities for children to access the necessary support to be able to participate wholly in their school experience (CanChild, 2015). Through educator and therapist partnership, when implementing P4C, therapists were able to identify children who had difficulties engaging in school occupations, many of whom may not have been identified or deemed appropriate for services without the therapist’s oversight (Missiuna et al., 2017). An additional finding from the implementation of P4C was the elimination of waitlists (CanChild, 2015; Missiuna et al., 2017).

Many positive outcomes of the P4C project have been noted, however, additional research is required to foster further success. The initial P4C project has set a firm foundation enabling opportunities to expand the P4C service within Ontario. The P4C model was specifically designed for the Ontario school and healthcare systems and is in the emerging stages of revealing generalisability to other school and healthcare systems (Campbell et al., 2023). The original P4C project did not address whether the model extends beyond occupational therapists, to fit with the roles of other school-based rehabilitation providers such as speech-language therapists or physiotherapists. Given the project has only seen short-term implementation, longitudinal research would be beneficial to better understand the outcomes over time (CanChild, 2015).

Phoenix and colleagues (2021) used participatory action research and qualitative case study methods to extend P4C research by utilising an interprofessional team consisting of OTs, special education resource teachers (SERT) and speech-language pathologists (SLP). The Ontario-based project, titled INtegrated serviCes for incLUsion anD Equity (INCLUDE), found that when time and support are in place, the interprofessional team was able to work collaboratively to develop and implement tiered services within the school setting. Similar to outcomes from the initial P4C project (CanChild, 2015), the benefits of the INCLUDE project included the provision of a timely service, capacity building, and student goal attainment. Barriers were also identified including service fragmentation, primarily associated with the SERTs and SLPs being employees of the school board whereas the OTs were employees of a community agency contracted for school-based services. This meant that team members had different access to resources contributing to confusion around gaining consent. Additional barriers included lack of time, workload, and the complexity of students' needs. Directions for future research could include considering the inclusion of psychologists and/or social workers, particularly for schools in disadvantaged or low socioeconomic areas, including trauma-informed training for the team, and gaining children's perspectives on their experience of the project (Phoenix et al., 2021).

2.5 The Need for Enhancing Child Development Services for Neurodivergent Children in New Zealand

2.5.1 Child Development Services

New Zealand CDS are described by the Ministry of Health (2012) through the service specifications as

> …non-medical, multidisciplinary allied health and community based. Whilst a significant component of the service is early intervention for preschool children who have disabilities or who are not achieving developmental milestones, the service is intended to promote and facilitate each child's developmental pathway so that their maximal potential is attained throughout their development and growth. (p.1)

A total of 31 providers are contracted to deliver CDS across New Zealand (Claridge, 2023). The types of services that are outlined in the CDS service specification include specialised allied health assessment by a multidisciplinary team, applications for equipment and housing modifications, and the provision of appropriate therapies to facilitate and enhance the development of neurological and motor skills and functions, swallowing and feeding skills, respiratory skills and function, and speech, language and communication. Additional services include the provision of therapy follow-up after surgical intervention or a medical episode related to a child's disability, support and education for whānau and other support persons directly involved in services delivered to the child and liaison with the school and relevant fund-holders for the Ministry of Education (MOE), particularly at the time of transition from early childhood services into school-based services (Ministry of Health, 2012).

The New Zealand Disability Strategy 2016 – 2026 (Ministry of Social Development, 2016) states that disabled people include "…those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (p.12). The 2013 New Zealand Disability Survey (Statistics New Zealand, 2014) showed that one in four (24%) New Zealanders have a physical, sensory, learning, mental health, or other disability. In 2013, 95,000 (11%) of New Zealand children aged between 0-14 years were identified as disabled. Learning difficulty was the most prevalent impairment, impacting 6% of all children and 52% of those with disabilities.

According to the service specifications (Ministry of Health, 2012), the CDS inclusion criteria for service users include:

- children and young people who have been identified as having a physical, sensory, or intellectual disability (ID), or a combination of these, which is likely to continue for a minimum of 6 months;
- children who are at risk of developing such a disability or have developmental delay;

- children who have ASD;
- whānau and advocates associated with those children.

The CDS service specifications were last revised in October 2010 and were due for review in 2012 (Ministry of Health, 2012). It is recognised that the current provision of CDS is insufficient in meeting the growing need for access to allied health support for children. This has resulted in service rationing (withholding and/or failure to carry out necessary tasks), lengthy waiting periods for service users, and unfortunate situations where some children are unable to receive the necessary support to achieve their goals and live their fullest lives (Claridge, 2023).

Throughout the duration of the current project, the New Zealand health system was reformed and the previously existing 20 District Health Boards (DHB) who were responsible for providing or funding health services within their district (Ministry of Health, 2020, February 12) merged into the nationwide health system of Te Whatu Ora - Health New Zealand (Department of the Prime Minister and Cabinet, 2022, September 06). Prior to this, CDS were provided by the 20 DHBs and 11 non-government organisations under the Ministry of Health (Claridge, 2023). However, with the introduction of Te Whatu Ora, the Ministry of Disabled People (Whaikaha) was established and CDS was transferred from the Ministry of Health to Whaikaha (Sepuloni & Williams, 2022, July 01).

The significance of the improvements required to modernise the national delivery of CDS is beyond the breadth of the current research, therefore a case study approach will be applied in the context of the Child Development Centre (CDC), the primary provider of CDS within the Waikato region. The McKenzie Centre and Conductive Education are also contracted as CDS providers within the Waikato region, however, their primary service provision involves early intervention support for children from birth to school age with developmental differences or disabilities (Conductive Education Waikato, n.d.; McKenzie

Centre, n.d.). The outcomes of the CDC case study may be beneficial in informing and streamlining nationwide changes within CDS.

2.5.2 The Child Development Centre

The CDC is based at Te Whatu Ora Waikato in Hamilton, New Zealand and comprises a variety of multidisciplinary professionals including psychologists, occupational therapists, physiotherapists, speech-language therapists, social workers, paediatricians, and visiting neurodevelopmental therapists. The service provides assessment for children aged 0-16 years, who have, or are suspected of having developmental problems including, but not limited to, developmental delay or ID, ASD, or neurological conditions such as DCD. Some age variations exist within the different services provided by CDC, such as the ASD coordinator service which is available for those up until 19 years (Waikato District Health Board, n.d.). Te Whatu Ora Waikato serves a population of more than 425,000 and covers more than 21,000km² (Te Whatu Ora Waikato, n.d.).

The CDS specifications currently describe key functions as specialist assessment, equipment and housing assessment, and clinical intervention to promote rehabilitation/habilitation outcomes for children. However, service rationing has resulted in the prioritisation of diagnostic assessment and assessment for equipment, at the compromise of the provision of intervention and therapeutic support (Claridge, 2023; Thabrew & Eggleston, 2018). Therefore, a primary focus for the current project will be considering the current and future delivery of CDC through the lens of the diagnostic assessment process. Gaining a comprehensive understanding of the perspectives of stakeholders and enhancing the processes related to diagnostic assessments may contribute to the overall effectiveness and efficiency of the service and assist in addressing the current challenges and limitations that hinder the service from fully meeting its specifications.

Although CDC supports children with a range of disabilities, the current prioritisation of multidisciplinary diagnostic assessments primarily consists of assessments for conditions that sit within the diagnostic umbrella of neurodevelopmental disorders, such as ASD, ID, GDD, and DCD (American Psychiatric Association, 2013). To manage the scope of the current research, the project will primarily focus on children with or suspected of having neurodevelopmental disorders which are assessed for at CDC and/or neurodivergence that affects their development.

The CDC hosts an array of different waiting lists depending on the service needs and age of the child. A summary from August 2023 of four of the main waiting lists most relevant to the current project is presented in Table 1.

Table 1

Summary of August 2023 CDC Waitlists

Type of clinic	Total number of children waiting	Number of children waiting longer than one year
Multidisciplinary assessment for pre-school children	268	5
Multidisciplinary assessment for school-aged children	232	51
Assessment focused on cognition and potential ID	119	23
Assessment focused on social communication and potential ASD	100	3
Total	629	82

2.5.3 Enabling Good Lives

Enabling Good Lives (EGL) is a social movement within New Zealand that responds to the oppression of disabled people. A review conducted by individuals in the disability sector in 2011 found that fundamental changes were required in the disability support system to address persistent issues in how the government provided assistance to disabled people. The resulting report was titled 'Enabling Good Lives'. In 2012, the Ministries of Social Development and Health worked with disability sector organisations to pilot the EGL approach in Wellington, Christchurch, and Hamilton (Enabling Good Lives, 2023).

The objectives of EGL are targeted toward making it easier for disabled people and their families to create good lives for themselves through the promotion of enhanced autonomy and influence over the support they receive and how resources are used. A principles-based approach has been adopted by EGL to ensure they stay on course towards realising their vision that in the future, disabled children and adults, and their families will have greater choice and control over their supports and lives, and make more use of natural and universally available supports. Eight core principles provide a foundation and framework to guide positive change for disabled people within the EGL approach: self-determination, beginning early, person-centred, ordinary life outcomes, mainstream first, mana enhancing, easy to use, and relationship building (Enabling Good Lives, 2023). Refer to Appendix A for a more detailed description of the principles.

Following successful trials of EGL in Wellington, Christchurch, and Hamilton, in 2021, the New Zealand government announced plans to implement the EGL approach to Disability Support Services on a national scale (Sepuloni & Little, 2021, October 29). With the proposition to implement EGL nationwide, CDS plans to better reflect the EGL principles within any changes or developments of current and future service policies and procedures (Claridge, 2023). Therefore, to ensure the current project aligns with the goals of nationwide CDS improvements, it is important to consider and apply the EGL principles.

2.5.4 Disability and Education in New Zealand

School is a primary environment for the engagement and participation of children; therefore it is important to understand the impact of the education setting on disabled children. Historically, children with special education needs were excluded from mainstream school settings, with the responsibility for providing education to this group of students placed on churches and voluntary organisations (Mitchell, 1987). Within a New Zealand context, the introduction of the New Zealand Education Act in 1989 granted disabled children the right to enrol in their local school, thus adopting a mainstream movement. The introduction of this Act prompted the establishment of satellite classes within mainstream schools, and some special schools were closed down (New Zealand Government, 2020, August 01). A major reform of special education occurred with the introduction of the Special Education 2000 policy. With the introduction of this policy, schools have been actively encouraged to move from a segregated educational system to an inclusive mainstream model (Ministry of Education, 1995). Under the Education and Training Act 2020, schools are required to be inclusive. The Act declares that all enrolled students regardless of learning support needs or disabilities, are entitled to attend school for the complete duration of school hours (Ministry of Education, 2020b). However, some students and their families have experienced schools limiting their attendance to part-time. The inclusion of disabled children in mainstream school settings means education communities now host children with a variety of strengths, needs and abilities, and have a responsibility to respond to their needs (Phoenix et al., 2021).

In New Zealand, the Ministry of Education (MOE) is the government’s lead advisor on the education system, shaping the direction for education agencies and providers, and contributing to the government’s goals for education (Ministry of Education, 2021, February 12). There are many facets of support available within MOE such as learning support and specialist services. The MOE advise that learning support is available for children and young people who are autistic, who are blind or have low vision, identified as deaf and hard of hearing, with speech, language and communication needs, and those with additional learning needs that require specialised equipment and technology to use in class to increase or improve their ability to learn and participate. The MOE provides specialist services that support students with physical disabilities, positive behaviour for learning, and managing difficult behaviour. Specialist staff may include Resource Teachers: Learning and Behaviour (RTLB) who are available to work alongside schools to provide learning support as required (Ministry of Education, 2022, October 13). The School High Health Needs Fund (SHHNF) supports children at school who have high health needs as a result of significant health conditions such as incontinence, diabetes, severe allergies, or seizures (Ministry of Education, 2021, July 19).

An additional support stream includes the Ongoing Resourcing Scheme (ORS): A government-funded scheme that provides support for students requiring a high level of ongoing need for specialist learning support. The ORS funding enables children to attend specialist schooling or satellite classes, or join in and learn alongside other children in mainstream classroom contexts with the provision of specialist supports such as allied health therapists (occupational therapists, physiotherapists or speech-language therapists), teacher aide support, and materials (Ministry of Education, 2021, March 30). Given that ORS funding is set aside for children with particularly high needs, most children who require additional support to reach their full learning potential rely almost completely on their classroom teacher to provide it (Mirfin-Veitch et al., 2020). In New Zealand, on average, 15% of each school’s students are identified on the school’s ‘special needs register’ (NZEI Te Riu Roa, 2018), however only around 1.2% of children and youth attending school meet the criteria to receive ORS funding (Ministry of Education, 2020, December).

In New Zealand, learning support is conceptualised within a tiered support model, comprised of three tiers, designed to improve student learning outcomes. This framework reflects the varying needs of students and the support available across a range of intensities (Mirfin-Veitch et al., 2020). Tier one, ‘universal learning support’, consists of inclusive practices whereby most children’s learning and behaviour needs will be met. Tier two, ‘targeted learning support’, recognises that some children may benefit from a more deliberate and direct approach which is likely to comprise of more intensive instruction and additional materials, for children who are not progressing under universal instruction. This may be carried out in smaller group sessions with frequent monitoring of individual progress. Tier three, ‘individualised learning support’, consists of intensive, specialist interventions and support, with more in-depth monitoring of progress (Ministry of Education, 2020a; Mirfin-Veitch et al., 2020). It is believed that most neurodivergent students in New Zealand currently have their needs responded to under tier one and tier two, however many would likely benefit from receiving a more individualised approach under tier three (Mirfin-Veitch et al., 2020). Neurodivergent children often learn and process information differently from others and as a result, a typical classroom environment and teaching style are unlikely to be optimal for their learning (Ministry of Education, 2019).

The Learning Support Action Plan 2019 – 2025 (hereafter referred to as the Action Plan) was released by MOE in July 2019. The Action Plan acknowledges the need for improvements to be made to better support disabled children and children with additional learning needs. It outlines the plan and priorities for helping children with disabilities in New Zealand, specifically focusing on supporting those with dyslexia, dyspraxia, ASD, and other learning needs that do not qualify for ORS. It is estimated that one in five children and youth currently in the New Zealand education system requires some form of additional support for their learning. This may be due to disability, learning difficulties, disadvantages, physical or mental health, or behaviour issues (Ministry of Education, 2019; Mirfin-Veitch et al., 2020). Almost all of these children do not meet the criteria to receive funding support through ORS (Ministry of Education, 2019).

The Action Plan includes six priorities to address recommendations received by MOE. Priority four is of particular relevance to the context of the current project: ‘flexible supports for neurodiverse children and young people’. This priority emphasises the need for an improved range of support and services for neurodivergent children, particularly those with moderate needs who do not meet the threshold for ORS support. Priority four acknowledges the importance of strengthening early interventions for neurodivergent children as well as providing ongoing support throughout their education. Ensuring neurodivergent children receive the support they need should help mitigate long-term effects that can negatively impact well-being, such as difficulty with transitions between education levels and settings, being excluded from school, youth offending, or mental health problems (Ministry of Education, 2019).

Mirfin-Veitch and colleagues (2020) undertook an integrative literature review commissioned by the MOE as one response to the fourth strategic priority within the Action Plan (Ministry of Education, 2019). This review revealed five key themes: prioritising and valuing relationships, developing agency, supporting students to understand and manage their own behaviour creating inclusive environments, and embedding inclusive strategies (Mirfin-Veitch et al., 2020). Within the prioritising and valuing relationships theme, it is acknowledged that a key component of successful inclusion for neurodivergent students involves a partnership between educators and other service providers. It is important for various professionals working with neurodivergent students to collaborate on identifying children’s strengths and needs and establishing collective ways to support optimal learning outcomes for the student (Alquraini & Gut, 2012; Mirfin-Veitch et al., 2020).

2.6 The Current Project

Neurodevelopmental disorders, which can result in difficulties with social, personal, cognitive, and/or occupational functioning, are estimated to affect 3-10% of New Zealand preschool-aged children (Cutfield et al., 2019). Although the symptoms and behaviours associated with these disorders may change as a child grows older, some difficulties persist and can result in lifelong challenges in a variety of contexts including academic settings and professional environments (American Psychiatric Association, 2013; Anderson et al., 2014; Faraone et al., 2006; Howlin et al., 2004; Magiati et al., 2014; Simon et al., 2009). It is recognised that the current delivery of support provided in New Zealand is insufficient in meeting the growing need for access to allied health support for neurodivergent children within both the home and education settings (Claridge, 2023; Mirfin-Veitch et al., 2020). Increased demand and resourcing confinements have resulted in the rationing of services within CDS, extensive waitlists, and situations where some children are unable to receive the necessary support to achieve their goals and live their fullest lives (Claridge, 2023). At present, there is no comprehensive data that exists on the viewpoints held by stakeholders in New Zealand regarding the accessibility and quality of CDS care provided for neurodivergent children and there is a lack of research conducted on ways to enhance the delivery of services tailored to the specific needs of these children within the New Zealand context. To create solutions that effectively address the needs of neurodivergent children, it is important to first identify and understand the challenges they encounter when attempting to access services and supports. Therefore, there is a need to explore alternative ways of delivering CDS in New Zealand with the ultimate aim of fostering improved health and social outcomes for this particular demographic.

From the reviewed literature, it is evident that adequately supporting the needs of neurodivergent children poses significant challenges on an international scale. Consequently, finding effective strategies to provide them with the necessary services and support is an ongoing process. One promising recommendation that has emerged within this research is the implementation of multi-agency collaborative approaches. However, despite ongoing research, training, and other resource development designed to improve collaboration between children's healthcare and education services, there is little research suggesting consistency within the development or implementation of these partnerships (Schwab & Gelfman, 2005; Shapiro & Manz, 2003). The generalisability and longitudinal outcomes of models attempting to enhance collaboration between child health and education settings are also limited (CanChild, 2015; Michel et al., 2018; Phoenix et al., 2021; Power et al., 2013; Talbott et al., 2021).

In addition to the clear need for service improvements, the reviewed literature also suggests that there is an ongoing need to further explore the potential effectiveness of collaborative strategies that involve multiple agencies. Given the gaps identified regarding the development and implementation of interagency partnerships, it is also worthwhile exploring whether there are alternative or novel approaches being suggested by those affected by the pressing need for enhanced access to support for neurodivergent children. To ensure the development of effective and practical solutions that are relevant for implementation in real-world settings and effectively meet the unique needs of these children and their families, it is important to gather and understand perspectives from those with lived experience as well as various individuals who have varying degrees of involvement with these individuals.

2.7 Research Aims and Questions

Drawing inspiration from grounded theory and co-design principles, the current research project will use the Waikato region as a case study to explore and investigate the perspectives of stakeholders regarding the accessibility and provision of support for neurodivergent children within the Waikato region of New Zealand. In addition, the study will also explore whether stakeholders perceive a multi-agency approach, as mentioned in previous literature (Bagnato et al., 2004; Bruder et al., 2005; CanChild, 2015; Drennan et al., 2005; Lyon et al., 2016; Phoenix et al., 2021), as a potential avenue for enhancing the provision of CDC services in Waikato. To minimise long-term adverse outcomes for neurodivergent children, research suggests the need for early diagnosis and earlier intervention to extend beyond the health sector into schools (Fleming et al., 2020; Power & Bradley-Klug, 2013). By identifying and understanding the strengths and weaknesses related to the existing access to and provision of support for neurodivergent children, as well as identifying the obstacles in implementing service changes and establishing multi-agency collaboration, valuable insights can be gained to inform recommendations for improved CDC service provision to increase responsiveness to individual needs. Such insights may assist in informing best practice policies that ultimately lead to the establishment of efficient and consistent care for neurodivergent children throughout the entirety of New Zealand.

The overarching aim of this project is to develop a proposed service delivery model encompassing an enhanced provision of CDC services within the Waikato region. To inform the development of a service delivery model that is grounded in literature and stakeholder insights, the research seeks to understand two key research questions:

1. What are the current perspectives of stakeholders regarding the access to and provision of support for neurodivergent children in the Waikato region?
2. How can the delivery of CDC be enhanced to ensure improved health and social outcomes for neurodivergent children in the Waikato region?

Chapter 3: Methodology

The structure of this chapter is inspired by Saunders and colleagues' (2019) 'research onion' approach to designing research methodology. The application of a pragmatic philosophical research paradigm is discussed. The project is divided into two distinct phases which employ the use of qualitative data collection methods including semi-structured interviews and focus groups. The relevance of inductive, deductive, and abductive reasoning approaches to theory development is considered. The research strategy draws upon principles of grounded theory and co-design. Lastly, my role as the researcher and my position within the context of the project are introduced.

3.1 Research Philosophy

The research philosophy is the foundation of any study as it describes the system of beliefs and assumptions the research is built upon (Saunders et al., 2019). Throughout every stage of a research project, researchers make a variety of assumptions both consciously and unconsciously (Burrell & Morgan, 2019). These may include ontological assumptions concerned with concepts of existence and reality, epistemological assumptions relating to the nature of justifiable knowledge, and axiological assumptions such as how much and in what ways the researcher's personal values and beliefs affect the research. These assumptions inherently influence how the research questions are understood, the methods applied to carry out the research, and how the findings are interpreted. Having awareness of and reflecting on worldviews and assumptions facilitates a credible research philosophy that ensures the research process is rigorous, ethical, and effective in producing valid and reliable results that can be used to inform decision-making (Crotty, 1998).

Of the many philosophical research paradigms, such as positivism and interpretivism, pragmatism was selected as the paradigm to underpin the current project. Pragmatism is a style of research philosophy founded in the 19th Century by Charles Sanders Peirce (Brown et al., 1996). Pragmatism is often applied in research that is focused on generating practical solutions and outcomes to assist in solving real-world problems (Saunders et al., 2019; Yvonne Feilzer, 2010). The ontological premise of pragmatism recognises that reality results from the practical implications of ideas and is constantly reevaluated and interpreted according to its relevance in specific contexts (Allemang et al., 2022; Saunders et al., 2019).

Pragmatic research aims to build knowledge and understand the world through human experience while recognising that knowledge is constructed based on interactions between people and their environments (epistemological assumption) (Allemang et al., 2022). Pragmatism approaches research from a practical, and reflexive point of view (axiological assumption), where knowledge is constantly questioned and interpreted, and meaning is created from human experience (Allemang et al., 2022; Denzin, 2012). Pragmatism offers an action-orientated research framework that encourages the researcher to fluidly apply the best tools available to address real-world problems and seek answers to the research questions (Hothersall, 2019; Johnson & Onwuegbuzie, 2004). A pragmatist commences research with a problem and seeks to provide useful solutions that influence current and future practice (Saunders et al., 2019). The overall aim and research questions of the current research project incorporate a pragmatic emphasis on practical outcomes as the research is focused on understanding stakeholders' experiences regarding the access to and provision of support for neurodivergent children and using this information to generate practical ideas on how service delivery can be improved.

3.2 Research Design

The research design is a framework that outlines how data will be collected and analysed to address research questions and aims. It supports the rationale for the choice of data sources, collection methods and analysis techniques (Saunders et al., 2019). The current project was interested in understanding stakeholders’ perspectives and using the data to facilitate the development of a service delivery model, therefore the most appropriate research design to achieve the aims of the project was a qualitative approach. This approach would allow participants an opportunity to openly share their thoughts and ideas about their experiences relevant to the provision of support for neurodivergent children. Semi-structured interviews and focus groups were selected as the qualitative methods of data collection for an in-depth investigation of attitudes and beliefs. Semi-structured interviews are recognised as being favourable for exploring in-depth experiences of participants, and the meanings they assign to their experiences. Semi-structured interviews are particularly beneficial in situations where the nature of the study question is exploratory (Kvale & Brinkmann, 2009). Focus groups were used to facilitate discussion of agreement and disagreement and to organically contribute to the research process (Flynn et al., 2018).

The project was divided into two phases. The first phase involved undertaking semi-structured interviews with key stakeholders to identify current perspectives regarding the access to and provision of support for neurodivergent children and ideas around how service provision of CDS could be enhanced. The second phase consisted of two focus groups where the findings generated from the stakeholder interviews and evidence arising from the literature were presented, enabling the focus group participants to inform the development of a service delivery model.

There are three main reasoning approaches to theory development: deduction, induction, and abduction. Each type of reasoning is responsible for distinctly different ways of producing knowledge. With deductive research, the research begins with established theory or hypotheses and the research strategy is designed to test the hypothesis and tends to be confirmatory. An inductive approach tends to be exploratory as data are collected to explore a phenomenon, themes and patterns are identified, and theory is generated from the collected data (Saunders et al., 2019). Abductive reasoning moves back and forth between deduction and induction and aids inductive conceptualisation (Birks & Mills, 2015). Data collection is applied similarly to an inductive approach to explore a phenomenon and identify themes and patterns but is then located in a conceptual framework, often incorporating existing theory, to generate a new or modify an existing theory which is subsequently tested (Saunders et al., 2019).

Phase one of the project primarily employed an inductive reasoning approach. Data from semi-structured interviews were collected and analysed without any pre-existing hypotheses or theories. Instead of generating a service delivery model purely based on the collected data, elements of deductive reasoning were applied for the second phase of the project to ensure data was adequately integrated with evidence. Knowledge of pre-existing models and literature was presented alongside the novel data to a focus group to allow participants the opportunity to share their thoughts and ideas on the connections and applicability of the literature and data to the project context. An abductive reasoning approach was applied throughout the analysis of the focus group feedback, leading to further deliberation with the literature and novel data to inform the development of a proposed service delivery model. Due to the movement back and forth between different reasoning approaches, the current research project as a whole can be regarded as primarily adopting an abductive reasoning approach. The application of abductive reasoning also aligns with a pragmatic philosophical perspective as abduction resembles the process of making practical influence. Charles Sanders Peirce compared abduction to pragmatism, where the value of a theory is based on its practicality and usefulness in leading to action. This connection between abduction and pragmatism can enhance comprehension of scientific usefulness and help differentiate between valid and invalid findings (Hartshorne & Weiss, 1974).

3.3 Research Strategy

A research strategy is a general plan of how the researcher intends to address the research questions. Common qualitative research strategies include ethnography, grounded theory, case studies, action research, and narrative inquiry (Saunders et al., 2019). As this project was divided into two phases involving different processes, it was difficult to align a singular research strategy that was applicable for conducting the entirety of the research. Instead, the research strategy was inspired by principles derived from grounded theory and co-design which were intertwined between both phases of the project. The project was designed around using the data gathered during semi-structured interviews (phase one) as a foundation for generating categories to inform the development of a model of service delivery, then working collaboratively with stakeholders to combine literature and data to consolidate and integrate the model with theory (phase two).

3.3.1 Grounded Theory

Grounded theory was selected as the primary research strategy for inspiring the data collection and analysis methods for phase one of the project. Grounded theory is described by Birks and Mills (2015) as an approach to research that begins with data collection and aims to generate a theory that is grounded in or derived from data, through the application of systematic analysis, rather than establishing a preconceived hypothesis and collecting data to prove or disprove the hypothesis. This primarily comprises of an inductive reasoning approach, as it involves moving from specific observations to pattern recognition and more general conclusions, rather than the other way around.

The concept of grounded theory was first introduced by sociologists Glaser and Strauss in response to the limitations of traditional qualitative research methods while working together on a study titled ‘Awareness of Dying’ in 1965 (Chun Tie et al., 2019; Glaser & Strauss, 2017). Glaser and Strauss’ grounded theory was deeply rooted in positivism, and it subscribed to the idea of objective reality, which could be assessed by a neutral observer who did not possess pre-existing knowledge of the topic (Saunders et al., 2019). A key element of Glasser and Strauss' approach was the development of the constant comparative method which involves an iterative process of analysing qualitative data by breaking it down into smaller parts, identifying codes and themes, and constantly comparing and categorising them. Within the constant comparative process, the data is constantly refined and developed as more data is collected. The Glasser and Strauss approach to grounded theory requires the literature review to be completed following data analysis as they felt that any prior knowledge of the research added bias and could negatively influence the content and quality of the generated theory (Sebastian, 2019).

Since its inception, variations in grounded theory have evolved and expanded with contributions from other grounded theorists. Key contributions have included the input of Strauss and Corbin (1990) and Charmaz (1995). Strauss and Corbin's approach to grounded theory emerged as a response to criticisms of the original Glaser and Strauss grounded theory method (Strauss & Corbin, 1990). One of the criticisms of Glaser and Strauss' approach was that their work did not discuss grounded theory as a methodological/methods package but instead focussed only on techniques/methods that could be used (Amsteus, 2014). When Strauss and Corbin first presented their perspective on grounded theory, reference to methodology and philosophical underpinnings were also lacking, however, they updated their perspective by highlighting the application of pragmatism and symbolic interactionism philosophy (Chamberlain-Salaun et al., 2013; Corbin & Strauss, 2008). Symbolic interactionism is a sociological theory that relies on the symbolic meaning that people develop and expand upon through the process of social interaction. The symbolic interactionism perspective believes that society is socially constructed through the subjective meaning, interpretation, and beliefs people attach to social interactions, objects, events, and behaviours, rather than what is objectively true (Carter & Fuller, 2015).

In comparison to Glaser and Strauss who felt the researcher should be a neutral observer, Strauss and Corbin (1990) recognised that the researcher cannot be completely blind or ignorant to their own perspectives, histories, and values, or earlier literature in their field of study. To avoid these effects having a detrimental influence on or steering the research emphasis, data collecting, or categorisation, Strauss and Corbin suggest researchers become aware of and acknowledge these impacts. These details can be used to improve the general focus and quality of the research, the development of data categories, and, ultimately, the theoretical underpinnings (Sebastian, 2019; Strauss & Corbin, 1990).

Charmaz (1995) described a contemporary form of the original grounded theory method coined ‘constructivist grounded theory’ (CGT). CGT is underpinned by the philosophical influence of pragmatism and constructivism (Sebastian, 2019). Constructivism is a theory that recognises that people actively engage with their surroundings to create reality rather than passively absorbing information from external sources (Birks & Mills, 2015).

Charmaz (1995) asserted that the researcher is a co-participant in the study rather than a neutral spectator. Within a constructivist approach, Charmaz emphasises the role of the researcher's reflexivity in the research process and that data, theories, and research processes are ‘constructed’, rather than discovered, through the interactions between the researcher and the participants. In line with Strauss and Corbin (1990), Charmaz (2014) asserted that prior knowledge can support a research project as long as it does not define the study. Instead of trying to forget or erase prior experiences or expertise, constructivist grounded theorists should acknowledge and reflect on their perspectives. Preconceived notions may serve as exploratory instruments rather than final ideas, creating an opportunity for enquiry as opposed to shutting it down. As a result, these ideas or areas of enquiry can facilitate development during the early stages of a project's growth.

Chun Tie and colleagues (2019) describe the different variations of grounded theory as distinct methodological genres; traditional grounded theory (associated with Glaser and Strauss), evolved grounded theory (associated with Strauss and Corbin), and constructivist grounded theory (associated with Charmaz). Although there are some variations within the philosophies, techniques, and terminology among the different grounded theory genres, many commonalities exist. To facilitate a consistent application of grounded theory, Birks and Mills (2015) present a framework that encompasses the essential grounded theory methods including; concurrent data collection and analysis, theoretical sampling, writing memos, theoretical sensitivity, constant comparative analysis, initial coding and categorisation of data, intermediate coding, identifying a core category, and advanced and theoretical coding. Within grounded theory, data collection and analysis, writing memos, theoretical sampling, and theoretical sensitivity methods are dynamic and occur cyclically throughout the grounded theory research process (Chun Tie et al., 2019). To maintain a consistent approach to applying ground theory, the essential grounded theory methods as outlined by Birks and Mills (2015) are explained and applied to the current research.

The grounded theory process begins with the researcher gathering data using a purposive sample of participants (Chun Tie et al., 2019). Kelly (2010) describes purposive sampling as a method of sampling that is used when respondents are selected purposefully because of their relation to the research context and their likely contribution of relevant in-depth and detailed perspectives. This initial data is coded and analysed before further data is collected and the analysis process is repeated (Glaser & Strauss, 1999). This process is a key component of grounded theory research design referred to as concurrent data collection and analysis. Following the initial purposive sampling method, theoretical sampling is applied for further recruitment of participants. For the current project, the application of purposive sampling guided and encouraged the researcher to consider the population groups and individuals within the groups who may be appropriate to approach for recruitment to participate in the study.

Theoretical sampling is defined by Birks and Mills (2015) as the procedure of finding and following clues that emerge during analysis in a grounded theory study. Theoretical sampling is used to focus and fuel the ongoing comparative analysis of the data. Participants are chosen strategically based on who will provide the most pertinent information to assist the researcher in pursuing leads appearing in the data. During the theoretical sampling process, writing memos is crucial as it supports the researcher in conceptually planning out potential sources to sample while also maintaining a record of decisions made regarding the research process.

The process of memoing is a fundamental analytical process in grounded theory. Memos are written notes of the researcher’s thoughts, feelings, decisions, and ideas throughout the duration of the grounded theory study. Writing memos is a continuous process of grounded theory research commencing at the beginning of the study design through until its completion. Memos are reflective, interpretive insights that contribute to the understanding of the theoretical connections between categories and assist with formulating the findings of the grounded theory research (Birks & Mills, 2015). Memoing assisted the application of a pragmatic approach to the current project by encouraging constant questioning and interpretation of observations and knowledge.

The ability to recognise and identify elements from the data that are pertinent to the evolving theory is known as theoretical sensitivity (Birks & Mills, 2015). The concept of theoretical sensitivity was initially described as a two-fold idea by Glaser and Strauss in 1967.

First, they recognised that a researcher's degree of theoretical sensitivity is highly individual and reflects their understanding of themselves and the subject matter that they are researching. Second, a researcher's theoretical sensitivity reflects their intellectual background and the theories they have read and assimilated, and currently apply to their daily thinking. Researchers are the culmination of all their experiences and this reality is acknowledged and taken into consideration in the research process by the concept of theoretical sensitivity. A researcher's theoretical sensitivity to analytical options will grow as they become more and more involved with the data (Birks & Mills, 2015; Chun Tie et al., 2019). An additional way of enhancing theoretical sensitivity involves the researcher interacting with the literature (Corbin & Strauss, 2008; Hoare et al., 2012; Strauss & Corbin, 1990). Within the current project, interaction with the literature occurred due to the requirements for the completion of a research proposal, thus building my theoretical sensitivity to carry out the research.

Constant comparative analysis is an analytical process that involves constantly comparing new data with previously collected data during the process of coding and category development. Constant comparative analysis involves continuous comparison of incident to incident, incident to codes, codes to codes, codes to categories, and categories to categories (Birks & Mills, 2015; Chun Tie et al., 2019). Incidents refer to actions, characteristics, experiences, phrases and/or explanations that occur repeatedly and can be analysed for underlying concepts that can be coded. A code is a shorthand method used by researchers to identify recurring patterns and similarities in the experiences of participants. A category is a broader idea that encompasses a collection of codes (Birks & Mills, 2015). Through an inductive reasoning approach, the iterative comparative process continues until a grounded theory is fully integrated (Birks & Mills, 2015; Chun Tie et al., 2019). Alongside inductive reasoning, utilising abductive reasoning in grounded theory methods has become more prevalent in recent literature (Charmaz, 2014; Reichertz, 2007). Abductive reasoning may be applied during all phases of analysis; however, it is more commonly applied when categories are continuously compared to one another to facilitate theoretical integration (Birks & Mills, 2015).

Grounded theory data analysis begins with initial or open coding (Birks & Mills, 2015). Initial coding serves as the first step in the process of fracturing the data so that incidents can be compared to one another and early trends in the data can be compared (Chun Tie et al., 2019). Through inductive reasoning, initial coding involves generating as many codes as possible from preliminary data (Charmaz, 2014). Important words or word clusters are noted and labelled appropriately. Labels may contain in vivo codes that are often direct quotes from participants and convey participants' words as representative of a larger idea (Birks & Mills, 2015). Related codes are then grouped within categories and as the categories begin to form, initial coding transitions into intermediate coding (Chun Tie et al., 2019).

Intermediate coding is the second crucial phase of data analysis occurring during the process of category development and involves the identification of properties, dimensions, patterns, and relationships. However, the researcher switches between initial and intermediate coding as data are simultaneously collected, analysed, and compared. In contrast to initial coding which is often described as the process of fracturing the data into discrete parts, intermediate coding involves reconnecting and organising the data, and developing categories by connecting subcategories. Following this, relationships between categories are identified and categories are linked together, at which stage, a core category begins to become evident (Birks & Mills, 2015; Chun Tie et al., 2019). Diagramming is identified as a useful technique to support analysis during the intermediate coding phase (Birks & Mills, 2015).

A core category captures a phenomenon that may appear in the sub-categories and categories that have been created, as well as the relationships between them. Following extensive reflection of the data and memos, it may become apparent that categories revolve around an overarching central insight that underpins most of the data; a core category. The core category may emerge from within the categories previously identified or a more abstract term that encapsulates and explains the main phenomenon as a whole may be applied. The categories will remain connected through their relationship to the core category (Birks & Mills, 2015).

Advanced coding encompasses the methods applied to facilitate the integration of the final grounded theory. The storyline technique and theoretical coding are recommended as strategies for advancing analysis and theoretical integration. The storyline technique is described as a dual-purpose strategy providing a tool for integration, development, and formulation, which assists in the production of the final theory, as well as providing a mechanism for presenting the research findings. The storyline conceptualises the core category by building a story that links the categories and gives rise to a collection of theoretical claims (Birks & Mills, 2015).

Once the storyline is established, the grounded theory is finalised through the application of theoretical coding. Theoretical coding integrates and combines the categories generated from coding and analysis to produce the final theory (Chun Tie et al., 2019). Through theoretical coding, the previously fractured data is interlaced back together into a coherent whole theory (Glaser, 1978). To assist theoretical integration, theoretical codes can be extracted from existing theories. By positioning the grounded theory within existing theories, the explanatory power of the findings is enhanced (Glaser, 2005).

Grounded theory is highlighted as being particularly suited to research situations where little is known about a phenomenon or when the desired outcome involves the development of a new model or theory (Birks & Mills, 2015; Chun Tie et al., 2019).

Grounded theory has also been identified as a useful research technique for creating frameworks for healthcare professionals that can be applied to improve care for those receiving healthcare input (Lutz et al., 2017; Ononeze et al., 2009).

Grounded theory was considered a suitable research strategy to provide a structured research approach that would create certainty in the process but also allow for freedom and flexibility to allow the research phenomenon to speak for itself. Principles of grounded theory are useful to apply for the current project to facilitate the development of a model that is based on the experiences and perspectives of the key stakeholders who are the focus of the research, rather than relying solely on preconceived ideas or assumptions. The grounded theory approach collects and analyses data directly from real-world participants in real-world settings, allowing for the establishment of a model that is grounded in the experiences of the people involved and therefore applicable to the real world. The use of specific grounded theory principles relevant to the current project is elaborated on during the phase one method section. The application of advanced coding and the storyline was beyond the scope of phase one of the project as phase one employed grounded theory principles to facilitate the identification of categories, at which point the project progressed to phase two comprised of principles of co-design.

3.3.2 Co-Design

To aid the theoretical integration process highlighted within the grounded theory approach and to finalise the development of a service delivery model, principles of co-design underpinned the primary research strategy for the second phase of this project.

Co-design is a research approach that involves the cocreation of solutions with participants who are experts in the problem or opportunity being explored (Sanders & Stapers, 2012). Co-design focuses on understanding and improving service users' experiences of services as well as the services themselves. The co-design approach is rooted in designing with people rather than for them and is often applied to improve the provision of healthcare services (Maher et al., 2017). Co-design attempts to actively involve representatives of relevant stakeholders such as service users, frontline workers, managers and supervisors, and policy advisors, in the design process to ensure the outcomes meet their needs and are able to be applied within real-world contexts (Eyles et al., 2016; McKercher, 2020).

Although slight variations of co-design are described within the literature (Mark & Hagen, 2020), Maher and colleagues (2017) describe a series of principles relevant to the application of co-design within the context of healthcare in Aotearoa; prepare, capture the experience, understand the experience, improve the experience, and measure the improvement. These co-design principles are also often referred to as experience-based design (NHS Institution for Innovation and Improvement, 2009). The elements of co-design often overlap and do not necessarily follow a linear process (Boyd et al., 2010; McKercher, 2020).

The preparation phase begins with identifying the scope of the opportunity, problem, or challenge to be explored. Individuals who are impacted by the problem or opportunity being explored, particularly service users, are considered and recruited as participants in the co-design process (Maher, 2017). Building the foundation for the co-design participants requires creating a space where power is shared, trust is built, and service users are enabled to participate in a meaningful and safe manner (McKercher, 2020). The recruitment involved with the preparation phase of co-design is complementary to the purposive sampling approach described within grounded theory.

Capturing the experience involves applying tools that provide an avenue for people to tell their own stories in their own words. There are many different methods of capturing people’s stories, however, one highly effective method of gathering stories is through one-to-one interviews. Interviews have been found to be an effective method to apply during the co-design process because of the detailed insights and richness of information that can be gathered. Focus groups are an additional tool that helps to facilitate an in-depth investigation of attitudes and beliefs. Within focus groups, the content for discussion is predetermined in advance and the facilitator guides the group through constructive discussion of a range of opinions and experiences (NHS Institution for Innovation and Improvement, 2009; Picker Institute, 2009). In relation to the current project, the use of semi-structured interviews in phase one of the project overlaps with principles of grounded theory and ‘capturing the experience’. ‘Capturing the experience’ was further enhanced using focus groups in phase two of the project to build on the previously obtained data.

Understanding the experience involves making sense of how the service is experienced by stakeholders and highlighting the areas that require improvement for the provision of a better service (Picker Institute, 2009). This may involve linking the participant’s emotions to a particular point of contact with the service or the process of accessing the service. The information collected during the capturing the experience phase is reviewed, analysed, and synthesised to collate initial insights and rationale for change (NHS Institute for Innovation and Improvement, 2009; Picker Institute, 2009). McKercher (2020) highlights that analysis may be carried out using a variety of methods such as Becker’s (2008) ‘tricks of the trade’ approach to social science research, Glaser and Strauss’ (2017) grounded theory, Ladner’s (2016) application of ethnology, and Sanders and Stapper’s (2012) convivial toolbox for generative research. The process of understanding the experience aids in providing evidence for change (NHS Institute for Innovation and Improvement, 2009; Picker Institute, 2009). For the current project, data collected during both phases of the project were used to support ‘understanding the experience’. To maintain consistency between phases one and two of the project, principles of grounded theory were applied to aid the analysis of focus group data collected during phase two of the project.

Improving the experience is about developing ideas and approaches to respond to the insights generated during the capture and understanding the experience phases. The initial insights may be presented to the group of co-designers comprised of service users and other key stakeholders. The group are facilitated to work collaboratively together to review the information available, identify themes, identify and prioritise improvements, and make recommendations for implementation (Maher, 2017; McKercher, 2020). To ensure success in improvement, it is of particular importance that service users are represented during this phase to corroborate discussions and ensure improvements are truly client-centred (Picker Institute, 2009). During this phase, it can be beneficial to explore other ways that organisations have addressed similar issues and consider the strengths, limitations, and applicability of other strategies and solutions to the current issues at hand. Attempting to start from scratch and neglecting to consider techniques that are already in place is considered a potential hindrance to productive design (McKercher, 2020; Picker Institute, 2009). This phase concludes with the co-design team preparing their ideas for testing (McKercher, 2020).

In terms of the current project, the application of the ‘improving the experience’ principle was the primary focus for undertaking the focus groups in phase two of the project. Initial insights gathered during semi-structured interviews were presented to a focus group comprised of key stakeholders alongside relevant literature to allow participants the opportunity to provide input regarding commonalities within the data and literature, priorities for improvement, and suggestions for ways to incorporate recommendations into actions. ‘Improving the experience’ relates to a pragmatic viewpoint because it connects experiences to action by offering solutions that influence future practice.

To measure the improvement, the prepared ideas are initially implemented as a trial to determine elements that do or don't work and ideas for adjustment. Following refinement, the final idea is implemented, and improvement is measured. Evaluation of the impact and success of the co-designed idea allows the co-designers to understand the difference they contributed towards and how the improvements can be sustained (McKercher, 2020; NHS Institute for Innovation and Improvement, 2009). The application of specific co-design principles relevant to the current project is elaborated on during the phase two method section, however, the implementation of co-designed ideas was beyond the scope of the current project.

Abductive reasoning is congruent with co-design research as it involves using the available evidence and data to draw logical conclusions and make recommendations (Roozenburg, 1993). In the co-design process, abductive reasoning can be used to identify the most promising solutions and to create hypotheses that can be tested through further research (Hurley et al., 2021). It enables researchers to make sense of complex data, identify patterns, and develop insights that can inform the design process (Dorst, 2011). Abductive reasoning can also be used to identify potential design solutions and to evaluate the feasibility of different options (Hurley et al., 2021).

Given a singular research strategy was not cohesive for application across both phases of the current project, the research strategy was informed by, but not wholly subject to principles derived from grounded theory and co-design. Principles of grounded theory were applied to generate novel data that were not attached to pre-existing theories or hypotheses. Following this, principles of co-design were applied to build on the data generated and collaboratively engage participants to develop practical solutions that address the issues identified within the data, thus, informing the development of a service delivery model. The application of both methodologies is complementary as grounded theory was able to provide data to support the theoretical understanding of the phenomenon being studied, while co-design supported the formulation of practical solutions that meet the needs of the participants. This combined methodological approach allowed for the development of a service delivery model that was grounded in both participant insights and literature.

There are ongoing discrepancies regarding the definitions of co-design and co-production, with the terms often used interchangeably, leading to some ambiguity between the two concepts (Vargas et al., 2022). While this study has adopted a co-design approach, some may interpret the methodologies employed as co-production. These differing interpretations are acknowledged, and the decision to use co-design was based on its suitability for the project's focus of fostering meaningful collaboration with participants to develop solutions together.

3.4 The Researcher and Reflexivity

As discussed, within the evolved and constructivist approaches to grounded theory it is recognised that researchers are unable to be completely objective and that an interrelationship exists between the researcher and the participants. It is important for grounded theorists to recognise the significance of their research, have an interest in the subject matter, and be dedicated to achieving quality outcomes. The pre-existing knowledge of the researcher assists in deepening the understanding of the phenomenon under study by building on the information contributed by participants (Birks & Mills, 2015; Charmaz, 1995, 2014; Strauss & Corbin, 1990). Reflexivity is an active, methodical process that researchers use to reflect on their work in order to gain an understanding that will inform future decisions and interpretations (Birks & Mills, 2015). Within the current project, memos acted as a written record of reflexivity as well as self-reflection and conversations with supervisors regarding reflections.

Coming into this project, I had a range of clinical and research experience encompassing child development including a Master of Science in Psychology and clinical experience working with children with behavioural, social and emotional challenges, neurodivergent children, and children and adolescents with mental health conditions. Throughout the duration of this project, I worked part-time in a clinical capacity as an occupational therapist at CDC in Waikato. During the completion of this project, I acknowledged my own subjectivity and recognised that I could not be distanced from the research. My familiarity with the phenomenon being studied was beneficial for understanding the context behind the information shared by participants. Without knowing the context of the phenomenon, a neutral researcher may have missed opportunities to follow appropriate leads provided by participants or may have deviated from the research topic to clarify the context with participants to assist in understanding their perspectives during the interviews and focus groups. Having pre-existing knowledge of the research topic also assisted in the process of coding and generating and linking categories for analysis of the data. I interpreted participants' reality as told in their interviews and focus groups as accurately as possible, within the context of their experiences. Due to my involvement working as a clinician, I had first-hand experience encountering several of the issues raised by participants which further enhanced my motivation to achieve quality outcomes that would ensure improved provision of service for neurodivergent children. However, I also had to acknowledge that I am only one person and can only cover so much within the scope of the current project.

Potential ethical issues associated with my pre-existing role working at CDC were considered. To avoid any influence of my pre-existing relationship with colleagues, my supervisors (Professor Matthew Parsons and Dr Amy Bird) carried out interviews with CDC clinicians. Recruitment of service users consisted of families whom I did not have any pre-existing involvement with.

With a background working in healthcare, I had former experience completing comprehensive interviews as part of clinical assessment processes. Although previous interviewing skills may help develop rapport and communicate effectively, it was important for me to acknowledge that the pre-existing interview skills are different to the skills required for carrying out research interviews to generate theory. The use of semi-structured interview guides for data collection assisted me in managing bias, minimised the chances of asking biased leading questions, and ensured the focus of the interview remained relevant to the research questions and the purpose of the project. At times, I found it challenging to withhold from interjecting and clarifying some misinformation that participants shared. Throughout the process of undertaking the research and reflection on a pragmatic philosophical perspective, I became more comfortable with acknowledging participants' perspectives, regardless of the accuracy behind some of the information, as their views were based on their perspectives which are shaped by their experiences. The semi-structured interview guides supported the process of encouraging participants to tell me about their reality, rather than what they thought I may want to hear. I allowed participants to freely share their perspectives during the interviews, and then upon the completion of the interviews, took the opportunity to have more of an open dialogue with participants to clarify any uncertainties they may have had.

Through the iterative and reflexive processes of the research journey, there was one quote made by a participant that resonated with me when considering the importance of allowing the data to speak for itself during analysis. At times, I experienced concern that some of the codes and categories that were generated may offend people or that people may become defensive when seeing or hearing certain elements within the data. The quote reminded me that if the negative experiences and weaknesses highlighted within the data are withheld then how can issues and areas for improvement be recognised and responded to?

Although there were strengths in holding a dual role as a researcher and a clinician, this also presented some challenges. During the processes of data collection and analysis it was particularly draining to be immersed in the unfavourable comments and experiences people shared about the access to and provision of support for neurodivergent children. Not only was I inundated with the bleak tone within the data, but I also experienced the issues first-hand while working with service users at CDC. Although some strengths and positives were evident within the data, the primary focus of the project was on making improvements, therefore, it was inevitable that the weaknesses and issues were going to be emphasised and come through as the primary categories within data analysis. Gaining more insight into the experiences of the participants assisted me in empathising more with service users and referrers about their experiences of navigating disability-related services and systems. I applied this in practice as a clinician by increasingly holding open, honest, and transparent conversations with service users about the strengths and weaknesses regarding how the current system can meet the needs of neurodivergent children, which service users appeared to appreciate.

An additional challenge for me was the desire to authentically represent the experience of participants. The generosity of participants to give up their time and openly share their perspectives was acknowledged and greatly appreciated. I felt an obligation to ensure their voices were heard, however, given the depth of data gathered, I had to accept that some contributions people made were not relevant to the research questions and aims of the project and therefore would not be represented in the current piece of research.

3.5 Research Methodology Summary

The current research is inspired by a pragmatist philosophical research paradigm focussed on generating practical solutions and outcomes relevant to real-world contexts. The project employs a qualitative approach comprised of semi-structured interviews and focus groups as the methods of data collection. An abductive reasoning approach is applied to interpret the data and assist the conceptualisation of a service delivery model. The project is undertaken in two phases. Phase one primarily applies principles of grounded theory to carry out semi-structured interviews with key stakeholders to identify current perspectives regarding the delivery of CDS and ideas around how service provision could be enhanced. Phase two primarily applies principles of co-design using focus groups involving key stakeholders to inform the development of a service delivery model. Reflexivity is applied to acknowledge the benefits and drawbacks of my dual role as a CDC clinician and researcher.

Chapter 4: Phase One Method

The focus of phase one was to gain an understanding of the current perspectives of service users and stakeholders regarding the access to and provision of support for neurodivergent children and to gather ideas on how the delivery of CDS could be enhanced to ensure improved health and social outcomes for neurodivergent children in the Waikato region.

The research design for phase one of the research project primarily consists of principles derived from grounded theory. Semi-structured interviews are carried out with key stakeholders who have experience and knowledge relevant to the research context. The interviews form the primary data source for analysis.

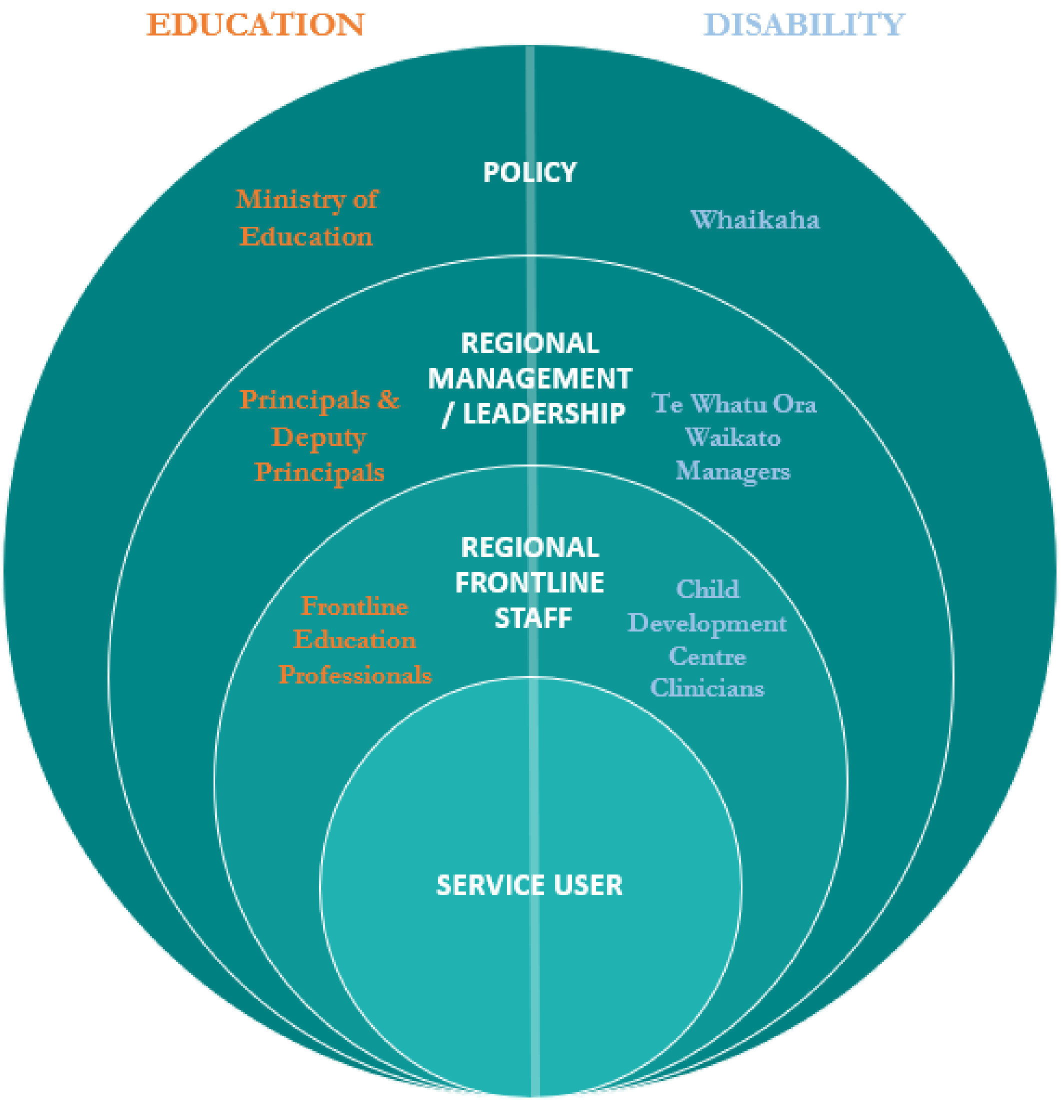
This chapter discusses the use of a purposive sampling approach for the recruitment of participants, a breakdown of participants involved in the interviews, data collection processes including the undertaking of semi-structured interviews, and the application of grounded theory principles for data analysis.

4.1 Participants and Recruitment

Purposive sampling is one of the essential grounded theory methods underpinning the beginning of the grounded theory process (Chun Tie et al., 2019). A non-probability purposive sampling approach was utilised for the recruitment of participants to ensure data pertinent to the research questions could be generated. To gain a range of perspectives regarding the access to and provision of support for neurodivergent children, a variety of stakeholders representing different levels and roles of involvement with neurodivergent children were recruited. This included parents/primary caregivers of children with neurodevelopmental disorders (service users) and representatives from both the disability and education sectors (see Figure 2).

Figure 2

Sampling Framework for Participant Groups



Note: The closer the stakeholder is placed to the inner circle of service users, the more direct contact they have with the neurodivergent child and their families.

Although phase one of the project primarily employed a grounded theory approach, participant criteria and recruitment aligned more with a co-design approach due to limitations of applicability of theoretical sampling and foresight of the requirements for phase two. Mottram (2011) highlights that some situations, such as institutional or ethical requirements, inhibit the ability to carry out theoretical sampling in grounded theory research. Within theoretical sampling, participant groups are not usually pre-selected but rather chosen throughout the constant comparative analysis process based on who will provide the most pertinent information to assist the researcher in pursuing leads in the data (Birks & Mills, 2015). In contrast, for effective co-design (as employed in phase two), it is recommended to ensure the inclusion of service users as well as a diversity of professionals who present with different perspectives, backgrounds, and identities (McKercher, 2020). The ability to effectively apply theoretical sampling was also hindered by relevant participant populations being capped with how many people were able to be recruited due to limited numbers of people fulfilling specific roles (e.g. within the disability sector, only a certain number of managers and directors are associated with CDC). Recruiting participants based more on a co-deign approach would ensure a balance of perspectives across the relevant sectors and continuity as the project transitions from phase one to the recruitment required to fulfil phase two of the project.

Schaefer (n.d.) highlights that a sample size of 15-30 participants is typically adequate to reach saturation in qualitative data. Hennink and Kaiser (2022) highlight that saturation can be achieved within nine to 17 interviews, particularly in studies with relatively homogenous sample populations. To allow the opportunity for adequate saturation and to capture diversity and balance of perspectives, it was intended that up to 10 participants per participant group would be sought, however, due to recruitment challenges and limitations with capped numbers available for recruitment within some participant groups, this was unable to be achieved. A total of 41 participants participated in phase one of the project. Refer to Table 2 for a summary of participants.

Table 2

Participants for Phase One Semi-Structured Interviews

Participant Group	Number of Participants
Service users	5
CDC clinicians	10
Frontline education professionals	10
Te Whatu Ora Waikato managers	6
Principals and deputy principals	5
Policy	5
Total	41

4.1.1 Service Users

Attempts were initially made to recruit parents/primary caregivers of primary school-aged children who had attended CDC for a multidisciplinary assessment clinic between June 2020 and April 2021 as this was considered to be the most recent period of consistent implementation of assessment clinics. Between March 2020 and June 2020, New Zealand experienced an Alert Level system in response to the outbreak of Covid-19 which significantly impacted the delivery of CDC services (New Zealand Government., 2022). Te Whatu Ora Waikato then experienced a cyber-attack in May 2021 which again impacted the provision of usual service (InPhySec Security Ltd., 2022). Based on the initial participant criteria, 30 families were contacted through a range of media including email, letter, and phone, inviting them to participate. Responses were received from three families expressing their interest to participate however no follow-up responses were able to be obtained for participation.

Given the difficulty with recruiting participants and acknowledging the importance of capturing the service user perspective, the initial restrictive criteria were withdrawn. Attempts were then made to recruit parents/primary caregivers who had accessed CDC concerning their child's known or suspected developmental disability. The project advertisement (Appendix B) was shared with community services that work with neurodivergent children including EGL, Cornerstone Therapy, and Enrich+. Five parents/primary caregivers responded to participate. A breakdown of the service user participants is provided in Table 3. The primary diagnosis for associated children was ASD. To protect anonymity, other diagnoses are not disclosed due to the rarity of singular or co-occurring diagnoses which may affect the identification of participants.

Neurodivergent children were not included as participants in the study. The decision to exclude child participants was made due to the exploratory nature of the research, which aimed to address systemic issues within CDS through the perspectives of parents, caregivers, and other key stakeholders. Additionally, ethical considerations regarding the capacity to consent, the risk of emotional distress, and communication barriers for neurodivergent children presented complexities that were beyond the study's resourcing and scope.

Table 3

Service User Demographics

Caregiver	Child with Neurodevelopmental Disorder Diagnosis	Ethnic Group	Locality Setting	Code
Great Aunty	7-year-old male	Māori, Samoan, and Cook Island	Rural	Service user 01
Father	8-year-old male and 11-year-old male	Māori	Urban	Service user 02
Father	6-year-old female	NZ European	Urban	Service user 03
Mother	10-year-old male	NZ European and Māori	Rural	Service user 04
Mother	6-year-old male	NZ European	Rural	Service user 05

4.1.2 CDC Clinicians

The regional frontline level within the disability sector included clinicians with experience working at CDC. Twelve CDC clinicians were invited to participate in the project through email communication. One declined to participate due to time constraints. Eleven indicated their interest in participating, however, one was unable to be reached for a follow-up response to participate. The 10 clinicians who participated comprised of psychologists, occupational therapists, speech and language therapists, and social workers. A specific breakdown of clinicians is not provided to protect anonymity.

4.1.3 Frontline Education Professionals

The regional operational level within the education sector included four Special Education Needs Coordinators (SENCO), two Resource Teachers: Learning and Behaviour (RTLB), and four Learning Support Coordinators (LSC) within the Waikato region who were recruited via email communication. Two SENCOs also held a dual role alongside deputy principal. The deciles[2] within the associated schools ranged from 3 to 10 with a mean of 6.

4.1.4 Te Whatu Ora Waikato Managers

The regional management/leadership level within the disability sector comprised of individuals in managerial-type roles (differing titles) who were currently or recently associated with CDC. Twelve managerial representatives were invited to participate through email communication. Six responded to participate, three declined to participate, and responses were not received from three despite follow-up attempts for engagement.

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[2] A school's decile measures the extent to which the school's students live in low socio-economic or poorer communities. Schools in NZ have a decile rating from 1 to 10 with decile 1 representing lower socio-economic communities and therefore more funding. From January 2023, deciles funding will be calculated using an Equity Index.

4.1.5 Principals and Deputy Principals

The regional management/leadership level within the education sector comprised of principals and deputy principals within the Waikato region. Contact was attempted with 60 principals and deputy principals through email communication and phone, with four principals and one deputy principal responding to participate. Two responded to decline to participate and responses were not received from 53. The five principals and deputy principals who participated represented school deciles ranging from 1 to 10 with a mean decile of 6.

4.1.6 Policy Representatives

Initially, contact was attempted with Waikato MOE to invite them to participate in the project. Some initial to-and-fro correspondence occurred with the sharing of ethics applications, consent forms, and information sheets, however, correspondence from MOE ceased before the confirmation of approval for MOE staff to be recruited to participate in the project. Given the inability to engage with local MOE, five nationwide MOE and Whaikaha representatives involved in the nationwide CDS improvement programme were recruited to participate. A specific breakdown of MOE and Whaikaha representatives is not provided to protect anonymity.

4.2 Data Collection

To determine the current perspectives of service users and stakeholders regarding the access to and provision of support for neurodivergent children, a semi-structured interview schedule comprised of open-ended questions was developed (Appendix C). Due to the varied roles of individuals representing the different participant groups, slightly different questions relevant to their role as a service user, or within the disability or education sectors, were designed for each group. However, to allow for comparison across groups, questions were grouped within a variety of categories that were designed to elicit responses that would assist in answering the research questions including introduction, CDC referral and assessment, school environment, well-being, collaboration, dream, and final thoughts. The questions for the service user participant group were piloted and refined in consultation with two parents of autistic children. In the application of grounded theory principles, the continued relevance of the semi-structured interview questions was considered following the completion of each interview and constant comparative analysis with thought around whether the interview questions continued to be relevant for the leads that were appearing within the data, or whether the questions needed to be revised to pursue emergent leads. During the process of iterative exploration of the data, the interview schedule remained applicable as a semi-structured guide to elicit data pertinent to the emerging concepts and did not require major revision as the study progressed.

Participants were recruited to one of six participant groups as outlined in the previous section. Participants were informed that the aim of the project was to develop a proposed service delivery model encompassing an enhanced provision of CDS. Participants were informed that the initial phase was particularly interested in exploring the current perspectives of service users and stakeholders regarding the access to and provision of support for neurodivergent children. To increase accessibility for people to participate in the project and to ensure the continuation of the project regardless of the impact of fluctuating Covid-19 responses, where appropriate, participants were given the option of whether they would prefer to attend the project session in person, or online via Zoom (Zoom, n.d.). Once a participant expressed their interest in participating in the project, a session was booked at a time and location of preference to them. Five attended the interview in person at CDC, 34 attended online using Zoom, and two interviews occurred via phone due to inaccessibility to Zoom. Due to my pre-existing collegial relationships with the CDC clinicians, the ten interviews involving CDC clinicians were carried out by my supervisors (MP and AB).

At the commencement of the session, participants were provided with an information sheet about the project and were presented with a consent form, including a request for consent to be audio recorded (Appendix D and E). For in-person interviews, written consent was obtained, and consent for Zoom and phone interviews was verbally recorded using the recording function on Zoom or using a recording device. Participants were also requested to specify their preference for having their interview transcribed by the primary researcher only or using Otter.ai, a third-party speech-to-text transcription application (Otter.ai., 2023); All participants consented to the use of Otter.ai for transcription.

In addition to the interview, service user participants were requested to complete a brief demographics questionnaire with information about their geographical location within Waikato, and their child's date of birth, gender, ethnicity, and diagnosis. This assisted with the provision of context regarding their perspectives, for example, considering the experience of those based in urban or rural locations.

Semi-structured interviews were carried out between January and July 2022 and were completed within 1 hour. Interviews were audio recorded to allow for later transcription. At the end of the session, participants were thanked for their contribution to the project and were offered to review transcripts. Consistent with grounded theory, data collection occurred concurrently with data analysis.

4.3 Data Analysis

Within grounded theory, data collection and analysis are cyclical and the analysis steps overlap and merge together (Birks & Mills, 2015). Data analysis for phase one followed the principles of grounded theory which involved constant comparison of data to facilitate the process of developing categories.

Familiarisation with data began during the interview process, except for the CDC clinician participant group who were interviewed by my supervisors. At the conclusion of each interview, initial thoughts, insights, and ideas were documented in memos. Audio recordings of the interviews were imported into Otter.ai and transcribed. To ensure the interviews were transcribed verbatim by Otter.ai, I reviewed and edited each transcription against the audio, allowing for additional familiarisation with the data. The transcription was then read and re-read in its entirety for immersion in the data and reflections on impressions, ideas, and assumptions were noted.

NVivo software (QRS International Pty Ltd., 2022) was used to assist with the initial process of open coding. The data was initially analysed for incidents. Codes were applied within each individual transcript as labels to capture concepts underlying incidents and features of interest within the data, and as a way of organising the data in a meaningful way. Each transcript was re-analysed to ensure any missing codes were captured. Throughout this process, comparisons between different groups of data were considered and memos on impressions, ideas, and assumptions were recorded.

Alongside NVivo, handwritten mind maps were created to assist the process of intermediate coding. The use of diagramming was beneficial for mapping out codes, comparing codes, determining relationships between codes, and grouping codes together within categories. Combining this with memoing regarding what a code or category contained and why it belonged where it was positioned was beneficial in assisting in the identification of the bigger patterns of meaning within the dataset and the relation of the patterns of meaning to the research questions. Due to the vastness of the data obtained, theoretical sensitivity was applied to recognise redundant categories that did not provide relevant data for the overall research aim or questions, or theory development.

The process of advanced coding was not carried out in-depth during the analysis of phase one as the process of phase two of the project built upon the data generated in phase one to assist the integration of the final grounded theory.

The dataset for each participant group was analysed to actively identify categories pertaining to each individual participant group. After categories had been generated within the datasets for each individual participant group through an iterative analysis process, the data was analysed collectively to generate key categories apparent within the dataset as a whole.

4.4 Ethical Considerations

Ethics approval was obtained from the University of Waikato Research Ethics Committee (reference HREC[HEALTH]2021#37) (Appendix F). The project was also registered with Te Whatu Ora Waikato and included Māori consultation with Te Puna Oranga Māori Consultation Research Review Committee (reference RD021061) (Appendix G and H).

4.5 Phase One Method Summary

Phase one of the project involved a total of 41 participants representing six different participant groups comprised of service users and a diversity of professionals from the disability and education sectors. Semi-structured interviews were carried out over 7 months either in-person, online via Zoom, or over the phone. Interviews were recorded and transcribed using Otter.ai. Analysis of the data involved principles of grounded theory. Datasets for each participant group were analysed in isolation followed by collective analysis across all datasets to generate common categories evident within the entire dataset.

Chapter 5: Phase One Findings

> *If it was everything running smoothly, there's nothing to see here. Unfortunately, there is a lot to see. (Principal and deputy principal 01)*

The focus of phase one was to gain an understanding of stakeholder perspectives regarding the access to and provision of support for neurodivergent children and ideas around how CDC service provision could be enhanced. Semi-structured interviews were carried out with participants and analysed using principles of grounded theory.

The purpose of this chapter is to present the findings from phase one of the research project. The findings are presented according to specific categories for each participant group, including service users, CDC clinicians, frontline education professionals, Te Whatu Ora Waikato managers, principals and deputy principals, and policy. The final presentation of findings consists of common categories evident within the dataset as a whole. Table 4 provides a summary of the categories identified within each of the participant groups. Square brackets are used within quotes to add missing context to aid the understanding of a quote or to represent the substitution of any identifying features within quotes to ensure the preservation of the anonymity of participants.

5.1 Individual Participant Group: Service Users

Within the service user group, five main categories were generated. Concerning 'insufficient support within the education setting,' participants expressed worry over the negative impact of limited educational support, leading to potential harm to children, exclusion from school, and significant family sacrifices. They highlighted a lack of clarity about MOE's role and difficulties in accessing MOE support. Discrepancies in support between specialist and mainstream schools, as well as a mismatch between the education curriculum and individual needs, were also noted.

Table 4

Summary of Participant Group Categories

Service users

Categories:

1. Insufficient support within the education setting.
2. You don’t know what you don’t know.
3. Inequity.
4. Stigma and understanding around neurodivergence.
5. Provision of therapeutic support.

CDC clinicians

Categories:

1. Insufficient support within the education setting.
2. Inefficient provision of CDC service.
3. The current CDC service setting is a barrier.
4. Bridge silos.
5. Provision of a community-focused CDC.

Frontline education professionals

Categories:

1. Insufficient support within the education setting.
2. Inefficient provision of CDC service.
3. Silos.
4. Provision of a community-focused CDC.

Te Whatu Ora Waikato managers

Categories:

1. Insufficient support within the education setting.
2. Inadequate provision of CDC service.
3. Silos.
4. Provision of a community-focused CDC.

Principals and deputy principals

Categories:

1. Insufficient support within the education setting.
2. Inadequate provision of CDC service.
3. Silos.
4. Provision of a community-focused CDC.

Policy

Categories:

1. Insufficient support within the education setting.
2. Inadequate provision of CDS.
3. You don’t know what you don’t know.
4. Silos.
5. Improving the provision of CDS.

In the category of ‘you don’t know what you don’t know’, participants discussed the challenges of navigating fragmented systems and services, resulting in gaps and confusion about where to seek specific support. They expressed a need for guidance in navigating services and identified inconsistencies in support criteria across regions.

Within the ‘inequity’ category, service users perceived limitations in support access in rural areas, encountered racial profiling for Māori participants, and faced situations where families had to self-fund therapeutic support.

Regarding ‘stigma and understanding of neurodiversity’, service users reported experiencing unwanted attention in public places, and children were excluded from certain initiatives. They expressed a desire for acceptance and suggested the need for more community-based programmes for neurodivergent children.

In the ‘provision of therapeutic support’ category, caregivers emphasised the benefits of increased access to therapeutic support for their children. They advocated for a single therapist working with the child across various contexts, highlighting the potential advantages of such a holistic approach.

5.1.1 Service Users Category 1: Insufficient Support within the Education Setting

Insufficient support within the education setting was expressed as a significant concern for caregivers. Caregivers mentioned a range of consequences as a result of limited support available within the education setting such as children getting hurt, children being excluded from attending school, and families having to make significant sacrifices for their children to access education. One caregiver spoke of their child getting hurt at school due to lack of supervision:

> *... he got hurt at school last term. Nobody was watching him. He came off the trampoline. He landed on the ground, and then do you know what she says to me? She*

> *goes, 'Oh, when he got up, he was dazed'. Steam was coming out of my ears, I tell you. (Service user 01)*

Due to the difficulty in accessing support within the school setting some children are excluded from attending full-time school hours. One caregiver spoke of their experience where a transition plan had been established between an early intervention service and the school with the agreed plan of supporting the child to attend school at least four full days per week. The school staff held a meeting without the family present, altering the transition plan without consultation to include a significant reduction in hours for the child to attend school:

> *And they come out and said, 'Here's the new transition plan'. And they wanted him to go for 1 ½ hours a day, four times a week, so what, 6 hours a week, that was all he was allowed to go to school, and I was crying… It's really triggered me, even now. I'm feeling triggered. (Service user 05)*

In this situation, the school placed responsibility on the family to provide education within the home environment:

> *She emailed back last night saying, 'Oh, no, we want to do a hybrid home learning programme so that when we can't find a teacher aide, you do learning with him, home-schooling him from home and we'll give you the stuff to do with him'. I've got two other kids, I've got, and a life. My husband's had to take so much time off work… I can't have a job, there's no way. (Service user 05)*

This scenario demonstrates some of the impact the lack of support within the education setting can have on families such as parents having to give up work to support their neurodivergent child. After exploring options of local mainstream schools, one other caregiver discussed the inaccessible environments and barriers within local schools which impeded their child's ability to attend mainstream education as a wheelchair user and resulted in a significant change of circumstances for the family:

> *So, when he started school, I looked at the mainstream options around us… But our closest ones, and where my other children all go, was quite steep terrain and the school would have required quite a lot of ramping to be able to use it. So, we looked at going down that track, but then the school would have been really financially disadvantaged, and the fact that they just did not have the funding to be able to have a person with him all the time. (Service user 04)*

This situation resulted in the caregiver and child uprooting from their home and family, to stay out of their region during the weekdays so the child could attend a specialist school that meets the child's needs:

> *We just travel over here… and I'm staying, well I first started staying in an Air BnB during the week and tried to get funding for that…. But they don't pay accommodation for that… So yeah, so we did first 8 weeks Air BnB, but now I'm staying with some family that's here, so stay Monday to Friday and then travel back home for the weekends. (Service user 04)*

Caregivers discussed some lack of clarity around the role of MOE and the lack of access to MOE support. Caregivers felt that these challenges regarding MOE were associated with how the system is functioning as a whole, rather than the individual professionals involved:

> *Oh, man, Ministry of Ed, I don't know what they do… there's this one lady, she's a nice lady, nothing wrong with this lady… But I understand her role is to represent Ministry of Ed, but there's actually nothing they bring to the table, other than ORS funding… And every time the school goes, 'Oh, okay, we're gonna need this, can we apply for this through Ministry of Ed', she'll go, 'Oh', and she'll put up barriers, or there's a waiting time of months and months before they even get it. (Service user 02)*
>
> *But the support from Ministry for physical, you know, for physio, OT, and speech, was shocking. Like, really shocking, like terrible… not the staff, the staff were fine, but it was just the whole system and just how often they visited was, like, you know, he might get seen once a term if he was lucky. (Service user 04)*

There are also inconsistencies between the support a child with ORS funding receives at a specialist school compared to when the child attends a mainstream school:

> *All they [MOE therapists in mainstream] do is come in, observe the child, and then tell the teacher aides, do this, try this, try this… Whereas when you go to a special school, the physio is working with that child on a regular basis, not just observing the child. (Service user 04)*

Caregivers expressed that the education curriculum was not always conducive to the priorities of learning for the child's needs. When asked about things that would be beneficial for supporting their child's well-being, caregivers emphasised that the education focus should be on fostering a child's strengths rather than requiring them to conform to a curriculum:

> *I don't think anyone should be forced into a curriculum. It should all be to deal with strengths and then helping with a bit of the weaknesses. (Service user 03)*

Caregivers also emphasised the importance of considering what is meaningful for the child from a longer-term perspective rather than expecting them to engage with the curriculum:

> *… he's got like a pen and paper, or stuff that's encouraged of him, but that's not bringing him any type of joy, or like, he's not going to understand the benefits of that for this future. So, my son's non-verbal, we're gonna have him with us for the rest of his life… So, I would rather set up a framework where he gets to enjoy his time… Rather than going, okay, we're gonna make sure you get a good job in the future, or we're gonna set you up for, nah, nah, nah, let's just give him whatever makes him happy. (Service user 02)*

5.1.2 Service Users Category 2: You don't know what you don't know

Caregivers expressed some challenges and confusion around navigating systems and services to access support for their neurodivergent children. The segregation between supports that are facilitated by CDC from a healthcare perspective and supports that are facilitated by

MOE from an education perspective adds to the confusion of who is meant to be fulfilling particular duties or roles:

> *… CDC, MOE, you know it's all, they're all different again. Like that consistency for that child… it's insane as a parent, it's like which ones that, who's doing that? Oh, my car seat now, do I go to the OT, who do I go to for that? There's an OT from CDC and then an OT from school, is that really necessary? (Service user 04)*

Families experienced gaps in service provision due to a lack of guidance or understanding of who or where to go for specific support and felt it was important to be connected to appropriate services dependent on the child's specific needs at a particular point in time:

> *I'd probably like to see a flowchart type of stuff… There was no like, referral or no link to, okay, we have this, this or this, or from here you can go to here, because your focus might be communication. There's just no link, I guess, once you do CDC, it felt like, fuck, that's it. (Service user 02)*

Many caregivers have come to learn about what support their child is entitled to through word of mouth from other caregivers rather than services informing them about what may be available for them to access and ensuring they get connected with relevant supports:

> *So, I didn't realise that [child] could have shoes, until I found out from another parent… And so, it's like, there needs to be a list of things, or like they're entitled to go in and under anaesthetic and get their teeth looked at… But you don't know that that's available to a child. And so, it's only through parents that we've been able to find these things out, not through the service. (Service user 04)*

Caregivers felt it would be helpful to have someone available who was able to guide them through the navigation of services and supports. Many had experienced the benefits of having someone support them along the journey through involvement from EGL:

> *They've [EGL] directed me in the right direction… She's helped with the respite care. And yeah, doors have just opened. I've been able to get things for [child] and for myself… Yeah, I've found that it's just been a godsend. (Service user 01)*

> *Enabling Good Lives changed everything, I think. It was everything for us. I don't think we'd survive as a household if we didn't have that. (Service user 02)*

One caregiver explained that they had limited knowledge and awareness about the support their child was entitled to within the school setting and therefore would not typically make requests. However, when EGL became involved with supporting the family, the caregiver was empowered with knowledge about what their child was entitled to, which gave them the courage to be more vocal about their concerns and advocate for their child:

> *I didn't know really what my rights were and what I could do until [connector] from Enabling Goods Lives said to me, 'Yes, you can, you can say something.' ... So yeah, I stood up and I said something. But otherwise, it was just, shhh, be quiet because I don't want to rock the boat, but now I know I can rock the boat if they're not on board. (Service user 01)*

Caregivers mentioned further confusion around the provision of support for their child due to inconsistencies and differences in the criteria for support within different regions of the country. In some situations, families were accessing care from a variety of regions because of being unable to access the same supports within Waikato:

> *So, we've still got, our paediatrician's still in Waikato. And our CDC team is still in Waikato. Yeah, we're just all over. So, his orthotics are still done in [out of region], And dentistry is usually in [out of region]. (Service user 04)*

The inconsistencies in access to support also highlight some issues associated with equity.

5.1.3 Service Users Category 3: Inequity

Families living rurally felt that they had reduced opportunity and access to support:

> *… we live rurally, so it's, yeah getting anything, so, I used to also argue that I wanted him to be seen more. So, I would say that I would travel over there [urban centre] to see them. Because them coming over once a month, or once every six weeks, just was not what I thought was enough. (Service user 04)*

Māori caregivers did not always feel that their cultural needs had been met when accessing care and support and they had experienced racial profiling, particularly when attempting to access support within the school environment:

> *Sometimes, I think it's [being Māori] a hindrance. I've noticed, I've got another couple of European friends that children go to the same school, and you know, they've gone, we've applied for the same thing, I haven't got it, but they have… I feel like because of my colour, you're down the bottom of the list. (Service user 01)*

One caregiver spoke of their experiences of racial profiling in the context of seeking the most appropriate school for their child to attend:

> *It sucks because you get profiled a lot… You know, my boy's got a Māori name, and as soon as I ring up a service, they put you in a box, and it sucks… there's a bunch of satellites and one of these satellites, we know, is in a rough area… it's mainly darkies there, and then you have all these other ones, that are like in nice areas or the service is, I guess you could say, is polished. I rung them up and I said, 'We want to look at all the satellites because we want to know which one's the best for our son'. And then the lady goes, 'Oh, hang on, but you're closer to [the one in the 'rough' area]'. She goes, 'Oh, so, you won't need to look at the other ones'. (Service user 02)*

The implications of financial inequities associated with accessing care were highlighted. As a result of unsuccessful attempts to access support via the public disability and education sectors, families have experienced situations of having to self-fund therapeutic support:

> *I had four jobs at one stage, four jobs. So, it's ridiculous. I learnt to live on five hours sleep a night, seriously, so that we could try and fund it. And my husband had two jobs. (Service user 04)*

5.1.4 Service Users Category 4: Stigma and Understanding Around Neurodivergence

Caregivers spoke of experiences where they often received unwanted attention when accessing public places:

> *We've got another friend that's got an autistic child as well, and they're afraid to take him out. They just don't do it. As in, we've sort of got our coping tools, which we use now to take [child] out. But it's still a mission. People just stare. I've had a couple of instances where I've turned around to the person who's staring and said, 'What the hell's your problem?' 'Oh, nothing, nothing, nothing'. (Service user 03)*

Caregivers wanted their child to be able to be accepted for who they are, regardless of the differences they may present with:

> *Don't judge a book by its cover. You know, he mightn't be able to talk but he's a human like the rest of us. (Service user 01)*

Furthermore, neurodivergent children may be excluded from certain programmes due to the differences they present with:

> *The healthy meals in lunch programme does not seem to consider or recognise people with disabilities like autism and how the programme can work with children with autism and different dietary preferences, which is more than a typical child not liking mushrooms. It really only covers children with allergies or medical reasons. (Service user 05)*

Caregivers felt it would be beneficial to have more community-based programmes established for neurodivergent children, so they were less excluded and had the opportunity to develop an increased sense of belonging:

> *She's always mentioned is she thinks she's different. Um, I guess maybe having a couple of days a week, out as a community with a whole heap of different children that are like her. So at least she didn't feel different. Just community-based, sort of go out, know that the other children are going to have the same sort of sensory issues, or same sort of reaction to anything that happens outside of the house. (Service user 03)*

5.1.5 Service Users Category 5: Provision of Therapeutic Support

Caregivers emphasised that their children would benefit from increased access to therapeutic support. As highlighted within the challenges associated with navigating across different systems, caregivers questioned whether it was necessary to have therapists that supported the child in the school setting (MOE), and then a different group of therapists supporting the child regarding what they need outside of the school setting (CDC or private therapy). One caregiver had a unique perspective regarding the need for increased provision of therapeutic support within New Zealand as they had experienced more advanced therapeutic support in Australia and the United States, compared to what is available in New Zealand. In this scenario, the child's quality of life would have been significantly impacted if the family had not self-funded to access therapeutic support overseas:

> *So, like he took his first steps there, he learnt how to walk there, I cannot describe how amazing. And if he'd been in New Zealand, under our system, he'd be in a wheelchair, that's it, that's all there was… Yeah, that's where if New Zealand could have those intensive therapy things set up… Yeah, and that's what you need. (Service user 04)*

5.2 Individual Participant Group: CDC Clinicians

The dataset from the CDC clinician group, which includes psychologists, occupational therapists, speech and language therapists, and social workers, generated five main categories. The first category, 'insufficient support within the education setting', highlighted various factors contributing to inadequate access to support for neurodivergent children. These included inconsistent support across schools, varying criteria for education support, restrictive

ORS funding criteria, challenging education environments, and insufficient special needs training for teachers.

The second category, ‘inefficient provision of CDC service’, highlighted factors affecting timely and efficient services, such as increased demand without corresponding resources, workload pressures, siloed funding and services, and unclear criteria and processes leading to lengthy waitlists. Referrals were sometimes declined due to insufficient information or not meeting criteria, leaving children without essential support. Overall, clinicians acknowledged the limitations of CDC but expressed a desire to do more for neurodivergent children.

The third category, ‘the current CDC service setting is a barrier’, emphasised the non-child-friendly and inaccessible nature of the current CDC building, leading to difficulties for families, especially those who have to travel long distances. On-site assessments were noted to create power dynamics and hinder children's engagement.

‘Bridging silos’, the fourth category, highlighted the challenges arising from siloed services for disabled children, contributing to communication difficulties and inadequate care. CDC clinicians recommended a more integrated approach to streamline services for families.

The fifth category, ‘provision of a community-focused CDC’, proposed that being located within the community and offering outreach appointments would enhance accessibility and outcomes for children. Collaborating with education professionals and increasing involvement in schools could facilitate timely assistance and referrals, recognising children who require further evaluation.

5.2.1 CDC Clinicians Category 1: Insufficient Support with the Education Setting

Clinicians expressed their concerns regarding inconsistencies and lack of access to support within the education setting for neurodivergent children. The access to support was considered to be insufficient for a range of reasons including variability in the provision of support across different schools, lack of clarity around the criteria behind applying for education support, the severity of disability required to meet criteria for ORS funding, disabling education environments, and lack of support and access to special needs training for teachers.

Access to support within the education setting appears to be extremely variable and is often dependent on the individual professionals involved or the individual school's approach to supporting neurodivergent children and the school's ability to access funding and resources:

> *It just feels like there's no typical service, like some kids, it very much varies about where they are, what school they're at, who in the Ministry of Education is involved with them. There's not like, some certainty that in school, this is what you'll get. (CDC clinician 10)*

Variability between the provision of support within schools also appears to be influenced by ongoing patterns of inconsistent understanding about the criteria for applying for support within the education setting. Access to learning support within education is meant to be needs-based, however, there seems to be an inconsistent perception among education professionals that a diagnosis is required to be able to access support:

> *So, we have been told from up high, the message is that nobody needs a diagnosis with an education to get supports. And yet we have these children on a waiting list for long periods of time, where education haven't done anything, supposedly waiting for a diagnosis, and these families are coming in waiting for a diagnosis. (CDC clinician 06)*

This confusion around the criteria regarding applying for support amongst education professionals can contribute toward skewed expectations families have regarding assessment and confirmation of a diagnosis. Families may be under the impression that confirming a diagnosis for their child may guarantee support at school:

> *I guess a diagnosis, we've [CDC] had to be really clear that a diagnosis of ASD doesn't mean that you get X number of hours at school. And that actually, school-based supports come from school and are function-based. (CDC clinician 05)*

In contrast, due to the perception that children require a diagnosis to access educational support, schools often make referrals to CDC pursuing a diagnosis without families truly understanding the purpose of the referral or that the assessment may result in their child being diagnosed with a neurodevelopmental disorder. A referral to CDC requires caregiver consent, however, CDC experiences situations where families arrive for their appointment unaware of the purpose of the referral or that the assessment may result in a diagnosis for their child. Additionally, some families also feel compelled to consent to and attend an assessment because of pressure from the school:

> *Every parent should be aware because our referral form does ask for parental consent. Whether the referrers do that or not is another story. (CDC clinician 05)*
>
> *... and I don't think schools understand that sometimes families don't want a diagnosis, and we get stuck in this kind of bouncing between services, which sort of doesn't make any sense. (CDC clinician 04)*

ORS funding is a funding stream available for education professionals to apply for, however, CDC clinicians emphasised the difficulty in obtaining ORS funding to support neurodivergent children. The influence of perception around criteria for applying for support and lack of resourcing available to provide support often means that those who don’t meet the criteria for ORS funding are left without any support in the education setting:

> *Unless you are severely disabled, and you qualify for like a special school or like a satellite school and for ORS funding, and that would be the minority of the children that we see here, I would say, there's really nothing there. (CDC clinician 01)*

The classroom environment can be disabling for neurodivergent children, particularly in the situation of 'modern learning environments' comprised of large, open-plan classrooms, populated by many more children than are found in cellular classrooms:

> *... it's not set up for children that don't learn in, in a very specific way in terms of teachers, their child's here, this is what I'm doing, this is my task, and especially with what do they call it, like the cohort classes or something where there's like 60 children. You could not get anything less appropriate for a child that has a learning difficulty, or autism, or something like that. (CDC clinician 01)*

In terms of managing the classroom environment and responding to the different learning needs of neurodivergent children, CDC clinicians also acknowledged that teachers were not always equipped with adequate training and knowledge to support children who learn and understand in a different way than what is considered the norm:

> *We have so many kids who get sent home, and it's behaviour issues, so we're asked to medicate them to make things better, so they can go back to school, but they don't have the teacher aide support, they're in these open classrooms with 60 kids. I would have sensory overload, and I don't even have sensory issues. (CDC clinician 02)*

> *I don't think the education training system prioritises special needs type of training for teachers. (CDC clinician 06)*

5.2.2 CDC Clinicians Category 2: Inefficient Provision of CDC Service

CDC clinicians expressed a range of factors that influence the ability to provide CDC services in a timely and efficient manner. CDC clinicians have seen increases in the needs and the population of families seeking access to CDC for support, however, resources and the provision of service have not grown to accommodate the increased demand. As a result, waitlists have substantially increased, resulting in untimely access to CDC services:

> *Because of multiple different issues from staffing, resources, all the different environmental issues, our waitlists have exceeded, and so our ability to provide a service in a timely, age-appropriate, equity manner just isn't, in my mind, being optimised at all. (CDC clinician 02)*

As identified by CDC clinicians, some barriers to the provision of a more efficient CDC service included time and workload pressures, siloed funding and services, and a lack of adequate human resources:

> *I've been at CDC now for [several] years, and in the time I've been here, the pace at which we've been driven to do stuff and get through the waitlist has just slowly, incrementally increased the whole time, so, your ability to do that extra stuff [multi-agency collaboration], that you can see needs to happen, is probably, it's harder now than it was. (CDC clinician 09)*
>
> *… the government teams don't work together. Definitely not… families are just going through all different systems being pushed from pillar to post and 12 months later, they don't know what waitlist they're on for what, they just know that they're burnt out, and frustrated, and just want the right thing for their child. (CDC clinician 02)*

The ability to provide efficient CDC services is also impacted by a lack of clarity around service criteria and processes:

> *The current system that we have now has lots of flaws. One of the biggest problems, I think, is that actually, even on our, on the CDC website, there's inaccurate information about what services we provide, and what referral criteria we have. (CDC clinician 09)*

Lack of clarity around service criteria and/or inflexibility in service provision can also result in some children missing out on care and/or getting passed back and forth between services when they don’t neatly fit the specifications for one particular service. Situations where this commonly occurs are with the overlap of mental health and disability symptoms. At times, it can be difficult to separate symptoms of ADHD (mental health) and ASD (disability) due to the overlapping nature of many symptoms as well as the probability of comorbidity. This can result in referrers being unsure whether to refer the child to CDC or mental health services as well as pushback between mental health and CDC regarding whether the provider determines the referral meets the criteria for their service or whether they believe the referral is more appropriate for an alternative service:

> *And there's a bit of a line between mental health and physical health as well, which I think from a referral perspective is, sometimes they're both. (CDC clinician 03)*

Contention also occurs alongside intellectual disability and specific learning disorders which can present with similar or overlapping symptoms, but CDC does not provide input regarding specific learning disorders:

> *… there's a really big group of kids who, that we get referred, and that probably have some kind of specific learning disability. You know, the kids who probably have dyslexia, and they don't meet criteria for our assessment and our funding, but they're really struggling in school. And so those, I think that's a really big group of kids who really get lost. (CDC clinician 09)*

Lack of clarity around the roles and responsibilities of services contributes towards challenges for people trying to navigate the systems. It is not only challenging for families and referrers to navigate the systems, clinicians also have difficulty knowing and navigating the system:

> *If you don't know the system, it makes zero sense. I have trouble getting my head around it sometimes. (CDC clinician 01)*
>
> *I think it's quite confusing for, and this is just, again, my feelings from what parents have told me, because navigating the difference between the education system and the*

> *health system, and where the funding comes from, or where the support comes from, is really confusing. (CDC clinician 08)*

At times, referrals to CDC get declined due to not having enough information or the referral does not indicate that the child meets the criteria for the service. The referral process relies a lot on the referrer's understanding of the process and criteria to access CDC and the ability to clearly communicate the needs of the child and the purpose of requesting support from CDC. It can be difficult for referrers to truly represent their request in a written referral, and this may result in children being declined from the service and missing out on support due to a lack of other services to meet the need:

> *I guess the ones that we decline, having a clearer pathway for them so that they're not missed from the system. Because I find that quite scary to think that there's kids that are missing, that should be seen, that on paper didn't look like they needed to be seen and therefore then they're just gonna carry on because there's no one in their bubble that's going to advocate for them. (CDC clinician 03)*

As a result of how CDC currently functions and the lack of other supports available within the education setting and the community, many children who do not meet the criteria for access to CDC or other services miss out on support:

> *There are a number of kids who don't fit into that disability group, but actually, their needs are going to be ongoing… we see a lot of kids who are in that borderline intellectual disability, so they're not low 70's [full-scale IQ], but they don't get an ID diagnosis. But you know, if you're functioning between 70 and 80 on a cognitive test, you're pretty impaired still. And that, a lot of those kids, even if they kind of can function in their sort of day-to-day skills, really, really, really struggle with the rigidity of the school system around academic learning. (CDC clinician 09)*

CDC clinicians acknowledged the shortcomings of the provision of the CDC service and expressed their desire to be able to provide more for neurodivergent children. CDC clinicians described feelings of helplessness because of the confinements placed on clinicians within the service specifications, knowing that there are children who could benefit from support who are missing out:

> *I will be a voice for clinicians in saying that we see the gaps, and we see the problems, and we struggle every day with what we can't provide… So, it's not that we've got, because I think a common perception is that we've got, you know, stuffy clinicians that are stuck in their ways, and they've been doing the same thing for years and years and years, like, that's actually not the case. The case is that we're in this job because we want to help children and that is always at the core of what we do. (CDC clinician 01)*

The functioning of CDC as an efficient service and the ability to make effective service changes are also impacted by a top-down approach where decision-making often occurs at a management level without consultation of those on the frontline whom the decisions directly affect. CDC clinicians reported feeling continual pressure to get through the waitlist to reduce wait times for families, often at the oversight of other important components within the role. Clinicians felt it was important for frontline staff to be included in decision-making that affects them and the delivery of the service, particularly because they are the ones who are the experts in what they do:

> *I feel like meetings happen where things are decided… yet actually, the people who are talking on our behalf, in terms of our management, don't really understand what it is that we actually do. And so, they can't really, you know, act on our behalf… they have quite a medical model approach to how they think things should work, and they don't have enough understanding of a need to look at the really complex needs of the children who come into our service. And they under-emphasise that, and they don't understand that actually doing good work with kids and families takes time. (CDC clinician 09)*

5.2.3 CDC Clinicians Category 3: The Current CDC Service Setting is a Barrier

CDC clinicians expressed that the current CDC building was not child-friendly or inviting for families and was not disability accessible. Due to various barriers around accessing the service, clinicians had concerns about children who may be missing out on accessing required support:

> *…our building is the least disability-focused building you'll find at the DHB… it's not wheelchair accessible for older kids, it's not designed with, you know, safe spaces, the parking's awful, we don't have air conditioning. It's just, as an accessible service, it's the least accessible service, and that, for all the vulnerable families we work with, puts them straight on the back burner. (CDC clinician 02)*

Because of the geographical spread of the Waikato region covered by CDC, families are often required to travel significant distances to access the service. Clinicians acknowledged that they're not always getting the child at their best if they've travelled a long distance which can impact their engagement in the assessment process:

> *I don't think that you're going to get anybody at their best when they've just done a 3-hour journey. (CDC clinician 10)*

Participating in assessments on-site at CDC can also contribute to power dynamics:

> *... when you've got parents and children coming in here [CDC], there's a power dynamic, straightaway, they're coming to us, and we are the hailed experts. (CDC clinician 01)*

Expecting children to engage in an assessment process with unfamiliar staff and an unfamiliar environment may also be inhibiting the engagement and observations of the child:

> *... the idea of bringing a child into a foreign, very medical, and strange environment, and then doing an assessment that is normed on European children, and expecting to come up with a result that is going to adequately help their needs get met in the community, it just, it seems very backward, it doesn't make a lot of sense. (CDC clinician 01)*

> *... you're talking about kids who have probably got comorbid, mental health issues of anxiety, coming into a new environment they're just going to stop, they're just not going to talk. (CDC clinician 02)*

5.2.4 CDC Clinicians Category 4: Bridge Silos

As mentioned, the lack of interaction with other services and the inflexibility around the provision of CDC services can result in children being passed back and forth between different services, waiting for prolonged periods on various waitlists, or not receiving input at all. Because of the complexities in the presentation of some children, a single-service approach does not always meet a child’s needs. It would be beneficial if services were able to work collaboratively to ensure a more seamless journey for children and their families:

> *I would really love to see the integration of mental health into disability because we've worked with enough kids with autism, anxiety issues, and like, I know that it's an assessment service, but I think that kind of the integration of different services. Not just having, look, we have disability over here, and we have mental health over here, and then you've got your physical issues as well, at the hospital. So, I think that for families, it's probably quite like, frustrating. It would be great if we were like, one child health system, or something like that. (CDC clinician 03)*

CDC clinicians recognised that it would be beneficial for families to get the answers, they were seeking by accessing one single service rather than being passed between different services because of confinements such as funding contracts:

> *I think it would be great if parents could come and get all the answers in one place. (CDC clinician 09)*
>
> *And we'd love to have a one-stop shop where you can kind of come in and get all of that, but, one day maybe. (CDC clinician 02)*

The segregation between health-provided disability input (CDC) and education-provided disability input (MOE) contributes to further challenges for families to navigate the system. CDC clinicians felt it would be beneficial to have more collaboration between CDC and education which could potentially consist of one therapist who supports the child from a more holistic perspective across the school, home, and community:

> *I think, the like split between two [health and education] makes it difficult because if you're seeing a child as a holistic person and like everything that they do is just part of their day, then having someone to be able to fully see that all in one go, makes it easier. (CDC clinician 08)*
>
> *I would most like, without time and resource constraints to be able to actually work in a service that ideally, magic wand stuff, cut across education and health, and actually followed up and provided support for these children over time. (CDC clinician 06)*

5.2.5 CDC Clinicians Category 5: Provision of a Community-focused CDC

CDC clinicians highlighted that being based in the community and/or having more flexibility to offer outreach appointments may reduce some barriers to accessing CDC and may facilitate better results when working with children. One clinician described situations where CDC clinicians have gone out into the community to provide assessment in a more accessible location for whānau due to challenges accessing CDC. It was emphasised that carrying out assessments on-site at CDC may be the most convenient approach for clinicians but perhaps that is not the most client-centred approach for meeting the needs of service users:

> *I think the reason we've done it is because the whānau haven't been able to get here [CDC]. So, it's often Māori whanau, or they've got mental health issues, they've got transport issues, they've got other children, they've DNA'd [did not attend] two or three appointments… It takes a big chunk of time to put on travelling, and doing the assessment, and coming back, whereas you potentially could see another child in that period of time. But again, it's about whose needs are we meeting?... And outreach services may be the way. (CDC clinician 02)*

Going out into the community and working more closely alongside schools provides opportunities to develop relationships with education staff, gain an increased understanding of what disability means for a child from a learning perspective, and reduces the power dynamics that may occur with on-site assessments at CDC:

> *Whereas if we go into their environment, and observe them, where they're feeling more in control, we will probably get better results as well. If we can take our service into the community, we'd probably again, build those relationships with school, we can give direct feedback to the teachers, and SENCOs, who seldom can come to these appointments [at CDC]. We'd probably start getting a better understanding of what disability means for these kids, and how they can be supported from a learning perspective. (CDC clinician 02)*

If CDC clinicians developed stronger relationships with education professionals and were more present in schools, this would facilitate opportunities to provide timely support and recommendations that were relevant to the context. This may also influence the flow of referrals to CDC. By being present in schools, clinicians would be able to assist in the identification of and differentiation between children who would benefit from a more individualised approach involving further assessment at CDC and those whose needs are able to be met with the application of some universal or targeted recommendations within the classroom:

> *I think the more visible you are, the more people are going to come and say, 'Hey, can you check out little Johnny?' or, 'I want to raise this, this, and this kid with you'. And so, you know that, yes, you're going to look at the class of 30 kids, but the teacher's identified five already for you that you need to keep an extra eye on. And I think education is so important because the more people know what you do, and how you can help, I think, actually more the referrals [to CDC] are going to flow. I guess it would also mean that somewhere like CDC would see the kids that it needs to see, like those top-tier of kids that need to come for a disability assessment come. (CDC clinician 05)*

5.3 Individual Participant Group: Frontline Education Professionals

In the frontline education professional’s dataset, comprising of the perspectives of SENCOs, RTLBs, and LSCs, four key categories were generated. First, within the ‘insufficient support within the education setting' category, frontline education staff expressed concerns about the inadequacy of support for neurodivergent students in schools. Despite schools’ efforts, limited funding and support from MOE, including challenges accessing ORS funding, were highlighted as significant issues. Education professionals lacked training and support for working with neurodivergent students and called for increased availability of relevant education and training.

The ‘inefficient provision of CDC service’ category highlighted issues including long wait times and service gaps in accessing CDC for diagnostic assessments. Lack of adequate resources surfaced as a barrier to change and delivery of optimal services, encompassing issues such as time constraints, workload pressures, and insufficient human resources. Frontline education staff emphasised that children who did not meet diagnostic criteria were often left without support, while those meeting the criteria might lack adequate follow-up. Referrers faced challenges expressing concerns in referral information, impacting the appropriateness of CDC referrals and potentially contributing to issues of equity.

Concerns within the ‘silos’ category centred on barriers arising from compartmentalised systems within Ministries and funding streams. Frontline education professionals advocated for bridging these silos to enhance collaborative efforts and better respond to the needs of neurodivergent children. The participants believed that breaking down these barriers would lead to more efficient coordination of services, a shared vision, and reduced confusion about roles.

In the ‘provision of a community-focused CDC’ category, education professionals suggested bridging the gap between schools and CDC through improved communication and relationship building. They recommended a more community-integrated CDC service, providing education on processes and assigning a key person at CDC to contact for clarification. This, they believed, would enhance mutual understanding, save time, and increase efficiency.

5.3.1 Frontline Education Professionals Category 1: Insufficient Support within the Education Setting

When asked about their views on access to support within the school setting for neurodivergent children, frontline education professionals expressed that they did not feel it was adequate. In many situations, because education staff have not been able to access funding or support through MOE, individual schools make attempts to provide support for the child where able:

> *To get funding is like banging your head against a brick wall. The funding is ridiculous to support our children. (Frontline education professional 05)*
>
> *So, at our school, we have kids who are diagnosed [with a neurodevelopmental disorder] and receive no support, no funding, apart from what we [the school] are able to cobble together and give them. (Frontline education professional 03)*

Frontline education professionals acknowledged that the situation where funding and support can be accessed is when children qualify for ORS funding. However, those who do not qualify for ORS funding are often left without adequate support:

> *Neurodiverse kids, I think it's very, very tricky for them. ORS funded kids get well covered. The kids that are not ORS, that huge bunch in the middle, they miss out left, right and centre. (Frontline education professional 03)*

Although education professionals can apply for ORS funding, they emphasised how difficult it is to obtain and even if a child does get accepted for ORS funding, it may not be enough to provide the child with the support they require:

> *The change has been that getting ORS now is particularly difficult, you've got to be very severe, so therefore, we're getting a lot more in the mainstream schools and that means that the resourcing doesn't have that level. Even though you get your .1 ORS teacher, and you get so many hours for a teacher aide, that doesn't take into consideration what it actually means to have a student with particular capabilities or lack of capabilities in the classroom with the kids. (Frontline education professional 10)*

A factor that also contributes to insufficient support within the education setting is associated with the lack of adequate access to training and support for education professionals working with neurodivergent children. Because of challenges accessing formal support through MOE, teachers are often expected to meet the needs of neurodivergent students. For many education professionals, access to professional development regarding working with neurodivergent children is self-directed or learned while on the job as teacher training does not adequately prepare teachers for working with this population of children:

> *There's very little in teacher training, which is frightening. Everything is on the job. (Frontline education professional 06)*

> *Teacher training does not address neurodiversity. It's really, really, it's really tragic, actually, that it's not given its due. And it really needs a whole year, in and out of it. (Frontline education professional 10)*

Frontline education professionals recognised the need for, and importance of teachers being adequately trained to work with neurodivergent children and that more education and training should be available for supporting these children:

> *The other thing I did think about is more teacher training at university… it definitely should be included in there as at least one whole paper around neurodiversity. (Frontline education professional 07)*

> *… to increase their overall well-being at our school, it would be, us being able to easily access professional development and training regarding best practice, supporting students with specific developmental needs. (Frontline education professional 02)*

Frontline education professionals have observed that the needs of children have changed and there appears to be an increased population of neurodivergent children, however, access to training, funding, and support has not increased to match the needs of the increased population of children requiring support in the classroom:

> *Because we are definitely getting more neurodiverse kids, we just are, and I don't know why. (Frontline education professional 03)*

> *And then if you look at how many children we're getting through with more diagnoses of neurodiversity, it doesn't reflect that, the support's not going up with it, like inflation. (Frontline education professional 06)*

It was acknowledged by frontline education professionals that the school environment is not always conducive to the learning of those with different learning needs. There are certain expectations regarding the fulfilment of the curriculum that may not align with different learning needs and the school and classroom environments can be quite overwhelming and overstimulating for those with neurodiverse needs:

> *Everything's a spectrum… and to be honest, that's where I come from, because otherwise we box people, and school's a box. Schools are one stream, this is the highway that we're teaching to, 'Oh dear, dear, dear, someone's not fitting that'. (Frontline education professional 10)*

> *I would like to see smaller classes and the learning support staff to help. The smaller classes full stop that aren't as stimulating… these little guys, they don't cope with class*

> *sizes of 30 odd, and everything hanging off the roof and walls, and noise value. And they need that extra little adult support there to encourage them and to be able to read when they're getting agitated, and when it's time to go out and have space when it's time to have a breather. (Frontline education professional 01)*

5.3.2 Frontline Education Professionals Category 2: Inefficient Provision of CDC

Regarding accessing CDC for diagnostic assessments, one of the challenges raised by frontline education professionals was the long wait times:

> *Some of the parents, carers, whānau, are so disillusioned with CDC, because of the waiting. And it's like, nothing gets helped, no one gets helped in that interim. It's horrible. (Frontline education professional 10)*

In recognition of an inefficient provision of CDC services, frontline education professionals highlighted barriers that may be impacting the ability to make changes and adopt different ways of delivering the services such as lack of time, workload pressures, and lack of human resources:

> *One of the big barriers has to be staffing, and has to be availability, and time. CDC are so busy, so many kids to see, if there was a better way to triage it, that would be good too. (Frontline education professional 03)*

> *They're [CDC] too busy. They just don't have enough people to do the diagnosis, as far as I know, and therefore, if they can't even get people diagnosed, you know, within a year, for example, how can they come into schools to talk to people? How can they actually, you know, do anything more? (Frontline education professional 10)*

Once children have accessed CDC for a diagnostic assessment, frontline education professionals expressed that they felt there were gaps in service provision. From scenarios they had experienced, education professionals felt that children who experience difficulties but do not meet the criteria for diagnosis of a neurodevelopmental disorder are often left without any input and when a child undertakes a diagnostic assessment and meets the criteria for a diagnosis, they also felt that the process neglects to offer adequate follow-up for that child and their family:

> *Sometimes they walk away and go, 'Oh well, they didn't tick enough boxes to be autistic, but they've got a whole pile of autistic tendencies'. So, what does it mean? Like, they're left in no man's land. And it doesn't actually help anybody. (Frontline education professional 05)*
>
> *It's not only just the diagnosis, it's also about a follow-up; It comes hand in hand. You know, give the diagnosis, give a follow-up to support the parents, and obviously, the person at school, so everyone's on the same page with the recommendations and how they look. (Frontline education professional 10)*
>
> *... it'd be quite nice if they were on a rostered, I don't know, two-yearly check-in or something, that then they had another assessment that could, because things change so much over time. (Frontline education professional 03)*

Frontline education professionals felt that access to CDC was often reliant on the ability of the referrer to adequately express their concerns within the referral information and it can be challenging to accurately depict concerns via written information and from an educational background of knowledge. The content represented within the referral could be the difference between a child getting accepted or declined for access to CDC:

> *The referral process is tricky because you have to really know how to word things, and what it is that CDC are looking for… as school people, we have an educational oversight and a sight on what's happening in our setting. And it's quite hard to capture that in a way that, and communicate to health professionals. ...And, I also have to get the form past a parent to sign. So, if I say to the parent, 'Right, I'm going to say in here very bluntly, your child is this, this, this, this, and this.' they're gonna go 'Holy shmoly, is that what you think of my child?' And it isn't necessarily what you think of the child, it's just that you have to capture those behaviours so precisely, and that can be really confronting for a parent. (Frontline education professional 03)*

Due to the confinements on the criteria for accessing CDC as well as education professionals coming from a background of education knowledge rather than health and disability expertise, frontline education staff highlighted that it can be problematic for them to know whether CDC is the most appropriate service to refer the child to. If education professionals do not refer the child to the most appropriate service, this can contribute to increased delays in children accessing support:

> *That can be a little bit tricky, making sure that we refer them to the right place, to get a diagnosis. I can't always tell, with neurodiverse kids, you can't always tell whether, and I don't want to label 'this child is autistic, this child's ADHD, this child is this', and we have to go to separate places for those assessments. And it can take you 18 months to get through Ngaa Ringa Awhina to get ADHD, and 'oh, it's not ADHD, maybe it's autism', and then another 18 months to get through the other health professional. So, it's hard to make that initial decision about which way to go. (Frontline education professional 03)*

An issue of equity was raised by frontline education professionals involving scenarios when children do not meet the criteria to access CDC, when there is a lack of clarity regarding other suitable services or which is the most appropriate service to meet the child's needs, or when families require timely access to services. These situations may result in caregivers paying privately for support. For those who don't meet the criteria for access to public or private services, or if the family are not able to self-fund private input, children may end up missing out on support:

> *"It's the ones, who they [CDC] say, we don't think they meet the criteria is the tricky one. And at the moment, some of those kids, you're not actually sure where to send them next. And so that's where parents often pay. (Frontline education professional 04)*

> *A lot of our families can't afford to go to Hamilton, or for the $600 fee for a dyslexia screening, or $1,000 screening for ASD, you know, that's not an option. So, it doesn't happen. (Frontline education professional 01)*

5.3.3 Frontline Education Professionals Category 3: Silos

Frontline education professionals acknowledged that one of the barriers that impact the ability to adequately respond to the needs of neurodivergent children and impacts the ability to apply a collaborative approach to supporting these children is that the systems seem to function in silos. There are separations between the relevant Ministries and funding streams. Not only are there separations between the different sectors, but there also appear to be separations and silos within the education and health sectors. The siloed systems and blurred specifications within the systems add to the confusion around who holds the responsibility for fulfilling particular roles:

> *And yeah, I mean, MOE's absolutely, MOE and health are really diabolical. Um, because they're, like we haven't got the differentiation between what actually comes under the Ministry of Health and under the Ministry of Education. There's a confusion, you know, very, very foggy line in who does the actual funding. (Frontline education professional 10)*

> *So, the overall picture of well-being, I think means that everyone is on the same page. There is not, I guess I'd use the word dovetailing, there's not a lot of dovetailing between the health, the home, and the education system, and any supports that are around. (Frontline education professional 03)*

When considering possibilities of ways to improve support for neurodivergent children, frontline education professionals felt it was important to bridge silos and enable a process where services were able to work collaboratively with a collective vision including less division between funding streams. Education professionals felt that bridging gaps would allow for a more streamlined and efficient approach to supporting children and families which would help reduce the chances of children falling into gaps and would make the processes easier for families to navigate.

> *I believe that if we worked together… it feels like at the moment, we've got little tasks, little roles to play, but we pass it on to the next person, but it would be nice to actually be seen as a team. Education and health are together. And that comes with the funding as well… let's work together, with the money together, and work out what the priorities are, rather than, 'Oh no, you pay for that', 'Oh no, we can't pay for that, you pay for it'. (Frontline education professional 06)*

5.3.4 Frontline Education Professionals Category 4: Provision of a Community-focused CDC

Frontline education professionals expressed that bridging silos could be assisted by creating more opportunities for connection between schools and CDC by CDC providing a more community-integrated service. Education professionals felt it was important to increase opportunities for open communication and relationship building. Some education staff had received education provided by CDC staff around processes for referring and accessing the service. Educational professionals had found this process to be extremely beneficial, aiding their understanding of pressures on the system and gaining clarity around the services CDC provides. Frontline education professionals felt this was a good strategy for opening lines of communication and thought it would be beneficial to maintain on a more regular basis. Education professionals also identified that facilitating their understanding of the CDC service could ultimately save time and enable processes to be more efficient for both parties:

> *Like when CDC came and just talked about the whole process of things, it just puts everything into perspective. Because sometimes you can get into that thing like, wow, why are they taking so long to pick up that referral, and often it's just because we're only seeing it from our side of the story… a face behind it as always good. (Frontline education professional 07)*

> *I know that the DHB provides information sessions or training for things like diabetes and other health concerns that schools need to manage. How awesome would it be if, even once a year, a couple of the psychologists from CDC run a workshop for SENCOs or learning support coordinators around diagnosis, around how to refer, what to include in your referral, when to not refer, you know, all that stuff... it might actually save CDC time as well because they're not going to be wading through rubbish referrals. (Frontline education professional 02)*

In terms of building relationships and connections, and CDC being more accessible for referrers, frontline education professionals emphasised the value of being able to have a to-and-fro conversation with someone from CDC. They suggested the benefit of having a key person to be able to contact to clarify any queries they may have, which again could aid the triage process:

> *So, I guess, maybe there's a way to check-point things as well. Because, if I've got a child, and I can see this, this, this, and this about this child, maybe I can save CDC time by talking to somebody and saying, 'I've got this, this, and this.' and they can say, 'No, don't even bother filling in the paperwork, because that's not our mandate, go this way'. (Frontline education professional 03)*

Another idea for maintaining communication was the suggestion of CDC to provide education staff with updated information throughout the year:

> *I think like, even like a monthly email of, 'hey, this is where we're at, these are the kids that we've got on our books that are coming from your school. This is kind of the timeframe that we're looking at'. I think that would be really handy. (Frontline education professional 05)*

> *And another thing is, maybe, if there was, it doesn't have to be individualised, but maybe if there were something put out to schools, once a term, from CDC indicating any news that we may need to know, change in referral process, current wait times, things to remember to put in your referrals, things that are helpful, things that are*

> *unhelpful, you know, just so there's some communication between them and school. (Frontline education professional 02)*

Additional ideas for increasing opportunities for collaboration, open communication, and building relationships included CDC staff carrying out more observations of children in the classroom environment and/or CDC staff becoming more integrated with providing support and recommendations for children within the classroom setting:

> *I think the psychologists could come in, and actually, you know, observe the kids face to face, I mean, observe, work with the teacher a bit as well, you know. (Frontline education participant 10)*
>
> *I think something that would also be really helpful is the CDC occupational therapists running some sessions about sensory profiles, and how to cater for kids with sensory issues in the classroom. I think that that honestly would be worth its weight in gold. (Frontline education professional 02)*
>
> *I think, in-school clinics, even if it's once a term, could actually be quite beneficial… whether or not you could have an in-school clinic that actually triaged, you know, people through the system, to say, well okay, this one's a definite, you know, even to triage and put them on the waitlist. (Frontline education professional 03)*

5.4 Individual Participant Group: Te Whatu Ora Waikato Managers

Within the Te Whatu Ora Waikato managers group, four main categories were generated from their perspectives. In the ‘insufficient support within the education setting’ category, Te Whatu Ora managers expressed concerns about the inadequacy of support for neurodivergent students in schools. They noted that support is often accessed only after a diagnosis, with a lack of funding for necessary assistance. This deficiency can lead to children with mild to moderate needs missing out on essential support, impacting their school attendance and pressures within family networks. The managers emphasised the importance of providing holistic, therapeutic support within the classroom setting.

In the ‘inadequate provision of CDC service’ category, managers identified factors affecting efficient CDC service delivery, including staff vacancies contributing to delays and longer wait times. The physical infrastructure and location of the CDC building on a hospital campus were highlighted as a barrier to service access. The medical approach in diagnostic assessments was critiqued for cultural inequity and the separation of services and unclear service specifications was thought to contribute to confusion in referrals.

The ‘silos’ category drew attention to the division between health and education sectors affecting support for neurodivergent children. Managers proposed building relationships and having regular communication with the education sector, advocating for collaborative, holistic approaches focused on the child's overall needs. A centralised triage process was suggested to streamline services and prevent children from being bounced between them.

In the ‘provision of a community-focused CDC’ category, the suggestions of relocating CDC to a community-based setting and conducting evaluations in schools for better accessibility and relationships with teachers were presented. The benefits of a community-based CDC included inspiring innovative ideas and approaching assessments in familiar, natural settings. In general, the managers advocated for a shift towards integration to enhance the availability and delivery of CDC services.

5.4.1 Te Whatu Ora Managers Category 1: Insufficient Support within the Education Setting

Te Whatu Ora managers acknowledged that they have a distant view and awareness of the supports available within the education setting as they do not work on the frontline, however, based on their knowledge of how the systems are currently functioning or through hearing other people’s experiences, they had the perception that the support available within schools for neurodivergent children is inadequate. Based on current criteria for accessing support within the education setting, children with mild to moderate needs may miss out on input:

> *You do hear that maybe a child needs more support in the classroom. (Te Whatu Ora manager 03)*

> *If we think about ORS, I'm not sure if it's still the same, was always there for the, you know, most disabled 5%. We actually know that that next bracket down of the more moderate impairment actually have more chance of improvement, than our severe. And I think it's a real lost opportunity in New Zealand that we actually don't fund and provide more into that space. (Te Whatu Ora manager 04)*

Te Whatu Ora managers perceived that support within the education setting often isn't accessed until confirmation of a diagnosis is made and that there is a lack of funding to provide adequate support:

> *What I find in schools is, you need that diagnosis, and then they'll look at doing things. And look, I think the therapists and the support workers, work really, really hard to provide support, but it's not, potentially isn't funded enough to make it work really. (Te Whatu Ora manager 04)*

The perceived lack of adequate support for neurodivergent children in the education setting was recognised as a contributing factor to a range of consequences such as children not being able to attend full-time school hours and the impact this has on the family network:

> *I think, the number of hours that children get for school for teacher aide, is not enough. So, [an acquaintance], her son has got autism, and he's at a normal school and he's five and a half now. She has to go to school on so many lunchtimes because the teacher [aide] is only 20 hours, and you do that over five days. So, he doesn't actually get to stay at school all day, and then she's got to bring him home, because there's no teacher aide… It made me think a lot more and I thought, well, how do*

> *parents that work full-time get on when they have got a child with special needs going to school? (Te Whatu Ora manager 01)*

Wider systemic gaps associated with inadequate provision of support for neurodivergent children were recognised. When school support is available, it is likely to be provided from an educational perspective rather than a more holistic view of what that child needs to engage in different contexts. When the child is not able to access support outside of the school context, their therapeutic gains may be more limited and more difficult to generalise beyond the education setting:

> *I think the services for kids, are, they're very school focused and they're not about the individual intervention, but they're about how does that kid interact, integrate within that classroom, which is the right focus for an education service. The problem is, that's the only service that that child is getting. And so, there is no focus on then how do they interact at home, and what, how do they, what's the individual needs for that child in a home environment? (Te Whatu Ora manager 02)*

Te Whatu Ora managers recognised the relevance and importance of therapeutic support being provided in the classroom setting:

> *The ability to maintain function is much more about incorporating it into your daily activities. Now school's a massive part of that. You're at school six hours a day, how can you use those opportunities within classrooms or in the playground, and that sort of thing, to maintain their level of function or improve their level of function? (Te Whatu Ora manager 04)*

5.4.2 Te Whatu Ora Managers Category 2: Inadequate Provision of CDC Service

Te Whatu Ora managers described a range of factors that influence the ability to provide CDC services in a timely and efficient manner. Staff vacancies were identified as a factor that impacts the adequate provision of CDC. When there are staff vacancies for an extended period of time, this can affect waitlists, resulting in longer wait times for children to be seen. The pressure and prioritisation of getting through the waitlist can also inhibit opportunities for CDC staff to engage in other aspects of their role such as collaborating with other services:

> *Any staff vacancy, we do try really hard to backfill, but again, you get to a point where you can't backfill, so, therefore, that is going to put a dampener on the waitlist and the length of time. (Te Whatu Ora manager 01)*
>
> *... the pressure of the waitlist and the lack of clinicians, and the fact that we do often hold vacancies, means that it's really challenging to give clinicians enough time to go and do that regular stuff [collaborating and building relationships with other services]. (Te Whatu Ora manager 05)*

Te Whatu Ora managers recognised that the current service setting of CDC may be a barrier to access and provision of support. Despite CDC being a service provider for disabled children, the building is not easily accessible for disabled people. The location of CDC on the hospital campus also creates barriers to access. Challenges with accessing the service setting result in issues of inequity and means that some children may be missing out on accessing support:

> *I think, this model, only sees people who are capable to bring their children into a hospital setting. So, we are missing, it's the people not on the waitlists that I think is problematic. And so, by that, I'm talking about equity, that there's, as far as I can make out, the proportion of what education will tell me that need to be seen by CDC who are Māori or Pasifika, aren't getting through. And then, of course, the other equity issue is the building is disability inaccessible and therefore if CDC was more community-based, it wouldn't matter. It's about who isn't getting there, that worries me. (Te Whatu Ora manager 06)*
>
> *I've seen parents and caregivers bring a disabled child in a wheelchair, to have to call up to reception go, 'I'm going to put my child in the lift', put the child in the lift, press the button, parent didn't fit, so the parent had to wait, and trust that someone at the top was going to get their kid. The kid is then taken out of the lift, then the parent can*

> *get in the lift when it comes back and they go up. But that, for a service entirely centred on disability, that's the entire reason it exists, it doesn't cater for disability almost at all. (Te Whatu Ora manager 05)*

It was discussed that the building infrastructure and being based on a hospital campus may contribute to inhibited innovation within CDC:

> *... because we are housed in a building on a hospital campus, we limit our view and our ability to be innovative. And I think then, therefore, the infrastructure or facility is a dis-enabler of innovation within the CDC service. Being on a hospital site makes us very, a very medical model… I think it limits the staff's view of what can be achieved. Yeah, so I guess it's the vehicle for restriction in our thought processes, maybe. (Te Whatu Ora manager 04)*

In addition to operating within a medical model framework, the approach to diagnostic assessments is heavily influenced by Western-centric approaches, which creates issues of cultural inequity. This poses a disadvantage for children who primarily identify with Māori culture and language, as the use of English assessments to gauge their intelligence fails to accurately capture their true abilities and meet their specific needs. Results on such assessments may show that their English language skills may be below average, but that does not accurately represent their level of intelligence:

> *CDC comes from a very Western medicine perspective, where you have and I think it's probably what I'm talking about is that disability perspective, where you come in for an assessment, we test you using this box test, and then you will have you'll either meet the criteria or you won't, I mean, that's a total Western mentality. And it's very much impairment-focused or, you know, health, physical health, or cognitive health-focused, as opposed to that wider spiritual, whānau, everything else that comes into that well-being for that child and how they develop. (Te Whatu Ora manager 02)*

The division between services and inflexibility in the provision of service specifications can result in confusion for referrers navigating the system and knowing who the most appropriate service to refer to is. As a result, CDC spends time triaging referrals that may not be appropriate to their service and children may end up waiting on incorrect waitlists. Increasing clarity and knowledge around what CDC provides as a service would assist in ensuring CDC is seeing the children it is meant to see:

> *The challenge, I guess, is CDC knows what it does, but referrers don't, and they see this kid's not quite right, Child Development Centre is where I should refer them. Actually, you know, all those different pathways that that child can go down and that complexity around, has this child got anxiety, has this child got attention deficit disorder, you know, all of those different pathways that go to different areas. And it's, I still don't really understand where a kid should go to each area, so how can you expect referrers to? (Te Whatu Ora manager 02)*

The ability to be flexible in the provision of CDC can be impacted by Ministerial expectations and restrictions on how resources can be utilised:

> *But it's challenging when the Ministry [of Health] measures us based on people seen, and the Ministry doesn't measure us based on hui [meeting] with, at education, you know, like resources shared or, you know, lives bettered in other ways. It's very bums on seats, like attendances and the waitlist is measured, which is why there's always the pressure to reduce the number of people that you're accepting. (Te Whatu Ora manager 05)*

5.4.3 Te Whatu Ora Managers Category 3: Silos

Te Whatu Ora managers acknowledged that the ability to deliver adequate access to and provision of support for neurodivergent children is impacted by divisions between health and education and that services across both sectors appear to function as silos:

> *So, there's this real mismatch between education and child development services. Education will say, we don't need a diagnosis, child development services are about diagnosis. And there's a big gap. So, the supports for the people living with*

> *neurodiversity, that are in educational settings don't come in a timely manner, because there's this happening. (Te Whatu Ora manager 06)*

> *Well, funding's a big one. I mean, you know, there's a limited budget for both health and education and where do you use that? How do you use it? And I guess that all roads kind of lead back to that expectation that if, you know, education expect health to be doing this, versus we expect them to be doing it, and never the two shall meet. (Te Whatu Ora manager 04)*

The importance of building relationships and regularly communicating with the education sector regarding access to CDC was highlighted as beneficial approaches to assist with bridging silos and facilitating understanding of CDC service criteria and processes:

> *I think regular hui [meeting] honestly would make such a huge difference. I think just having people in the room, knowing that they've got your phone number, you know, when they're like, 'Should I refer this kid? Shouldn't I? Is this a big waste of time?' Having someone to actually have the five second conversation, instead of filling out the six pages of forms, and then having someone have to read the six pages of forms and write this reply to you to say, 'No, sorry, this is not going to meet our criteria.' (Te Whatu Ora manager 05)*

Te Whatu Ora managers recognised the need for services to work more collaboratively and that the provision of input should be determined by the child's overall needs rather than whether they require support at school or home. Provision of a more collaborative approach would enable more continuity for the family:

> *I think that having this health, education split is a massive disadvantage to children. They need a therapist that can see them and be able to work with them in both contexts, and work with the parents… thinking about that from a what the kid needs perspective. (Te Whatu Ora manager 02)*

> *… go back to that continuity of care for that family, making that family journey more pleasurable. So, collaboration and being able to drop those boundaries so that the Ministry of Education therapist and the Ministry of Health therapist that they could*

> *work, either one, work across both, or they work together, or they could cross over. (Te Whatu Ora manager 01)*

A centralised triage process was suggested as another strategy for collaborative working and responding to the needs of the child. Facilitating a central triage process would help to mitigate children getting passed back and forth between services and would reduce the pressure on referrers trying to guess where to refer children:

> *We actually need to be part of a broader paediatric referral process. So, a single point of entry type model, where families are not pushed from pillar to post between medicine, development, and mental health. So, I think what happens is a lot of children come into a service and then are passed around services, until such time as maybe the right service actually does something. (Te Whatu Ora manager 04)*

5.4.4 Te Whatu Ora Managers Category 4: Provision of a Community-focused CDC

Some ideas around improving the access to and provision of CDC services included CDC being based in the community rather than on a hospital campus and CDC staff carrying out assessments within the school environment. For a community-based CDC, there would be benefits in being positioned in shared facilities with or nearby other relevant services:

> *It would be so good to have a more purposeful space, that enabled access, especially for higher-need whānau. Because I think right now, having no good parking, having a lift that doesn't allow wheelchairs of like a certain size in, that it's quite overwhelming being on the hospital campus. I think all of those things make it really challenging for whānau to engage… And being off-campus, being not on the hospital grounds… and ideally, having a model that then allowed a mixed-model of having some assessment at that place, and maybe some at schools. (Te Whatu Ora manager 05)*

> *CDC was meant to be where ICAMHS is… If we were there, around the corner is Oranga Tamariki, all these conversations are already there. Then, as a team, my God, could you imagine if the mental health specialists and the CDC specialists, and their allied health multidisciplinary teams went out to schools and ran clinics, even if it was once a month. God, that would be cool. And some of those discussions that we wait for*

> *weeks for would just naturally happen. So, I do think a hub. (Te Whatu Ora manager 06)*

As a result of CDC being a hospital-based, medically associated service, it was recognised that this setup may hinder innovative thinking within CDC. The opportunity to operate in a community-based context may inspire alternative ways of thinking and working:

> *If we were community-based, if we were in with maybe a community provider, or, you know, co-located with kaupapa Māori services, or something like that, you know, would we be delivering the same service? Probably not. (Te Whatu Ora manager 04)*

Te Whatu Ora managers highlighted some benefits to carrying out assessments within the school environment such as schools being accessible environments, increased contact and relationship building with teaching staff, and a reduction in the likelihood of children not engaging in the assessment process due to an unfamiliar environment. From an allied health perspective, it is also considered best practice to observe children in their natural environments:

> *I think, it should be more in the community. I think that assessment should be happening more in schools. I think assessment should be happening more in early education centres and kindergartens. I think that's where allied health should be going. I find no evidence for requiring people to come to you in a hospital setting. That actually, we're meant to collect information from schools, observe things. That is best practice in allied health. (Te Whatu Ora manager 06)*

> *… the number of clinics that we've had, where a quite complex child, who clearly has anxiety, but also has co-morbid autism, or intellectual disability, would come into our centre, not feel comfortable, all these strangers they've never seen before, in a setting they've never been to, and they would just close up. And so, we couldn't do an assessment at all… And that's not only a waste of our resource, but it's a waste of parent's time, and it's a waste of children's time, and it's not getting a good outcome for anybody. So, if we had the perfect system, and we could send a psych and an OT*

> *out to a school… they could actually observe the child in their learning environment. (Te Whatu Ora manager 05)*

5.5 Individual Participant Group: Principals and Deputy Principals

Four main categories were generated from the perspectives of principals and deputy principals. In the ‘insufficient support within the education setting’ category, concerns were voiced about the limited support for neurodivergent students in schools. Challenges in accessing funding and support, along with insufficient training for educators, were highlighted. The bureaucratic constraints and detachment from the school's culture hindered external support from MOE and approval for support was seen as more likely after a formal diagnosis. The importance of enhancing educators' capacity to work with neurodivergent children was emphasised.

Regarding the ‘inadequate provision of CDC service’ category, principals and deputy principals described extended waiting periods, unclear access processes, and insufficient follow-up as key challenges. The confusion over how to access CDC has contributed to misunderstandings, and the struggle to get children assessed has resulted in some people exaggerating the child's difficulties to increase the likelihood of their referral being accepted. The assessment process does not provide sufficient follow-up and support for implementing recommendations. The recommendations CDC make regarding school support can put education staff in a difficult position contributing to clashes between education staff and families who have specific expectations.

Regarding ‘silos’, education leaders noted the separation between health and education sectors and suggested a more collaborative approach. They recommended a designated contact person at CDC and emphasised the importance of building relationships among professionals working with the child and family to address siloed working.

In the ‘provision of a community-focused CDC’ category, principals and deputy principals proposed a community-integrated service, collaborating with children, families, and education staff locally to reduce barriers for those unable to attend on-site appointments. They stressed the significance of observing children in their natural environment for accurate diagnosis of neurodevelopmental disorders.

5.5.1 Principals and Deputy Principals Category 1: Insufficient Support within the Education Setting

Principals and deputy principals shared their concerns regarding access to support for neurodivergent children in the school setting. When asked about their views on access to support, they felt that support was challenging to access and was not adequate:

> *It is very erratic. It depends on how well you sell your issue to the supporting agencies. It's who you know, that's providing supporting service that gets access to it. We do have to go through the Ministry [MOE] for a lot of this, initially, and sad to say the Ministry does not provide a sufficient service. (Principal and deputy principal 01)*
>
> *... there's gatekeepers at every step of the way. Yeah, I find the Ministry don't come to the party, unless like if they're violent they do, because they provide, that is a safety issue for the bigger picture. But, if they're just, need support in their classroom, they're not that great at funding that. (Principal and deputy principal 02)*

Principals and deputy principals highlighted challenges around accessing ORS funding for students and pointed out that supports that have been assured in the past, such as an increase in the provision of ORS funding, have not come to fruition:

> *Yeah, my opinion is poor. And the fact that such a limited number of children can access ORS, and the amount of effort and time that's invested in making ORS applications. (Principal and deputy principal 03)*
>
> *I guess, the introduction of special education 2000 was when the special needs crusade started coming more to the fore. The only problem is that the funding has*

> *never matched what we were promised. So, for example, kids on the ongoing resourcing scheme [ORS], 1% of the population receive that funding. We were promised, and I remember the meeting clearly just before education 2000 it was gonna go to 3% and it's never happened. (Principal and deputy principal 05)*

With the establishment of the Learning Support Coordinator (LSC) role, issues of equity have arisen as not all schools have been allocated an LSC:

> *The system doesn't create equity at all, it creates the opposite. So, if you have, see contestable funding has become the new way over the last 10, 20 years. There's not enough money to go around, so you have to apply for it. And it's contestable, and some will get it, and some don't. So, as soon as you have a system like that, then equity is lost. I'll give you a small example. So, there's a certain number of schools that got given learning support coordinators, and some haven't. See, we haven't, and I see rich schools up the road, have it, and we're a mid-socio-economic school, and we don't, so is that equitable in anyone's eyes? (Principal and deputy principal 05)*

As a result of insufficient support available within the school setting, some children are unable to attend school for full-time school hours:

> *… there was a thing in the press the other day from some parents who, their children don't come to school every day, because the funding is insufficient for them to be there. So, the law says that you are allowed full access and that the state will provide education for all students. And so, schools are having to break the Education Act 1989, because of the fact that they can't look after those kids. We've got a severely delayed student here, we pay way over the odds for what we get given. So, that's pulling money out of other things, and he still can't come to school every day, for the full-time that school operates. So, that must be a huge issue for so many parents. And I mean, we feel bad about that. (Principal and deputy principal 05)*

Principals and deputy principals acknowledged that access to support and training around neurodivergence for education professionals is limited. Lack of access to training around supporting neurodivergent children may mean that teachers and teacher aides prioritise academic learning rather than having the skills to recognise and consider alternative needs of the child:

> *If somebody has gone in for three- or four-year teaching degree, or diploma, or whatever is now on offer, you have a very limited opportunity to do any work in that space [neurodiversity]. You'd be lucky to do one paper… to me, we are not preparing our teachers for the vastly increasing neuro-level of students that everybody's talking about. (Principal and deputy principal 01)*
>
> *… we've currently got one in the school, who's a 5-year-old, and I keep saying to his teacher, your programme is far, far too structured for what he's capable of doing. But it's falling on deaf ears at the moment… Teachers are great for wanting kids to learn to read, learn to write, and all that, but actually do some fun stuff and some big stuff, you know, around getting those motor skills. (Principal and deputy principal 02)*

The importance of building the capacity of teachers and support staff around working with neurodivergent children was discussed:

> *I think if money and time were no object, I think actually having people working with the children who are actually trained in working with these types of children. I mean, we've got wonderful teacher aides, and they do an amazing job, but they're not necessarily trained in working with these children. And same with our teachers, they're not necessarily trained specifically to work with these types of children. (Principal and deputy principal 04)*

Having support provided by MOE which is external to the school is not always successful. Principals and deputy principals discussed situations where some teachers can feel challenged or confronted when an external professional comes into their classroom environment to provide feedback and recommendations. Support provided by MOE can be hindered by bureaucratic confinements on the role and external education professionals may also be detached from the culture within a particular school:

> *We also can access support through the RTLB services. And even that is, the way that service is provided changes on a regular basis. So, that is not what it should be doing, or is not sufficient to cater for the needs we have. The way the services is rolled out as well, there's also an issue with that, because, for example, the RTLB services, when we make a referral, they look at improving the teacher's practice. Now, not many people want to change their practice after working for X number of years, and the thinking is that if I've called out, I've reached out for support, I'm coming in with ideas for the student, and they look at it as, people coming in to look at, and criticise, and change me. So, there's a negativity around it. (Principal and deputy principal 01)*

> *Because RTLBs are external to the school, they are not invested in the school culture. (Principal and deputy principal 05)*

One principal gave an example of how their school has implemented a student support worker position, which has proven to be highly advantageous for the students. This role has provided numerous positive outcomes. One major advantage is that the school has control over the parameters of the role, enabling them to tailor their support to meet the specific needs of each student. In contrast, external support services affiliated with MOE are typically bound by bureaucratic restrictions that may limit their ability to address the individualised needs of each child:

> *... hugely beneficial role [an internal student support worker]. Can do whatever the principal says. Whereas with LSC, the bureaucracy wants to control what they do. (Principal and deputy principal 05)*

Although MOE describes access to learning support as being a needs-based approach, principals and deputy principals felt that support is more likely to be approved when a child has a diagnosis:

> *... and then ticks a box for us to access funding, if there's a diagnosis. If there's not a label, that's where we get into that whole murky water. (Principal and deputy principal 02)*

> *So, some parents are quite happy, kind of not to have their child fully diagnosed, but then they do not have access to reader/writers or any additional support for the rest of their education past primary. (Principal and deputy principal 03)*

5.5.2 Principals and Deputy Principals Category 2: Inadequate Provision of CDC Service

Principals and deputy principals identified a variety of factors that influence the adequate provision of CDC services. Concerns around long wait times, lack of clarity around access to service, and lack of follow-up were highlighted as some key issues. Principals and deputy principals emphasised the long wait times to access CDC and that the criteria and process for accessing CDC lacks consistency, honesty, and fidelity:

> *…, by the time teachers realise they can't do what they need to do for a student, it's kind of like, the ambulance is already at the bottom of the cliff, and we need support now, not we'll see them in 9-months. (Principal and deputy principal 02)*

> *I know the process has been in the media recently for a number of not-very-positive reasons. The delay in getting assessments done is the major, major, major issue at the moment. That is a severe flaw, it doesn't help the situation should we say. And the negative press and the negative media exacerbates it instead of helping the situation. But the process is not consistent and that's an issue. And, and I think the delays make the process even more convoluted. (Principal and deputy principal 01)*

Lack of clarity about the processes to access CDC for external stakeholders has contributed to some inaccurate perceptions, such as the mentioning of anecdotal advice that a referral from a GP will support the child in being accepted for assessment at CDC and influence their positioning on the waitlist. A significant priority for referral information to assist triaging at CDC includes information about how the child is functioning in the school setting. Therefore, a referral from a GP that does not include school information may delay accepting or declining a referral until school information is available:

> *The fastest way to have an assessment, in my opinion, is through a GP. So really, a lot more lengthy and difficult to access CDC through a referral from primary school. (Principal and deputy principal 03)*

As a result of ongoing difficulties getting children accepted to be assessed for neurodevelopmental disorders at CDC, principals and deputy principals explained that when writing the referral, they feel it pays to make the child's shortcomings sound as deficit as possible to reach criteria and get accepted for access to CDC.

> *The advice once again, anecdotal advice is that the learning support coordinators, special education needs coordinators, principals, RTLBs to make student's shortcomings, problems, issues, criteria, seem to be much worse than it is, so that you go to the top of the line, so to speak. (Principal and deputy principal 01)*

Regarding the assessment process at CDC, principals and deputy principals understood that the process consists of the completion of an assessment and a report. They felt that the process was lacking any follow-up or support regarding the implementation of recommendations:

> *... how, what is their [CDC] role in terms of supporting us? And at the moment, it appears that it's just identification. Then, if that is their whole role, I guess, then there's a piece of the jigsaw missing about where to now? Or follow up? How do you take that initial report, and have support around fulfilling the recommendations within it? (Principal and deputy principal 03)*

Principals and deputy principals discussed areas of conflict that can arise as a result of recommendations that are made within assessment reports from CDC. If clinicians from CDC recommend specific supports that should be accessed within the school setting, this can put education staff in a difficult position where the family have specific expectations but there are confinements on the school's ability to access and provide support:

> *And sometimes what comes out of the reports that they've written up there [CDC], which is not helpful for us, is that recommendations for school support and teacher aides support are recommended, and we don't have any resourcing to make that happen. So, it causes conflict between the whānau or the families and the school, because they come with an expectation that something's going to be provided because it's written in some report from that organisation and doesn't transfer that there is any. (Principal and deputy principal 05)*

5.5.3 Principals and Deputy Principals Category 3: Silos

Principals and deputy principals recognised that services within the health and education sectors appear to operate in silos. They expressed that they had not had face-to-face contact with CDC staff and that their interaction primarily consisted of the completion and exchange of paperwork:

> *... just that probably that we all live in these little silos and we don't really know what each other does. That's probably what needs to be broken down…. They [CDC] don't reach out to us, and we don't particularly reach out to them. They might provide us with a report or ask us for some information. It's more along those sorts of lines, really. (Principal and deputy principal 05)*

Principals and deputy principals recognised the need for a more collaborative approach between health and education sectors and suggested the idea of having a key person at CDC whom they could contact for any queries:

> *Yeah, or just an option to ring somebody and be able to chat through it, would be really helpful, or video call someone or something, you know, just so you make sure that you have got the right end of the stick, and that what you're going to put in place is going to address the real problems, would be really good.*
>
> *(Principal and deputy principal 02)*

Increased opportunity to develop relationships and build connections was also highlighted as an important component of addressing siloed working:

> *There's no opportunity to build a relationship up. Now, all good practice in the jobs that we are in is based on relationship. If there's no relationship, then pretty much you know, you can expect artificial intelligence to take over these jobs. Right? And especially in neurodiverse situations, there's an even bigger emphasis on creating that relationship. Not just with the client, the student and us, or the student and CDC, it's all parties involved. Because, as soon as we have a breakdown in one of, or the other, of all the stakeholders, then any processes, any interventions you put in place, is bound to fail. (Principal and deputy principal 01)*

> *I suppose, from a school's perspective, that, to the Child Development Centre would be probably an invitation from principals' associations and the like to have people from the development unit come and speak to them at professional development days… some information, I suppose on what child development aims and objectives are. (Principal and deputy principal 05)*

An additional idea for bridging silos was to bring together the different professionals who work with the child and family. This process would allow for a more consistent and collaborative approach to supporting the child and their family and would minimise miscommunication and repetition of information:

> *...so, you know, can you imagine the stress on that one child, he's got to see 15 different specialists. Already, we've identified that the child is neurodiverse, and here we are loading again, on the person x5, x10, however many, but if we all get around the same table, and he has one interaction with everybody, it's reduced all of those stress levels. He says, or the family says one thing and 5 or 10 people hear it, instead of them going out and saying it 10 times, omitting a piece of information that may or may not be vital, and those sorts of things. It's like being on hold, you complain to somebody, and they say, 'Hold on, I'll get you, my manager' and you just told your story, 'Hold on, let me pass you on'. Each time, you relay your problem, you traumatise yourself again. (Principal and deputy principal 01)*

5.5.4 Principals and Deputy Principals Category 4: Provision of a Community-focused CDC

Alongside the other mentioned suggestions for bridging silos, principals and deputy principals mentioned the idea of CDC providing a more community-integrated service by going out into the community to work with children, families, and education staff. This approach would help reduce barriers for those unable to attend their appointments on-site at CDC:

> *Maybe some satellite sessions, rather than, because it's quite daunting, and people will put barriers up about the whole traipsing into Hamilton, finding a park, you know, all of those kinds of things. Just to try and lessen the barriers, because even if they're not real barriers, they'll make them barriers. Yeah, so maybe, you know, satellite sessions or clinics out this way sometimes. (Principal and deputy principal 02)*
>
> *Well, surely that if they're [CDC] making diagnosis and making suggestions about students, then they should support the schools in implementing the practices that would meet the needs of those students. So, at the moment they write their report, send them to us, and never the twain shall meet. (Principal and deputy principal 05)*

In consideration of the process for diagnosing a child with a neurodevelopmental disorder, principals and deputy principals emphasised the importance of observing a child in their natural environment:

> *To get an authentic diagnosis of any particular child's problems, you have to have a close relationship and dialogue with all stakeholders. How can you create a template, a suggestion, or an intervention, with only interacting with one person, at one time, in your chosen environment? We haven't had a single visit from any psychologist from CDC to come and look at the learning environment, authenticate that the report that the teachers fill out is accurate. I haven't heard of any psychologist from CDC going out to a child's home, which is bound to give you masses and masses and masses of*

> *very valuable information. How then do you draw up a programme? Based on the information that you have. (Principal and deputy principal 01)*

5.6 Individual Participant Group: Policy

The dataset gathered from five nationwide MOE and Whaikaha representatives generated five main categories. In recognising ‘insufficient support within the education setting’, policy representatives expressed concerns about inconsistent and under-resourced support for neurodivergent students in schools. Funding eligibility issues resulted in potential gaps in support, prompting families to switch schools for better support. Inadequate training for educators in supporting neurodivergent students was identified as a contributing factor to insufficient school support.

The category of ‘inadequate provision of CDS’ highlighted concerns about long wait times, lack of support during the wait, and inconsistent service delivery due to limited funding and resources. As a result, the focus has been placed on diagnostic assessments at the compromise of other components of service delivery, contributing to inconsistencies in the way services are provided nationwide and exacerbating issues of inequity.

Under ‘you don’t know what you don’t know’, policy representatives discussed the complexity of navigating the system, exacerbated by segregated services and confusion about each service's responsibilities, particularly impacting Māori and Pasifika families and potentially leading to disengagement from services.

‘Silos’ were identified as a significant obstacle to collaborative support for neurodivergent children, with separate budgets for the Ministry of Health and MOE contributing to segregation. The lack of coordination within the health sector, particularly between child development, child health, and mental health, posed challenges for professionals, referrers, and families. Policy representatives suggested a more centralised, coordinated approach for referrals and emphasised the need to bridge organisational and funding silos for more effective support.

In the context of ‘improving the provision of CDS’, policy representatives highlighted insufficient access to therapeutic support for neurodivergent children in the public sector. They advocated for community-based CDS in familiar settings, acknowledging flaws in the current delivery system and stressing the importance of establishing a more modernised system for providing CDS.

5.6.1 Policy Category 1: Insufficient Support within the Education Setting

When asked about their perspectives regarding the availability of support for neurodivergent children in a school setting, policy representatives commented that support in schools was variable and lacked the resourcing required to meet the needs of children. Many who do not meet the criteria for ORS funding miss out on support:

> *I think, there's an insatiable need, really, in a way for more, but we probably aren't providing the basics. I think the ones who miss out still are the moderates. So, if you're moderate and you don't quite click the ticket for ORS funding, you're at sea really, because you're in, the school can't, the school still have to manage your needs as a young person, but they don't actually get any extra resource for that unless it's built into their sort of group funding in some way. So, you know, I think we should still be concerned about the moderate need. (Policy representative 01)*

Supports available within education appear to vary between different schools. Challenges in accessing support within schools may result in caregivers moving their child between schools to find the best fit for their child’s needs:

> *I mean, some children, in fact, the parents get onto this, and they start moving schools… And moving school isn't necessarily the solution. Because sometimes a large school has lots of resources, they've got more collateral, to somehow find the expertise around that child. They might have a teacher aide with particular ASD knowledge, or*

> *particular knowledge about the child's condition… Whereas sometimes, actually for the child, a smaller school is better because there's less social challenge. You know, classes are smaller that sort of thing. So, it's, both access can vary from school to school, but also the whole context of the school can vary. (Policy representative 01)*

Policy representatives acknowledged that the lack of training and support for teaching staff regarding working with neurodivergent children contributes to a gap in the provision of support within schools:

> *And I think another big gap, in terms of school support, would be just even teacher training. I know there's such a limited amount of time put aside in their training for working with children with diverse needs. That would be another place I think would be really good to invest more, so then they were upskilled more from the beginning. (Policy representative 03)*

> *I think a lot of our teacher aides have really good core skills, so will have some really broad knowledge and understanding, but they often, the most important skill you can't gain from a book, which is the understanding of the actual child, the individual child themselves. And often teacher aides come in, and you find yourself having to go through a phase of letting them show their authority, and then slightly nurturing them to come around to actually, the person in charge here is the child, and they're the ones that are going to allow you to be a successful teacher aide, or not be a successful teacher aide. (Policy representative 04)*

5.6.2 Policy Category 2: Inadequate Provision of CDS

Long wait lists were highlighted by policy representatives as an issue for access to and provision of CDS. There is also a lack of support available for families while they spend time on the waitlist for CDS input:

> *The waiting lists, I mean, they can be anything up to 36 months, across the country, all varying different levels. (Policy representative 02)*

> *I mean obviously a lot of CDS have big wait times, and so, often for families and for schools, knowing kind of what to do in the meantime, while they're waiting. You know, that need doesn't go away while they're waiting. So, what support can they access in that time? (Policy representative 03)*

Not only are long wait times challenging for families, but the process also has an impact on the clinicians responsible for accepting and declining children onto waitlists:

> *I know what it's like to be a family member sitting on a waitlist, it's shocking. But I also see the look in the professional's eyes when they've got to put you on that waitlist. And you look at them, and you think, you know, you guys are fixers, and this is super, super hard for you, particularly when you know that the waitlist you're putting me on is not potentially going to be the answer that I'm seeking. (Policy representative 04)*

Policy representatives identified a range of factors contributing to the inadequate provision of CDS within New Zealand. Limitations with funding and lack of adequate resourcing have contributed to arbitrary adjustments as to how different CDSs around the country deliver their services. Although the population and needs of neurodivergent children have increased, the funding has not been adjusted to meet the increased demands and as a result, many CDS within New Zealand have placed priority on the completion of diagnostic assessments, however, diagnostic assessments are only a small part of the service specifications outlined for delivery of CDS:

> *CDS have had a capped bulk funding model for 30 years… And a lot of the resources of CDS have been focused on achieving a diagnostic assessment for the child, whereas that's not actually what CDS should, it's not what it is. It's not what their service specification says they should be delivering. (Policy representative 02)*

Policy representatives acknowledged that the arbitrary delivery of CDS within New Zealand varies between districts which creates an issue of equity:

> *Child development is, right across New Zealand, it's done quite differently by DHB. So, there's no consistent things. And, you know, we have cases where families will misrepresent their address, just to stay inside a postal area, because that's where they feel supported. (Policy representative 04)*

> *I think it's really hard for families, depending on, I think it depends a lot on locally. Regionally, like your GPs and your paediatricians, and your school, it's really reliant on schools, feeding through that info and being proactive about being able to refer. I mean, even within CDS nationwide, I think it's hard because it's not consistent. You know, some would accept referrals from schools, whereas not all CDS do. Some of them have to go through like a GP, or paediatrician, or something first. So, I think that inconsistency makes it really tricky. (Policy representative 03)*

Depending on the referral pathways within different CDS, some children may miss out on access to service because they aren't connected with the referrers, such as not being enrolled with a GP:

> *… some of those really tricky parts of just knowing who's accessing the pathways to, you know, who's actually enrolled with GP and the kind of chain reaction that that requires to get into paediatrics. There's some equity challenges there for me. (Policy representative 05)*

Another issue of inequity was highlighted, acknowledging that the current way CDS is delivered may not be accessible for all cultures. One participant discussed that Māori populations are often overrepresented within disability statistics, however, there appears to be a low rate of Māori accessing CDS:

> *One little survey I did in my local patch was the rates at which Māori children accessed our Child Development Service, and it was an incredibly low rate. Hugely underrepresented when I know from other data that they're overrepresented in child disability. So, why is it that Māori children are not accessing our public services? So, the big title of this is equity, and I don't think our services have really engaged with equity effectively. The cultural competency hasn't been raised to the point where*

> *people are welcomed in in the right sort of way. I think there's a whole lot of reasons that need unpicking and some sort of monitoring across our services that says, are we really seeing the same level of access? I think that's a pretty big thing that I would like to see, I think that an injustice in society. (Policy representative 01)*

5.6.3 Policy Category 3: You don't know what you don't know

As a result of siloed services and lack of clarity around the roles and responsibilities of different services, policy representatives highlighted the challenges for families and referrers trying to navigate the system to ensure children are connected to the right pathway for getting the appropriate support in place:

> *…from a family's perspective, child development is a really confusing space. (Policy representative 04)*

> *…if you put in the barriers to entry that between the Ministry of Education and the Ministry of Health have designed with a very complex entry system of different ages entering different services, different allied health teams available in different places, it becomes really complex. And a child can sit on multiple waiting lists. (Policy representative 02)*

As a result of challenges navigating the processes around access to appropriate supports, some families, particularly Māori and Pasifika families, may disengage from services:

> *The other issue that we often hear from community, and it was something that even I personally came across, was the lack of understanding between the difference of child development and child health… My son's paediatrician, for example, I assumed for the first two years that she was part of child development, and then discovered that actually, she had nothing to do with child development. And so, when she would say to me, I'm talking to the team about particular things, I assumed she was talking to the child development team and actually they weren't. So, to me that, and we hear this from families right across the country, the connection between the diagnostic side of things, and the child development side of things can be quite disjointed. And when*

> *you're a young family in that state of, 'I don't know, what I don't know', it becomes very, very overwhelming. And so, we see families, particularly Māori families and Pasifika families disengaging. (Policy representative 04)*

It was highlighted that even health professionals who work in the industry find it challenging to navigate the system, therefore it must be even more challenging for those without industry-related knowledge of the systems, such as families and other referrers:

> *I have a colleague who has a two-and-a-half-year-old boy who's been acknowledged to be autistic since he was one-and-a-half, he's never once managed to have a speech and language therapy assessment or an intervention or a therapy session. Not one. He went to CDS, they pushed him to MOE, he went to MOE, they pushed him back to CDS, it's heartbreaking. This guy's a doctor, he can't find services. If he can't find services, what the hell's happening to everybody out there? (Policy representative 02)*

5.6.4 Policy Category 4: Silos

One of the barriers identified by policy representatives that impacts the access to and provision of support for neurodivergent children and the ability to work more collaboratively in supporting this population is that systems and services appear to work in silos. Of particular note was the segregation between the Ministry of Health and MOE and their associated budgets:

> *The barriers are the funding divisions. Yeah, you know, the geographical barrier, they [CDS and MOE] work from different places, they work in different teams, they have different team configurations, which doesn't necessarily help. And the fact that there are two agencies with the same remit, with different structural entities behind them creates a barrier. (Policy representative 02)*

> *… budget. You know, we think this is a really cool idea, but we can't do it, because that's not in our budget, that's in education's budget, but the child doesn't meet criteria under education for that… we'll hold on to the whole budget silo thing. So, I often say to families, when they go, 'Oh, there's just not enough money in the system'. I actually often say to families, 'There's more than enough money in the system, we just don't*

> *invest it terribly well'. That's one of the biggest challenges I see… I don't care where it comes from, you know, we all want the same thing, which is success. (Policy representative 04)*

As well as segregation between the health and education sectors, siloed working within the health sector was also noted where there appears to be a separation between child development, child health, and mental health:

> *... but the relationship of mental health to health and the artificial separation that sits there, and the difficulty it is actually to get into the fortress called mental health… we often struggle in the, if you take ASD, a lot of these children with ASD, particularly as they hit sort of middle school years, they strike significant anxiety and we don't have particularly good tools to help alleviate that… and that's the same issue of not child well-being orientated funding, but sector-orientated funding… So, there needs to be some way of saying actually, if we were to sit around the child and say, 'Oh, what do they need?' You know, some mandate that, you know, if we think they need mental health, they have to get on board or if they think they need health. I just think we've got it round the wrong way. (Policy representative 01)*

Siloed working creates challenges for health professionals, referrers, and families when attempting to navigate the system and connect with CDS. The idea of creating a more centralised, coordinated approach for referrals to ensure a more streamlined process for accessing the correct service for the child's needs was suggested:

> *I think having, I think for school or families, I think, having a 'no wrong door'. Knowing that when they, you know, send you a referral, or ask someone for help, that information, being able to kind of go somewhere central, where it's kind of co-ordinated, and someone can then go, right, this needs to go this direction, rather than sort of a piecemeal thing where people don't know what other people are doing. (Policy representative 03)*

Policy representative 03 was aware of an initiative called CHIRP (Child Health Integrated Response Pathway) that had been implemented at one DHB which was found to be a beneficial approach to triaging and processing referrals:

> *…they had like a CHIRP, what they called a CHIRP. Which was basically where CDS, paediatrics, some mental health, and education, would meet together once a week, and they would talk about some of those referrals that come through where they think, 'Oh not quite sure if this has come to the right place'. I think areas where they have that working well, is awesome, really helpful. (Policy representative 03)*

Increased opportunities for forming connections and relationships were also emphasised as a key component for bridging silos. Dividing larger geographical groups of professionals into smaller clusters was described as a suggestion for enhancing opportunities to meet with and develop relationships with other colleagues:

> *One thing we did [several] years ago was divide our urban territory up into six. So geographic localities, and the concept basically, was this, if you're in a room with 100 GPs, that's a lot of handshakes. That's a lot of different people to know. But if you cut those groups down to 15 to 20, I could list those off by name. So, what if we were to divide our territory up, a big sort of amorphous territory, and put it into chunk-size items that have teams of paediatricians with each group? So, operate more like a small regional service… the barrier is not knowing your team, because it's too big and diverse, but the enabler would be knowing your team. (Policy representative 01)*

Policy representatives discussed the importance of bridging silos and highlighted that access to funding and support should be needs-based rather than dependent on whether the child meets specific criteria within one particular sector. It would also be beneficial if there was more opportunity for either direct integration between education and health for disability supports or at least more flexibility with structured overlap between CDS and MOE:

> *We shouldn't have to split it like that, that's just crazy. And yeah, if we could have a child well-being framework, then there would be no, there's no boundary, you know, is*

> *it a child accessing something in the community, or at home, or at school, doesn't really matter, it's around what does a child need to access life. (Policy representative 01)*

> *I don't think they [CDS and MOE] should be separate. So, CDS actually just need a multidisciplinary team, including education… It should be the same team, it shouldn't be separate teams. And the boundary between education and CDS needs to go. It just needs to go. It makes no sense to anybody, except, technically they have different Ministers, they have different philosophies, there's different legislation, and different funding mechanisms. But I believe all of those things can be changed. So, if we had a fundamental concept that services to support disabled children from allied health people come from one place, have one Minister, and have one model, we would be saving everybody a lot of grief. (Policy representative 02)*

Although differences between MOE and CDS are noted, the similarities between the overall goals of CDS and MOE were highlighted:

> *Because yeah, there's a perception that it's two, that the philosophies are too different… the direction that we want to go, fits so well with the Ministry of Ed work. It's not different. Sure, there's a different approach… but in terms of the essence of what we're trying to achieve, we're all paddling the same direction, and I feel like there's a bit of a perception that they're too different, whereas I think we've got more in common than we haven't. (Policy representative 03)*

In line with bridging silos and creating more integration and/or overlap between the Ministry of Health and MOE provision of disability supports, it was suggested by policy representatives that children should have one therapist that supports them across different contexts rather than having different therapists that support them separately at home and school:

> *I would combine learning support and CDS. So, you didn't have two OTs, you know, one at school, one at CDS. Or this SLT that does feeding, this one who does communication, you know, I'd have it all, at least so that you're all sitting in the same*

> *room, so you could communicate… Ideally, I think it should all be out of the same pot, because really, they come in that one door, and you can kind of go, the family has this kind of need, at school they're probably gonna have the same need. You know, why do you need two therapists for that? Two funding systems? Yeah, that's my dream. Combine them. (Policy representative 03)*

There is often a perceived lack of resourcing and staff available, however, policy representatives questioned whether it was necessary to have one therapist that provides support from a home perspective and one that provides support from an education setting. If resources were re-allocated to allow for one therapist who worked with the child across all settings, that may reduce some of the resourcing pressures:

> *…one common conversation I hear is lack of resource. There's not enough speech language therapists. There's not enough occupational therapists. And then I sit there and go, 'Well, I've got two if you want one of them', you know, 'and we've got two OTs, do you want one of them?' Yeah, I just, and the one that really makes me laugh is when you see, and particularly in rural communities when the therapist is actually the same person, but they're walking in two different spaces because they're on contract. (Policy representative 04)*

5.6.5 Policy Category 5: Improving the Provision of CDS

Within the current delivery of CDS, policy representatives feel that neurodivergent children are lacking access to therapeutic support within the public sector. One participant described a charitable trust that provides additional resources for children with disability and that many who access the trust are requesting funding support to access private therapeutic support as they are unable to access therapy in the public sector:

> *And the purpose of the fund is for things that will improve the quality of life for the child. Okay, that's fairly broad. And it's surprising how many people come to that charitable fund asking for money for physio, or asking for money for additional speech therapy, or music therapy or so on. And what that's telling me is that they can't get what they believe their child needs in the public sector. (Policy representative 01)*

Policy representatives acknowledged that CDS should be providing more access to therapeutic support for neurodivergent children:

> *I think it's really useful for autistic children to have some speech therapy sessions. Not for the child, for the parents. Yeah. This is how you roll on the floor. This is how you go underneath a child to make a connection, you know, all that sort of teaching parents how to interact. That's one-to-one. (Policy representative 02)*

Policy representatives highlighted positive outcomes associated with scenarios where CDS therapists have gone into the child's environment and the benefits associated with observing and spending time with the child in an environment that is more natural and familiar to them. One policy representative shared an experience about their child outgrowing their car seat and needing urgent OT input for a reassessment of the equipment. Although the OT worked under the CDS contract, given the urgency of the situation, she sought consent from the family and school to visit the child at school instead of bringing him to the clinic. This approach proved beneficial as the therapist gained valuable insights from the school environment, interacting with teachers and aides. Working together collaboratively had a beneficial effect, preventing any disturbances to the child's routine and resulting in positive outcomes relevant to both the home and school contexts:

> *So, I think when, so if you've got a child at school, or you've got a child at home, or whatever, I think when a clinician comes into that child's natural environment, they get to see the child in a very different space. And they get to see all of the other levers and all of the other triggers in that child's world. So, I think when they're making decisions, their decisions are somewhat more informed. (Policy representative 04)*

The benefits of having autism coordinators go out into preschools, schools, and homes to complete a pre-assessment process for children on the waitlist who were triaged as suspected of ASD were highlighted. Completing assessments in this manner allowed for richer information than what would be gathered in a clinic setting and assisted in triangulating all the available information:

> *… our coordinator will go out and observe in the preschool, or the school, and also at the home. And that paves the way with a lot of really useful information, which I think is a lot richer than we would get if they came to a half-hour clinic… So, having that more pre-assessment, comprehensive view, or triangulated view is really helpful. Parents will see it through one perspective, but some parents amplify, and some parents normalise, and so you get this, but how do they actually function in the community? How do they actually function in the home? Those observations of function are hugely useful, I think for the whole child development question… have we really got a fundamental problem or is it a contextual issue? (Policy representative 01)*

An example of a jointly funded Ministry of Health project between CDS and MOE where representatives of each service worked together and collaborated in schools was described as a successful approach. The programme allowed the facilitators to liaise with teaching staff, intentionally observe and screen children who were already on the CDS waitlist, and access some hard-to-reach families as the school staff already had a relationship with them, and this pre-existing relationship could be used to support the family to engage with CDS:

> *There has been a really amazing co-design and delivered piece of work between education and health, part of the FASD [fetal alcohol spectrum disorder] action plan, around the Alert Programme, within schools. So, a universal curriculum-based intervention, that OTs and ed [MOE] staff have gone in and actually worked alongside teachers for a universal, deliberate teaching of social-emotional regulation, and that kind of scaffolded approach, which actually has community, you know, we've got families who are part of that. So, that kind of collaboration. (Policy representative 05)*

> *CDS were able to, I guess, have a bit of a face in the community. You know, parents could come in and ask questions or teachers, you know, they could ask, 'Oh I've got this kiddie in my class, I don't know what to do'. And the team could kind of help, you know, get them on the right path. (Policy representative 03)*

Policy representatives highlighted the challenges associated with attending a child development appointment within the hospital setting and suggested that CDS should be community-based:

> *… things don't go well for our children [attending child development appointment at the hospital], they become completely overloaded, the hospitals are so noisy, and you've got all this sensory stuff going on, you walk into a clinic, into a waiting room with 30 or 40 other people, and you again, as a family feel that whole pressure of everybody around you judging you, so you become very stressed, your child now doesn't feel safe… get the Child Development Service out of the clinical, get it out of the hospital. You know, because hospitals are there for sick people. You know, our children are not sick. So, get it out of that clinical space and bring it into an environment that's culturally more sensitive to our children, for our families, just bring it into a really normal environment… (Policy representative 04)*

Overall, policy representatives recognise the shortcomings of how CDS are currently delivered within New Zealand and acknowledge the need for establishing a more modernised provision of CDS:

> *Addressing the resource issue is really, first and foremost. Addressing the entry to service; how people enter service, how they can inform themselves, tools that are accessible for them to gather information. Development of whakawhanaungatanga [establishing relationships] entry models for families who wouldn't have the resources or who need support to understand what choices they have. And I mean, that's kind of what the whole CDS improvement programme is aiming to do, to modernise the CDS to enable the principles of EGL to be first and foremost, that parents can uplift themselves, that they can lead themselves, that there is somewhere for them… it's*

> *about the development of the society that enables access to expertise, but also uplifts whānau to enable whānau to access what they need.* (Policy representative 02)

5.7 Collective Group: Findings across the Complete Sample

The collective participant group findings consist of common categories evident within the dataset as a whole. Five main categories were identified with each category containing subcategories. The main categories included: ‘access to and provision of support within the education setting’, ‘access to and provision of support within Child Development Services’, ‘factors that may contribute towards improved health and social outcomes for children with neurodiverse needs’, ‘barriers to making change and adopting multi-agency collaboration’, and ‘improving the provision of Child Development Services’. Table 5 summarises the categories and subcategories generated within the dataset as a whole.

When analysing the collective dataset from all participant groups, five main categories with several subcategories were identified, providing a comprehensive overview of challenges and potential improvements.

Under ‘access to and provision of support within the education setting’, two subcategories, ‘insufficient support within the education setting’ and ‘inadequate training and support for education staff’ were generated. Participants expressed disappointment with the lack of consistent and adequately funded support for neurodivergent children in schools. Issues with obtaining ORS funding and variable criteria for support access were noted, impacting the education environment's ability to adequately provide for neurodivergent children. Educators’ lack of training in this area was highlighted as a barrier to recognising and supporting neurodivergent students.

Table 5

Collective Participant Group Categories and Subcategories

Category 1: Access to and provision of support within the education setting
Subcategories: A. Insufficient support within the education setting. B. Inadequate training and support for education staff.
Category 2: Access to and provision of support within CDS
Subcategories: A. Untimely provision of CDC service. B. You don’t know what you don’t know. C. The current CDC service setting is a barrier.
Category 3: Factors that may contribute towards improved health and social outcomes for neurodivergent children
Subcategories: A. Increased understanding and reduction of stigma around neurodivergence B. Support for the family network around the child. C. Increased support in schools
Category 4: Barriers to making change and adopting multi-agency collaboration
Subcategories: A. Working in silos. B. Lack of adequate resources. C. Different professional ideologies and a lack of understanding of each other’s roles.
Category 5: Improving the provision of CDS
Subcategories: A. Bridge silos. B. Provision of community-focused CDC integrated with schools. C. Increased provision of therapeutic support. D. Access to support across ages and stages.

The third category, ‘factors that may contribute towards improved health and social outcomes for neurodivergent children’, featured three subcategories: ‘increased understanding and reduction of stigma around neurodiversity’, ‘support for the family network around the child’, and ‘increased support in schools’. Participants stressed the need to reduce social stigma, educate peers about acceptance, and provide comprehensive support to families and schools.

Within the ‘barriers to making change and adopting multi-agency collaboration’ category, three subcategories were generated: ‘working in silos’, ‘lack of adequate resources’, and ‘different professional ideologies and a lack of understanding of each other’s roles’. The separation between the health and education sectors, coupled with resource constraints and professional differences, impeded collaborative efforts.

Finally, four subcategories were generated within the ‘improvement of the provision of CDS’ category: ‘bridge silos’, ‘provision of a community-focused CDC integrated with schools’, ‘increased provision of therapeutic support’, and ‘access to support across ages and stages’. Recommendations included enhancing collaboration, creating a needs-based system, integrating CDC into communities and schools, increasing therapeutic support, and ensuring continuous support across developmental stages.

5.7.1 Collective Group Category 1: Access to and Provision of Support within the Education Setting

Regarding ‘access to and provision of support within the education setting’, two subcategories were identified: ‘insufficient support within the education setting’ and ‘inadequate training and support for education staff’.

Regarding ‘insufficient support within the education setting’, participants expressed disappointment and that there is not enough support available:

> *It’s really disheartening actually. (Frontline education professional 05)*
>
> *There's not nearly enough. (CDC clinician 01)*
>
> *... it's like going backwards, not forwards. Like I just don't understand how these, especially these high needs kids are getting the support that they need. (Service user 04)*

Access to support within schools was identified as being variable between different schools and difficult to access:

> *I certainly don't think that it's robust. And I certainly don't think that it's accessible by any stretch of the imagination, probably could be more. (Te Whatu Ora manager 01)*
>
> *From what I see, very variable, and it's that moderate group that miss out. (Policy representative 01)*

Although ORS funding is a support stream available to apply for, participants expressed that ORS funding is difficult to obtain and for those who are successful in obtaining ORS, the support available is often still not enough to meet the needs of the child. Due to challenges acquiring ORS funding, the 'moderate' group of children often end up left without access to support in the education setting:

> *I've seen a lot of kids that kind of were like, yes, you meet the criteria for intellectual disability, but you don't meet the criteria for ORS funding. So, it's like this gap… you might have a teacher's aide, dependent on what school you go to, whether the school is funding this teacher aide. I don't know what schools are supposed to do with limited funding. (CDC clinician 03)*
>
> *Have you heard of Ministry's [MOE] high health needs fund? Most of the CDC diagnoses isn't a health need. Yeah. So, we have got children in the school that because of their disabilities, or, and their diagnoses, they require full-time, one-on-one support. And there is no pie for them. They don't fit into anything… no one can bloody get ORS funding. Yeah. It's very, that was an exaggeration, but it's very, very hard to get. (Frontline education professional 02)*

Participants discussed a range of consequences as a result of the lack of support available for neurodivergent children in the education setting including children moving schools to find the right fit of environment and support, and families having to make compromises to be able to support their child's access to education. The lack of support available within the school can become a health and safety issue for children and staff, and therefore may result in children being excluded from attending full-time school hours:

> *So, the demographic of our school, a little bit less so now, but especially when I first started, is that we were a destination school for children with additional needs because we were doing quite a good job, well we still are. And, because of that, we were getting referred to by people, which meant that we were absolutely overrepresented, which comes with its own challenges, right? But we were having students with neurodevelopmental differences coming from all over Hamilton and beyond. (Frontline education professional 02)*

> *I have to keep him [child] home when they can't find a teacher aide. And he's hardly, been at school for the last four weeks… two weeks was because the teacher aide's been sick and they haven't found anyone. (Service user 05)*

As mentioned within previous sections of the findings, access to and the provision of support within the education setting appears to be influenced by inconsistencies and lack of clarity around the criteria for accessing support. Although access to learning support is described as being needs-based rather than requiring the child to have a diagnosis, there continues to be some inconsistencies in the application of this which has contributed to conflicting perceptions with some believing that a diagnosis is required to access support:

> *In order for anything to happen around an ORS application or a, later on, if children progress into secondary, they're going to need to have a diagnosis. (Principal and deputy principal 03)*

> *I will admit, sometimes I put children through there [CDC] hoping to get a formal label so that can be used as power to try and get more funding or help for these children. (Frontline education professional 01)*

An additional factor that contributes to inconsistencies in access to and provision of support within the school environment is the turnover of MOE staff:

> *We have a very high turnover of specialist staff in the Ministry. This turnover of specialist staff is so severe that we don't know from a day-to-day basis who our psychologist is, who our occupational therapist is, or any such people… I've got a list of the North Waikato team of support services that we have, and going through the list, there's probably everybody now that's moved on. It's an obsolete list. So that's very erratic. (Principal and deputy principal 01)*

> *… and even within the Ministry [MOE], you know, like, I've held six different psychologists for one child, in a year. Just the turnover. It's unsettling for families and the kids. (Frontline education professional 01)*

The school and classroom environment and expectations can be disabling and were recognised as not always being conducive to meeting the needs of neurodivergent children:

> *We've got a Learning Support Centre we set up here because we've got a bunch of kids that just need to be in and out. In, separate, and together, you know. They can't work in a classroom, you know. (Frontline education professional 10)*

> *I think, that sometimes it's, it's not the child, but it's the environment that is disabling for them. That's really apparent. And the expectations of the environment. (CDC clinician 09)*

In relation to 'inadequate training and support for education staff', participants expressed that the lack of training and support available for educational staff around working with neurodivergent children may influence the ability to provide adequate support in the school setting. Participants felt that special needs training for teaching staff is not prioritised and that access to professional development (PD) is often triggered by a specific need and/or is self-directed:

> *One of our new graduate teachers did an hour at university on special needs children, you know, an hour, finished her three-year degree, and now there's seven children in her class of 25 that have some kind of learning needs… So, not only do we have to support her as a school in general, 'This is how you're a teacher, this is how you teach on the floor with real people in front of you', we also say, 'and you've got seven*

> *folders here of children with different learning needs'. (Frontline education professional 01)*

> *We haven't had any PD ourselves in terms of neurodiverse children. We did a few years ago when we had a child who was rejected by 16 schools. So, we took them on under the proviso that the Ministry [MOE] provided pretty much full-time teacher aide. So, and he came with a psychologist who actually did some PD with the staff, around dealing with him and how to integrate him into the school, which was very good. (Principal and deputy principal 04)*

The lack of exposure to formal training around working with neurodivergent children in an education setting is further exacerbated by training initiatives that condense the teaching degree into one year:

> *... you can acquire a degree in any subject, and I often refer to an arts degree… And then people go in and do a one-year postgraduate course, and whatever it's called… Because it's not for a full year either, it's only for nine months that it's open. Now I've got vast experience around the world in four different education systems, I haven't seen any capable teachers coming out of any system, after 9 months of instruction. So that's the first issue; how much can you learn in nine months, especially in a primary school situation, where you've got the full range of curriculum areas that you have to cover? (Principal and deputy principal 01)*

Due to a lack of training for teachers in regard to supporting neurodivergent children, teachers may miss picking up on subtle cues that relate to a child's challenges with learning. Teachers may be more inclined to recognise the externalising expressions of behaviour rather than noticing the children who express their challenges more inwardly, and as a result, children who need help and support may not be identified:

> *But in the mainstream class, one of the other things that happens quite a lot is the more the teachers struggle, and often, it's the behavioural components that they're struggling with, not the learning. They don't notice the little girls sitting down the back*

> *who don't learn, they're not worried about them. It's the ones who are presenting with annoying behaviours or disruptive behaviours. (Frontline education professional 09)*

5.7.2 Collective Group Category 2: Access to and Provision of Support within CDS

Three subcategories were identified regarding access to and provision of support within child development services: ‘Untimely provision of CDC service’, ‘you don’t know what you don’t know’, and ‘the current CDC service setting is a barrier’.

Within the subcategory of ‘untimely provision of CDC service’, a key issue identified by participants regarding the access to and provision of CDC was the long waitlists. Waitlists have substantially increased meaning that access to CDC services is not available in a timely manner:

> *I think the biggest thing that anyone will tell you is our wait times, and that that isn't necessarily meeting the needs of the children and their families within an appropriate time frame. (CDC clinician 02)*
>
> *… those massive waitlists are pretty awful, really. Being able to deal with that, would be, to be able to give families timely access to support would be, I think that would be really nice to be able to solve that one somehow. Yeah, I think that waiting time they get stuck sort of in limbo, it's really hard. (Policy representative 03)*

Because of the inconsistent perception amongst education professionals that a diagnosis is required to be able to access support in the education setting, children often get referred to CDC for a diagnostic assessment before support options are considered within the school. Delays in accessing CDC may mean that children go for an extended period without receiving additional input that could be beneficial in supporting their engagement at school:

> *So, if it's going to take me eight months or more to get somebody through CDC to get even a beginning of a diagnosis, that's almost a whole year in a child's schooling life, before we begin. (Frontline education professional 03)*

As mentioned within previous findings sections, the ability to provide CDC services in a timely manner is impacted by various factors such as frequent staff vacancies. Opportunities for CDC staff to engage in other facets of their role, such as collaborating with other services, are hampered by the pressure and prioritisation of working through the waitlist. The demand to work through the waitlist also impacts the ability to provide a more holistic approach to assessing children for neurodevelopment disorders:

> *... I guess one of the challenges we have at CDC is that our focus is usually on the child, and it's all about identifying assessment and identifying pathology in the child, as opposed to having the time to really look and think actually, where this child's at, and where they're functioning, what's going on for them is actually about their family, and their environment, and their community, and their early development. And, of course, we do a developmental interview, and we take all those things into consideration, but actually, we don't really go down the route of actually putting together a, sort of a solid analysis of all of that because we just don't physically have the time to do it. (CDC clinician 09)*

Within the subcategory of ‘you don’t know what you don’t know’, one of the challenges regarding access to and provision of CDC services for neurodivergent children included the difficulties associated with navigating the systems. Although not isolated to the provision of CDC, participants emphasised that lack of clarity regarding the specific roles and responsibilities of services can make it difficult for families and referrers to know which service and pathway is the most appropriate for a particular child to access.

> *... particularly with Child Development Services, it's just recognising that, actually, for most of the families, are entering a period of ‘I don't know what I don't know’. And to enter into something that is so siloed, so confusing, and so pillar to post, it almost keeps you in this state of ‘I don't know what I don't know’ for an extended period. (Policy representative 04)*

> *Yeah, it must be an absolute minefield, I guess, for parents and caregivers of kids with disabilities to try and, and you know, one parent, I remember used to say, 'I'm the CEO of my child's life.' because that's kind of where it gets to, is that they are literally running a business because their child has got so many interactions with so many different agencies. (Te Whatu Ora manager 04)*

Not only is it challenging for families and referrers to navigate the system but clinicians and those working in the health industry also have difficulty navigating appropriate pathways for neurodivergent children:

> *... because at the moment, we're all just working in our silos and we just, there you go, you go to that service, go to that service, you pick them up, you do this thing. And it's confusing for families too. I think, like well, it must be confusing for the families, because we've got so many people involved, and they don't seem to be communicating with each other. (CDC clinician 01)*

The lack of clarity around the criteria for access to particular services may mean that children get passed back and forth between services, increasing an already lengthy wait time to get answers and support, or children may miss out altogether:

> *Recently I've been quite involved with one of our students who, he didn't go to CDC because when he was initially referred, they said he was too young, so they put him to the paediatrician at the hospital instead. So, he had two visits with her, and now we've been referred back to CDC. So, I've been following his whole process from the beginning of him working with us. And he's now working with ICAMHS and then they're also going to have him at CDC. (Frontline education professional 04)*

Participants highlighted that it can be difficult to differentiate a child’s challenges between mental health features and disability-related features which increases the challenges around determining the referral pathway most appropriate for them:

> *I guess one thing that I haven't touched on is our colleagues that are in mental health. I mean, I know that's a little bit different from neurological issues, but if you're talking*

> *about children with, you know, who are a little bit grey, where do they sit? I think that's an area that those poor kids seem to ping between each one and nobody seems to really want to nail it or take those children on board. I definitely think we don't do that well. (Te Whatu Ora manager 01)*

In relation to the subcategory ‘the current CDC service setting is a barrier’, the CDC setting was identified as a barrier to access due to its location within the hospital campus and the inaccessibility of the building for disabled people:

> *The building is just horrendous. Because you need a lift to get here. Like you're literally working with children with disabilities, you have to go in a lift, and there's no fire exit, like the fire exit is down some stairs, and it's just so inappropriate. (CDC clinician 01)*

> *Even the parking at CDC is horrific. Whānau often come in, they've brought multiple children with them because they don't have other care, and both parents would like to be present, or it's a single-parent family. There's no free parking. For an autistic child to have to park at the other end of the hospital, walk through a very busy, very stimulating environment, to come back out and down to CDC, come up the very tiny, rickety lift into the space. Of course we're not going to get the best out of them, like the building makes no sense and it has terrible parking. (Te Whatu Ora manager 05)*

Participants highlighted that bringing children into a hospital-based clinical environment is not a normal or natural environment for the child and may inhibit the engagement and observations of the child:

> *Going into, particularly going into a clinical hospital space, for particular types of assessments and things like that, from the minute you enter, it's not normal, it's not natural. (Policy representative 04)*

5.7.3 Collective Group Category 3: Factors that may Contribute towards Improved Health and Social Outcomes for Neurodivergent Children

Three subcategories were identified in relation to factors that may contribute towards improved health and social outcomes for children with neurodiverse needs: ‘Increased understanding and reduction of stigma around neurodiversity’, ‘support for the family network around the child’, and ‘increased support in schools’.

Relating to the subcategory of ‘increased understanding and reduction of stigma around neurodivergence’, when requested to share their ideas around what would be beneficial for supporting the overall well-being of neurodivergent children, participants acknowledged the prevalence of stigma:

> *So, I've taught and worked in schools that range from very low socio-economic and diverse communities to very high socio-economic communities, which lack any diversity. And what I noticed is the less diverse and the wealthier the community, the less accepting they are of difference. And whether that's a fact, whether those two go together or whether that's just my experience, that's what I noticed. (Frontline education professional 09)*
>
> *I'm so saddened by the closed mindset around neurodiversity. We've got a real social culture that disorders and intellectual disabilities as negative, it's a negative connotation… we've got to actually find places for these kids to feel like they belong. To feel like that they're actually they're a nice person. They're actually okay. Yeah, they're a little shit sometimes, but they're actually nice kids. They're not say, ‘Harry, naughty Harry.’ It's Harry, whose behaviour is sometimes not okay. (Frontline education professional 10)*

In consideration of ways to support positive health and social outcomes for neurodivergent children, the importance of increasing understanding of neurodivergence and the need to reduce the associated stigma was discussed. Some participants pointed out that there are many health promotion initiatives in place regarding things like smoking cessation but there seems to be a lack of initiatives aimed at promoting acceptance and understanding of neurodivergence:

> *Because it's hugely prevalent in the community, but no one really talks about it… Which then causes ongoing issues and police callouts or whatever it might be, because people don't understand neurodiversity. But I think acceptance. Nothing's gonna change until people start to recognise, appreciate, and value, and accept. And that comes from families, from GPs, from schools, from everyone. (CDC clinician 02)*

> *I think some of the education for people, outside of the people working in the space, could be a powerful enabler in terms of helping people understand their responsibilities under some of those really key kind of overarching documents like the UN rights of the disabled persons, and your rights of children, and those kinds of big, Te Tiriti, all of those sorts of things. (Policy representative 05)*

Neurodivergent children may be excluded from social circles and the isolation may impact their emotional well-being. Participants highlighted the importance of educating other children and peers of neurodivergent children to encourage acceptance of who they are as individuals:

> *…and often I wonder if it's to do with friends, particularly if, maybe it's the age that our kids are at, kids can be really mean. Yeah, unless they find their tribe, often kids can be quite lonely. (Frontline education professional 07)*

> *… when we talk about neurodiversity, unfortunately, sometimes we only focus on those that are neurodiverse. And oftentimes, those that are neurodiverse can't do much to change… when we talk about neurodiversity is also looking at all the others who are considered to be average and normal. Because what we do, makes and creates that environment for them [neurodivergent children] to succeed or not… So, the focus should be on us. For all those other 25 other kids in the classroom, and what they can do to change. It's not just the climate and the environment in any classroom as much as the one adult in the room influences it, it's the climate that students in the class create that is significant. (Principal and deputy principal 01)*

As raised in previous sections of the findings, participants felt it was important for neurodivergent children to be included and accepted for who they are, regardless of the differences they may present with.

Within the subcategory of ‘support for the family network around the child’, it was recognised that having a child with a neurodevelopmental disorder impacts the whole family system around that child. Participants highlighted that the impact on the family system is often overlooked when accessing support for the child and it would be beneficial to receive education relevant to the impact on the family:

> *70% I think, of special needs children, their parents’ divorce, and there's no surprise, highly stressful. (Frontline education professional 04)*
>
> *... and you have your kid and they're diagnosed, what we learned is that your relationship has to become a focus just as much as your kid is with ASD. That's what we learned. And that, to me, is one of the, I guess you could say up there with priorities. I don't know what it looks like, but something that red flags that, especially when they're early diagnosis because like your focus becomes ASD, ASD, ASD, and it's like, hang on, actually, the focus should be equally your relationship as well, and making it strong and having those foundations. (Service user 02)*

The importance of supporting the wider family network around the child and empowering the family were discussed as factors that may support the overall well-being of neurodivergent children:

> *I think the place I would start is equipping the parents, and earlier the better and just equip them. None of this waiting till stuff falls over before you can access social support, none of this waiting till you're desperate. (Policy representative 01)*
>
> *... there's such a crossover between our vulnerable families and diagnoses, and we notice that a lot of these families are incredibly isolated. And they perhaps don't have a high level of understanding about what's going on, in regards to implications of diagnosis, and they don't have a massive support structure around them. I think this is*

> *a big disappointment for a lot of families who are just hanging out for some form of help, and then when the help is so stretched, that it's not actually able to be effective, it's quite disappointing for our families. (Frontline education professional 02)*

Participants highlighted the value of opportunities for caregivers to develop connections with other families experiencing similar situations:

> *And I think for parents, like groups to support the parents, and have someone else to go, 'Hey, do you know what, my child is doing this.' and someone else going, 'Yep, mine did that, because of this, this, and this, have you tried this?' And giving them a better understanding. (Frontline education professional 05)*
>
> *So, my biggest connection is when I go to Australia, and I'm with other parents, with these kids doing the therapy, understanding, you know, that that's, I get more support from Australia than I do in New Zealand, which is like so weird. We don't have the support for parents. (Service user 04)*

Within the subcategory 'increased support in schools', increasing the support available in schools was highlighted as a factor that may support the overall well-being of neurodivergent children. Ideas around ways to increase the support available in schools included having smaller classrooms and more teacher aides:

> *And I guess more support in school… smaller classes with kind of more teachers or more teacher aides in the smaller class. (CDC clinician 03)*
>
> *I think, first of all, every classroom should have a teacher aide, absolutely 100 percent. So, the NZEI [union], that's what they're bargaining for at the moment, is not a pay rise, but they're looking at resources for students with needs. So absolutely, teacher aide, every classroom, who's well-trained, and is able to support the needs of all students, but also support the teacher to support these children more. (Frontline education professional 04)*

In recognition of the lack of adequate access to training for teaching professionals, building teacher capacity may also contribute to improved understanding and provision of support within the school environment:

> *I also think that teachers need more support and training around neurodisability because most teachers won't have good training in that and so if they have a kid in their classroom, they don't know what to do, they may be very well-meaning, but they don't have a clue. So, if you have that training, and I'm thinking from a resourcing perspective, but if you train them, then those mild-moderate kids don't need as much input from, they don't need an individual clinician, unless it's something specific. (Te Whatu Ora manager 02)*

As highlighted in previous findings sections, the expectation for neurodivergent children to fit in with the education curriculum was not always realistic or conducive to the priorities of learning for a child. Increasing the support available in schools may allow flexibility to support children in other ways beyond the focus of meeting the curriculum, such as having extra staff or resourcing to support children who need a break from the classroom due to overstimulation:

> *... what's happening in the classroom is distressing for them, it rains, and that can be distressing. So, having a support person for that child, so the teacher's time is not being sucked up, or feeling like a failure for not being actually able to meet that child's needs. (Principal and deputy principal 04)*

The importance of acknowledging that neurodivergent children each have individual needs and that a one-size-fits-all approach may not be the most beneficial for the child was highlighted. The recommendation for more flexibility regarding the transition to school process for children was mentioned:

> *Lots of schools have almost an induction programme… the induction programme can be over quite a long period of time. So, we go on with this whole train of thought, that*

> *the more one-off visits for one hour that we spend with the child in the school environment, the better they're gonna be equipped for the day that they actually arrive… For my son, once we'd done the first visit, he's now established a new routine. So, taking him in and out of that environment created a massive drama for quite a long period of time, because the schools again, won't deviate from their scripted plans. (Policy representative 04)*

5.7.4 Collective Group Category 4: Barriers to Making Change and Adopting Multi-agency Collaboration

Within the identification of barriers to making change and adopting multi-agency collaboration, three subcategories were identified: ‘Working in silos’, ‘lack of adequate resources’, and ‘different professional ideologies and a lack of understanding of each other’s roles’.

In relation to ‘working in silos’, participants identified services working in silos as a significant barrier to the ability to make service changes and adopt a multi-agency approach to the provision of services. Siloed working is particularly evident with separations between the Ministry of Health and MOE and the associated budgets:

> *Funding streams. Yeah, that's a massive one. Because we are funded for disability, not for education. So, yeah, if they're getting helped by education, we sort of go, well, we're not funded to help those kids, if they can be helped by education. And it's kind of like a back-and-forth thing because education goes, well, this child has a disability, you guys need to be helping us and we go, well, they're already involved with Ministry of Education, what more can we do? And that's been a historic issue also between disability and health, because they're separate funding streams too, which, again, it doesn't make much sense. (CDC clinician 01)*

> *… even just like the physical difference, as well, like being in two different places. You can't go and see each other, you can't communicate, there's like time restrictions. School therapists also work within school hours and school holidays. And so like, over the summer, I had a kid that I needed something from a school physio, but the school physio didn't work over the holidays. It became quite a palaver. (CDC clinician 08)*

As well as siloed working between the health and education sectors, separation between services within the health sector, such as child disability, child health, and child mental health was noted. As referred to in previous sections, the siloed approach to working makes it unclear who is responsible for carrying out particular duties.

Within the ‘lack of adequate resources’ subcategory, lack of time, workload pressures, and lack of adequate staffing resources were highlighted by participants as barriers that impact the ability to create change and work collaboratively between child development and education services:

> *I think time and resources from both sides. Like I know, teachers are swamped, under-resourced and underpaid. And well, CDC have got limited clinicians, which means they've got more pressure on their waitlists, and you know, the waitlist is probably growing. Yes, lack of resources, lack of time. (CDC clinician participant 03)*
>
> *I just think under-resourced. They're [CDC] understaffed, time constraints, staffing constraints, costs. So again, it's a resourcing thing around their ability to see children on a realistic timescale. (Principal and deputy principal 03)*

In relation to ‘different professional ideologies and a lack of understanding of each other's roles’ these differences in paradigms were highlighted by participants as barriers that affect the ability to work more collaboratively between services. The ethos between child development and education is different and the terminology and language used within each sector are different which impedes communication:

> *… words matter. So, I think really having some alignment in the language that the education and health, broad speaking here but, and disability are using to understand, think about, and plan for the children and young people that broadly fit within our respective cohorts. I think that's where we fall down. You know, that we all use a slightly different word perhaps. (Policy representative 05)*

> *I found one of the barriers is not understanding each other's paradigm. I mean, health, we're problem, we live in a world of problems, and we like to try and solve them. Education sits in a world of opportunity and likes to develop strengths to achieve those opportunities. So, they're different paradigms. And the parent lives with the whole lot. The child lives with the whole. If you put them together, you've got a very powerful model. (Policy representative 01)*

Lack of clarity around the different roles and responsibilities of the child development and education sectors contributes to a lack of understanding of what each sector is trying to achieve:

> *There'd have to be a lack of understanding of what each organisation is trying to achieve. (Principal and deputy principal 05)*

5.7.5 Collective Group Category 5: Improving the Provision of CDS

Four subcategories were identified regarding improvement of the provision of child development services: ‘Bridge silos’, ‘provision of a community-focused CDC integrated with schools’, ‘increased provision of therapeutic support’, and ‘access to support across ages and stages’.

As recognised within the ‘bridge silos’ subcategory, when participants were requested to share ideas on how child development and education could work better together, they emphasised the significance of bridging silos. The importance of finding a way to enable more collaboration between child development and education was raised:

> *There needs to be a bigger collaboration between the Ministry of Education and CDC as well. Why those two organisations are not aligned, I have no idea to me? (Principal and deputy principal 01)*
>
> *You know, just really, it's really simple, to me, it's really simple, low-level stuff, and if we can get those foundations right, if we can develop a system that is not siloed, but more about the child and the family, I think we'll be far more successful, because, you*

> *know, we're at, that's, when you're engaging with child development, and all of that sort of stuff, you're at the most critical part of that child's life because it's setting you up for the journey. (Policy representative 04)*

In line with bridging the separation between child development and education, participants presented ideas around bridging funding silos and creating a system that allows for a more comprehensive needs-based approach, rather than compartmentalised funding:

> *... one of the problems to address is the separation of school and home and Child Development Services. What if we were to actually join the funding, you know, for Nirvana, just join up the commissioning so that the fund follows the child? So, we've got a problem with two Ministries. And from a practical point of view, it does mean, you know, if children who quite clearly need some sensory OT type stuff, and the school may or may not see it as their business. Or, the health for that matter might not see it as their business. Where this particularly comes up is children with a, I had a boy with a condition where he's got a posture problem, and he was getting all sorts of pain and I wanted a physio involved. Could I get health involved, or could I get education involved, it was like a game of tennis. Same boy had problems at school and at home, you just need someone to own it, but their funding won't allow them to own it. (Policy participant 01)*

> *Every child should just get what every child needs. But it should be based on need, shouldn't be based on budget. (Service user 04)*

As mentioned within previous sections of the findings, participants highlighted the complexities and overlapping neurodevelopmental and mental health traits that children may present with. Due to difficulties differentiating the symptoms a child presents with, siloed working contributes towards challenges when attempting to navigate the system and get connected with the most appropriate pathway for a child. Participants felt it would be beneficial if a child’s needs were able to be met within one service rather than being passed back and forth between different waitlists and services. By bridging the separations between child development, child health, mental health and education, the journey of navigating systems would be more seamless for children and families, and the likelihood of a child falling through the gaps and not receiving input would be reduced.

One idea for bridging silos included more opportunities for information sharing such as access to live forms and IT systems that are accessible by both education and CDC. Having information available in this way would facilitate a more seamless approach to supporting children and would mean that information could follow the child wherever they move:

> *We need information sharing. We need some, with the technological era, you know, we've got to actually find ways forward. I know there's a whole lot of stuff around privacy, confidentiality. However, you know, whose interests are we looking at here? (Frontline education professional 10)*

> *Just communication. It seems like, unless you ask them [child development and education] to communicate, there is no communication. I guess ideally, it would be to have one platform for communication for everything. So, I don't know whether it would be an app or a website where the school logs on saying this happened with [child] today, Enrich log on and say, [child] enjoyed doing this, and another programme logs on and goes, oh [child] struggled with this and melted down or whatever. So, then there's just one place where you can see everything, and everyone can see everything. (Service user 03)*

Previous sections within the findings highlighted additional ideas around bridging silos such as an increased opportunity to develop relationships and build connections, having a key person at CDC for referrers to contact with queries, and a centralised referral/triage process.

Within the ‘provision of a community-focused CDC integrated with schools’ subcategory, participants highlighted that it would be beneficial if CDC was provided as a more community-focused service with the opportunity to be more integrated with schools. As mentioned in previous sections of the findings, it would be beneficial if CDC was based in the community in a more purposeful space rather than on a hospital campus. It would be advantageous to position a community-based CDC in shared facilities with or close to other related services.

Participants highlighted the importance and relevance of observing children in environments that are familiar to them and that there is a need for more flexibility for CDC staff to go into schools to carry out assessments:

> *... it just made me think like, why can't we go to preschools, kindys, schools, home, and observe?... I've had the experience where I've been in clinic, and this is like, the second time a child has come in, and we're still scratching our heads wondering what's going on. So, we go to school as a last resort, and all of a sudden, it's so clear what is happening with this child, you know, this is the child that can sit down and attend to tasks in school because that environment works for them. But then they get out into the playground and completely lose the plot, and they're just spinning, and banging their heads on things… we never would have got that information doing a face-to-face sterile assessment. (CDC clinician 01)*
>
> *I thought having occupational therapists in schools would be great. (Frontline education professional 07)*

Within previous sections of the findings, participants highlighted a range of benefits of CDC being based in the community and working more closely alongside schools. These benefits include schools being accessible environments for children and families, triangulation of information, increased opportunity to develop relationships with education staff, CDC staff gaining an increased understanding of what disability means for a child within the learning environment, and decreased possibility of children not participating in the assessment process because of an unfamiliar setting. If CDC clinicians were more present in schools, they would be able to provide prompt assistance and recommendations for teaching staff regarding supporting a child with neurodiverse needs within the school setting. Clinicians would be able to help distinguish between children whose needs would likely be met by the implementation of some general classroom recommendations and those who would benefit from a more individualised assessment and recommendations. This approach may also influence referrals to CDC, ensuring CDC is seeing the most appropriate children for their service.

Regarding ‘increased provision of therapeutic support’, participants felt that children needed to have increased access to therapeutic support. As mentioned in previous sections of the findings, funding restrictions and a lack of sufficient resources have contributed to arbitrary alterations within how various CDS deliver their services. Even though the population needs of neurodivergent children have grown, funding has not kept pace with these changes. As a result, many CDS have prioritised the completion of diagnostic assessments rather than the provision of therapeutic support. Participants identified a gap within the provision of support for neurodivergent children and described how the process with CDC appeared to comprise of a diagnostic assessment for children without the opportunity for access to follow-up support or intervention:

> *But, you know, it's almost like when they leave CDC, and they've done their bit, and it's not, maybe not quite as approachable, or there's not a, an opportunity to follow up. (Principal and deputy principal 02)*

The importance of increasing the provision of therapeutic support was raised:

> *I'd always thought but I think it would make it too big of a beast, is having more therapy sessions rather, you know how we do a lot of assessments here, so like your clinical psychologists doing treatment plans. But, that'd be something I would like to see, is more group work and more therapy interventions. (Te Whatu Ora manager 01)*

> *So, in Auckland, they have a centre called Homai, which is for vision-impaired children… they had a series of professionals look at [child]. So, he was seen by an ophthalmologist, he was seen by a child psychologist, a music therapist, a physiotherapist, a speech-language therapist, and this is all in regards to vision. So,*

> *but they all work together, all assessed him, in that week, all taught you, and then at the end, they saw you again, and then they basically wrote a plan for him, and spent time with you, like teaching you different things to try and do with your child. That needs to happen on a regular basis for a child, but not just with vision, like it should just be an overall for a child. (Service user 04)*

As well as increasing the provision of therapeutic support, participants felt it would be beneficial to have one therapist who supports the child across all settings rather than different therapists working separately within different settings. For this to be possible, there would need to be integration or structured overlap between child development and education sectors:

> *... so, children over there [in Australia], get a plan put around them, of whatever their needs are, and they get money put to that plan. And then that supports their life, I suppose. And whatever the child's needs are. (Service user 04)*

> *They need a therapist that can see them and be able to work with them in both [education and home] contexts. (Te Whatu Ora manager 02)*

Within the subcategory ‘access to support across ages and stages’, providing support to neurodivergent children across ages and stages was highlighted by participants as a key component for improving the provision of CDS. Children’s needs change over time and it would be advantageous if they were followed up over time:

> *Our kids go through journeys, ages, and stages. And just remembering that we're on a life journey. And it's a long journey. (Policy representative 04)*

> *So, if we all like, education, and whoever the support is, all came around and did integrated supports and ongoing review, because children change over time, and somehow, we expect them that, you know, this assessment that was done a year ago is still gonna be the truth. So, the dream would be that they were regularly monitored, and helped, and supported. (Te Whatu Ora manager 06)*

Children go through different transitions and it would be beneficial if there was more support available for children as they navigate different transitions:

> *... it's always been a tension, is the transition from, you know, paediatric services through to adult services, and that they, that doesn't line up between health and education either. So, you know, how are we preparing these kids for life as an adult with a disability? ... And so, I don't know whether actually having, it's not the right word but, connectors and that sort of thing within disability, is helpful for these families so that education and health, and all of those aspects of a child's life can actually be coordinated. (Te Whatu Ora manager 04)*

> *I think, once they leave school at sort of the 17 and 18, more programmes or university type programmes that can support sort of transition into working life, ... also life skills, are very difficult to learn on top of, if you already have trouble learning about how the world works, and getting your day-to-day needs met. Yeah, so I think almost like real, real-life transition. (CDC clinician 01)*

The idea of having access to a key person who supported the child and their family from a holistic perspective including coordination of access to supports at the appropriate time was suggested:

> *... a layer on top of that would be a caseworker, kind of situation, where there's a person who has chosen to be in that role for one, and who links between home, community, and schools. So, that that person can advocate for the student around what may be in their local environment that they can participate with, source support for the family around groups that they can join, support networks that they can participate with, and facilitate maybe supported gatherings where kids can go. (Principal and deputy principal 03)*

> *I think it could be really helpful, would be some kind of overall co-ordination of the services so the families weren't sort of having to repeat their story to multiple people, trying to figure out who's going to do this bit, and where do I go now for that bit. I think in terms of the well-being of family, just taking some of that load off them, of navigating the system. I think that would be really helpful. (Policy representative 03)*

5.8 Phase One Findings Summary

Through the use of grounded theory analysis principles, data obtained from semi-structured interviews generated various categories in both individual participant groups and the entire dataset. The category of ‘insufficient support within the education setting’ was identified within each participant group. The service user group's additional main categories were ‘you don't know what you don't know’, ‘inequity’, ‘stigma and understanding around neurodiversity’, and ‘provision of therapeutic support’. The CDC clinician group's additional categories included ‘inefficient provision of CDC service’, ‘the current CDC service setting is a barrier’, ‘bridge silos’, and ‘provision of a community-focused CDC’. The additional categories for the frontline education professionals group were ‘inefficient provision of CDC service’, ‘silos’, and ‘provision of a community-focused CDC’. Additional categories identified within the Te Whatu Ora manager participant group and principals and deputy principals group included ‘inadequate provision of CDC service’, ‘silos’, and ‘provision of a community-focused CDC’. Lastly, the policy group's additional categories were ‘inadequate provision of CDS, ‘you don’t know what you don’t know’, ‘silos’, and ‘improving the provision of CDS’.

When all participant groups were analysed as a collective dataset, five main categories were identified including ‘access to and provision of support within the education setting’, ‘access to and provision of support within CDS’, ‘factors that may contribute towards improved health and social outcomes for neurodivergent children’, ‘barriers to making change and adopting multi-agency collaboration’, and ‘improving the provision of CDS’. The categories and subcategories evident within the collective dataset formed the basis of content to share and discuss within focus groups for phase two of the project.

Chapter 6: Phase Two Method

Phase two of the project aimed to verify the findings from phase one and facilitate a process for participants to explore the findings in conjunction with relevant literature. The goal was to establish priorities for improving CDC services and create a proposed service delivery model.

Phase two of the research is primarily inspired by principles of co-design, specifically the principle of 'improving the experience' (Maher, 2017). Two focus groups were carried out with representatives from relevant stakeholder groups including service users, frontline health and education workers, and a health management representative.

This chapter discusses the use of purposive sampling for the recruitment of focus group participants, the processes of focus groups for data collection, and the application of grounded theory and abductive reasoning approaches for data analysis.

6.1 Participants and Recruitment

As utilised in phase one, a purposive sampling approach was applied to recruiting participants for phase two of the project to ensure adequate data relevant to the research questions and aim of the project was generated (Coyne, 1997). To ensure that the outcomes of the project meet the needs of relevant stakeholders and can be applied in real-world situations, co-design principles recommend involving representatives of service users, frontline workers, and managers (Eyles et al., 2016; McKercher, 2020). Therefore, service users and stakeholders who took part in the first phase of the project were considered for recruitment. When selecting participants with lived experience (service users), McKercher (2020) suggests choosing individuals who have firsthand experience regarding the research phenomenon, people who can represent their experience, and people who are interested in sharing their thoughts and learning. The criteria for choosing professionals, such as frontline workers and managers, to participate in the co-design process includes individuals who are open to listening, sharing and learning. They should demonstrate respect for lived experiences, focus on enhancing dignity and choice, offer diverse perspectives and identities, lend legitimacy to the process, exhibit sensitivity to inequities, possess self-awareness, adaptability in various interpersonal situations, a willingness to embrace discomfort, and a sense of dissatisfaction with the current state of affairs. These criteria were considered when purposively selecting participants to approach for participation in phase two of the project.

A total of four participants were recruited including one service user, one CDC clinician, one frontline education representative, and one Te Whatu Ora managerial representative. Participants had engaged with phase one of the research project, with the exception of one who had not participated but had become available to participate in phase two. Attempts were made to purposively recruit a principal or deputy principal to represent the leadership level from the education sector, however, these attempts were unsuccessful. The focus of phase two was targeted towards a regional perspective for the establishment of a service delivery model for CDC, therefore the nationwide policy category of participants was not included.

Literature suggests that focus groups typically consist of six to 12 people. The group needs to be big enough to allow for adequate participation, but not so big that it lacks cohesion. An appropriate group size ensures that everyone can participate and that the group provides more coverage than an individual interview (Merton et al., 1990). Small groups can be dominated by one or two members, while large groups can lack participation, break into side conversations, or participants may feel frustrated if they have to wait for their opportunity to participate or give their response. However, there is a need for the number of participants to be determined by the research objective, with smaller groups (four to six participants) preferred for topics where participants have an intensive experience to share

(Krueger, 2014). The participants selected to recruit for phase two were considered to hold extensive knowledge and experience regarding the research context, therefore a focus group sample size of four was considered adequate to provide rich, in-depth contributions to the data.

6.2 Data Collection

Prior to the commencement of phase two of the project, amendments were made to the ethics application associated with phase one of the project. These amendments were approved by the University of Waikato Research Ethics Committee (reference HREC[HEALTH]2021#37) (Appendix I).

Phase two was carried out in two parts involving two focus groups comprised of the same participants as outlined in the previous section. Refer to Figure 3 for a summary of the content covered in each of the focus groups. The first focus group consisted of a facilitated discussion around the findings generated from the stakeholder interviews carried out in phase one, alongside evidence arising from the literature. All previously obtained data were considered to inform the development of a drafted model of service delivery for improved provision of CDC services that best meets the needs of neurodivergent children in the Waikato region. The second focus group included the presentation of the draft model of service delivery for feedback. The data obtained during the second focus group were used to amend the drafted service delivery model to enable the development of a proposed model of service delivery for improved provision of CDC services.

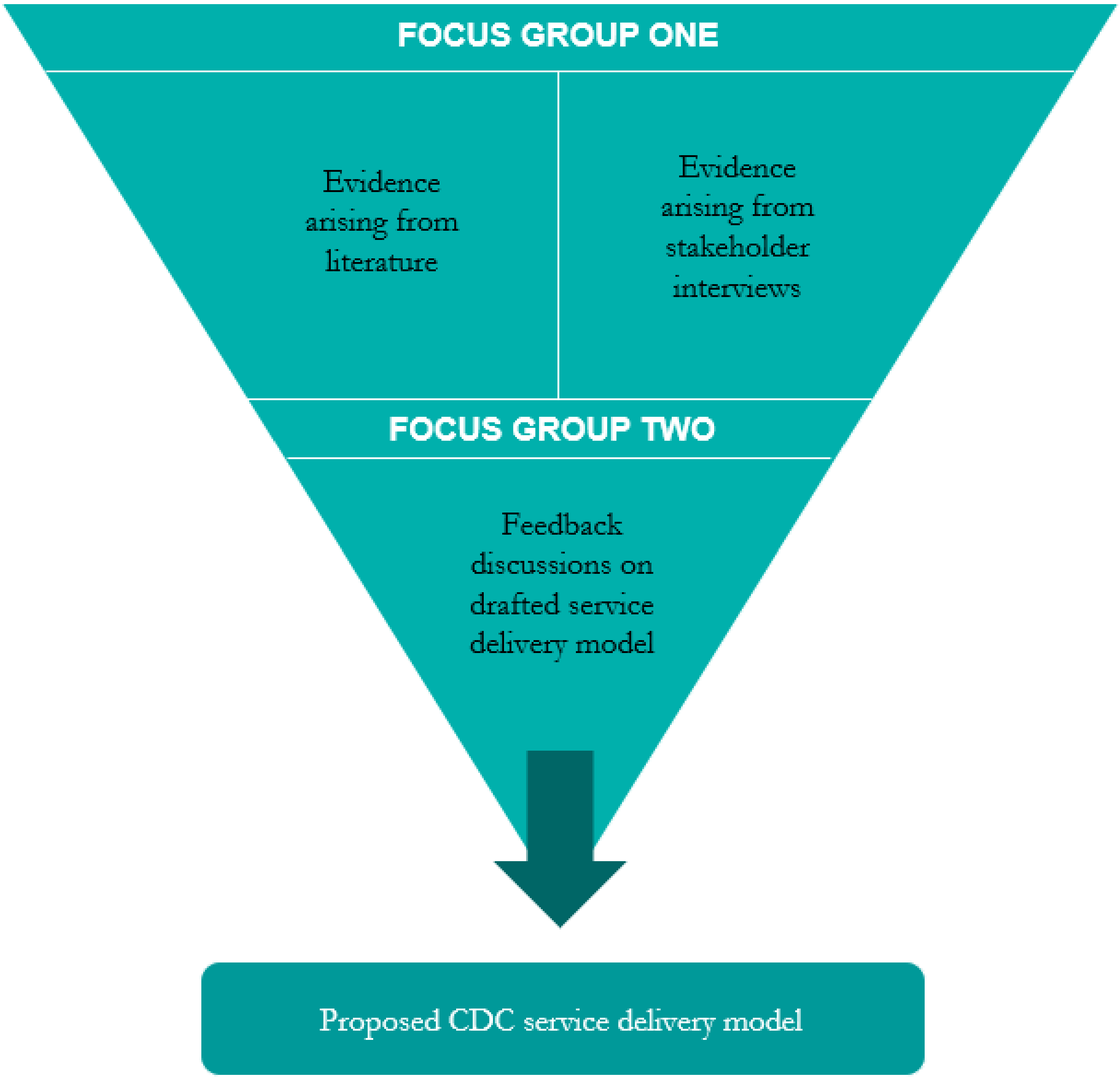
Participants were informed that the focus of phase two of the project was to develop and seek feedback regarding a proposed service delivery model for improved provision of CDC services. During recruitment, participants were provided with a participant information sheet regarding phase two of the project (Appendix J). It was disclosed to the participants that the group would comprise of different stakeholders to encourage a collaborative feedback process, and to ensure participants felt comfortable agreeing to participate alongside service users and professionals. To increase accessibility for people to participate in the focus groups and to ensure the continuation of the project regardless of the impact of fluctuating Covid-19 responses, focus groups occurred online via Zoom. An online poll using Doodle (Doodle, n.d.) was created as a meeting scheduling tool to determine time options for when all participants were available. Focus groups were then scheduled at a time when all participants were available and were facilitated by the primary researcher. The focus groups took approximately 1 hour to complete.

In preparation for the first focus group, participants were provided with a summary of the research process thus far (Appendix K), a summary of the findings from stakeholder interviews (Appendix L), a summary of relevant evidence within the literature (Appendix M), and a copy of the Enabling Good Lives principles (Appendix A). Participants were requested to complete a consent form (Appendix N) prior to participating in the focus groups.

The first focus group began with the facilitator thanking participants for joining. Participants had not completed the consent form before attending the first focus group. Although their attendance at the Zoom meeting was assumed as their consent to participate, before the focus group commenced, the consent form was shared and discussed, with participants opting to provide verbal consent which was recorded using the recording function on Zoom. Participants also consented to the researcher using Otter.ai (2023) for transcription of the focus group conversation. A brief round of introductions took place to ensure participants knew the roles of each other and the participant groups they were representing. Guidelines for the participants to follow during the focus group were shared. They were requested to keep the information discussed and the identities of the other participants confidential. Although they did not need to agree with one another, they were expected to listen respectfully to everyone's opinions. Participants were encouraged to share their views and it was emphasised that there were no right or wrong answers. While the conversation was intended to be interactive, they were asked to take turns speaking since the meeting was being audio recorded. Focus groups were audio recorded to allow for later transcription using Otter.ai.

Figure 3

Content of Phase Two Focus Group Discussions



The facilitator briefly discussed the information that had been shared with participants before the focus group including the research process thus far, the Enabling Good Lives principles, the findings from stakeholder interviews, and relevant evidence within the literature. A semi-structured focus group schedule comprised of open-ended questions was then used to facilitate conversation among the participants regarding their thoughts and ideas on commonalities within the data and literature, priorities for improvement, and preferences regarding the relevance and incorporation of proposed recommendations (Appendix O). At the end of the session, participants were thanked for their participation and were informed about the forthcoming stages. They were advised that this would include the researcher using the interview and focus group data, along with existing literature, to develop a preliminary service delivery model. Subsequently, another focus group would be carried out to gather their feedback on the proposed model. The first focus group took place in November 2022.

The second focus group began with confirming participants' consent to participate. Participants were reminded of the focus group guidelines. Focus groups were audio recorded using the recording function of Zoom to allow for later transcription. Participants were presented with a summary of the analysis of the data that was gathered in the first focus group (Appendix P). A draft model of service delivery was also presented for feedback (Figure 4). A semi-structured focus group schedule comprised of open-ended questions was used to facilitate conversation among the participants regarding their thoughts and ideas in relation to the proposed model. At the end of the session, participants were thanked for their participation and the valuable contributions they had made to the research project. The second focus group was carried out in February 2023.

The findings of the second focus group were used to amend the drafted service delivery model to enable the development of a proposed model of service delivery for improved provision of CDC services. Following the completion of the two focus groups, outputs from the data and the proposed service delivery model were informally presented to key Whaikaha policy representatives involved with the nationwide CDS improvement programme.

6.3 Data Analysis

As discussed in the methodology section, a variety of methods can be applied to analysing focus group data (McKercher, 2020). To maintain consistency between phases one and two of the project, principles of grounded theory were applied to aid the analysis of focus group data collected during phase two of the project.

Familiarisation with the data commenced during the focus group sessions. Following each session, initial reflections were recorded in memos. The focus group audio recordings were imported into Otter.ai and transcribed verbatim. To ensure accurate transcription, I reviewed each transcript in comparison to the audio. This facilitated further familiarisation with the data. The transcript was then read and reread in its entirety for further immersion in the data, supporting additional reflections on impressions, ideas, and presumptions.

Through the use of NVivo software (QRS International Pty Ltd., 2022), grounded theory principles were applied to identify and analyse patterns of meaning in the qualitative data gathered from the focus groups. This involved an open coding process, whereby codes were assigned to the transcribed data with a focus on identifying important aspects that participants emphasised. In an iterative process, codes were critically re-examined to identify categories that further refined and focused the data.

Abductive reasoning was applied to facilitate theoretical integration. Following the first focus group, movement back and forth between evidence within the phase one interviews, evidence within the literature, and the evidence arising from the first focus group occurred to inform the development of a preliminary service delivery model. The process of abductive reasoning was repeated following the completion of the second focus group to incorporate participants' feedback regarding amendments to the preliminary model alongside the integration of evidence to refine the development of a proposed service delivery model for improved provision of CDC services. This process allowed for the development of a service delivery model that was grounded in both the valuable insights of participants and relevant literature.

6.4 Phase Two Method Summary

Within phase two of the project, two focus groups were carried out with four participants including a service user and three professional representatives from the education and health sectors. The first focus group discussed the results from stakeholder interviews and literature to inform the development of a draft service delivery model for providing improved CDC services to neurodivergent children in Waikato. The second focus group provided feedback on the draft model. The feedback was used to make changes and develop a proposed service delivery model. Focus groups were audio recorded and transcribed using Otter.ai. Analysis of the data involved principles of grounded theory and abductive reasoning.

Chapter 7: Phase Two Findings

The second phase of the project was designed to verify the results of the initial phase, while also providing participants the opportunity to consider those results within the context of applicable literature. This was carried out to identify priorities for enhancing CDC services and inform the development of a proposed service delivery model. Focus groups were carried out and analysed using principles of grounded theory.

This chapter presents the results generated during phase two of the research project. Part one begins with summarising the findings from the first focus group. The categories generated within the findings are then presented in more detail, followed by the presentation of a drafted service delivery model. Part two begins by summarising the key findings generated from the second focus group where feedback on the drafted service delivery model was received. Each category is then discussed in further detail. The insights gathered from this feedback and analysis of the data enabled the development of a proposed CDC service delivery model.

7.1 Phase Two Part One: Focus Group One

In a focus group discussion, four participants, including a service user and representatives from the education and health sectors, engaged in dialogue through semi-structured open-ended questions. The aim was to explore their perspectives on literature, phase one data, improvement priorities, and the suitability of proposed recommendations. Data analysis of the discussion generated five main categories: ‘clarification regarding the roles and responsibilities of CDC’, ‘missed opportunities for therapeutic support’, ‘key worker model’, ‘silos’, and ‘provision of a community-focused CDC’.

In relation to the ‘clarification regarding the roles and responsibilities of CDC’ category, challenges in funding and resources have impeded CDC services, limiting their capacity to fulfil service specifications beyond assessments. This has led to a perception that assessment is the primary role of CDC, potentially misrepresenting its actual scope of service delivery. Additionally, the current name of CDC does not accurately represent the services it provides and may mislead expectations.

Relating to ‘missed opportunities for therapeutic support’, the scarcity of therapeutic support for children results in missed intervention opportunities, with schools ill-equipped to fill the gap. Limited access to therapy raises equity concerns, favouring those who can afford private support.

In reference to the ‘key worker model’ category, participants advocated for a key worker model but questioned its alignment with CDC's role, suggesting it might be better suited for another service like EGL. There was uncertainty about the specifics of the model, such as access criteria and the necessity for every neurodivergent child to have a key worker.

Within the ‘silos’ category, the lack of collaboration among services emerged as a major obstacle to providing effective support for neurodivergent children. Participants stressed the importance of bridging the gap between CDC and education. They supported shared IT platforms to enhance communication and emphasised the need for a stronger connection between CDC and EGL.

Relating to the ‘provision of a community-focused CDC’ category, enhancing collaboration and integration between CDC, schools, and MOE was considered important. Participants welcomed the idea of CDC being more community-based and closely aligned with schools. The P4C model received positive responses and participants believed a similar approach to CDC provision would improve referrals and offer a proactive means of support.

7.1.1 Focus Group One Category One: Clarification Regarding Roles and Responsibilities of CDC

The first phase of this study showed that due to limited funding and resources, many CDS in New Zealand focus primarily on conducting diagnostic assessments, even though this is only a small part of their overall service responsibilities. CDC is currently delivered with a primary focus on diagnostic assessments, therefore participants external to the service perceive assessment as CDC's primary role and responsibility rather than the provision of therapeutic support:

> *... maybe the biggest problem CDC is under-resourced… to me CDC is okay, if that makes sense. In the perspective that it just does assessments. (Service user)*
>
> *From a school's perspective, I see CDC as an assessment, you know, pathway, but I have never kind of expected CDC to kind of provide the intervention side of things. I think where it falls down is when the intervention isn't available. So, it has to be like a whole system change, doesn't it? (Frontline education professional)*

These perspectives regarding the services provided by CDC highlight the need for clarification around their roles and responsibilities. As depicted in the following dialogue between participants, it was pointed out that based on the current delivery of CDC services, the name of CDC can mislead expectations:

> *CDC might need to change their name. The CDC might have to be Child Assessment Centre or something. Yeah, I mean, you could definitely mistaken it for like, you know, development, is very vague. (Service user)*
>
> *Can I ask [service user participant], if we had a name like Child Disability Service, would that be okay? I mean, if you, just going back in time, and if it was the first time you're getting referred to Child Disability Service, how would that make you feel? (Te Whatu Ora manager)*

> *... So if you were to call it Child Disability Service, then that's also vague, and it doesn't really, you can mistaken that for a service that actually goes long-term, which was why I thought, oh, Child Assessment Service, because then it's in the name, you know, you're not going to expect any more than that because it's not very vague, assessments an assessment. (Service user)*

Participants highlighted the importance of clarifying the roles and responsibilities of CDC which would assist in identifying the gaps in service provision that require addressing:

> *…the thing I can see CDC doing differently is being more definitive in what their roles and responsibility is to the community. Because once that's defined, then someone else can pick up that gap. (Service user)*

> *EGL do great work, I know that is where we're heading as a service, as a CDS, is to incorporate those values into our service. How that looks in reality in terms of resourcing, budgeting, staff, rollout, or who, you know, which group of children you're going to apply to, that really needs to be thought out well, before we make a commitment to the community that this is what we're doing. Then once again, we set this great expectation, and then we fail because we don't have the tools to deliver it. (Te Whatu Ora manager)*

> *What's the next pathway? And does CDC lead you on to that definitive pathway? Even if it is with somebody to, I duno, key worker who umbrellas everything else, or whatever it is, but from CDC, what's the next definitive pathway? (Service user)*

7.1.2 Focus Group One Category Two: Missed Opportunities for Therapeutic Support

Participants identified the lack of availability of therapeutic support, resulting in missed opportunities for intervention that may be beneficial for a child, particularly in the space of early intervention. The following dialogue between participants highlights the missed opportunities for input:

> *From experience, so our oldest son was diagnosed just before he turned 2, and we waited a year before we got into McKenzie Centre [early intervention provider]. So, between that time, I mean, he was only 2, whatever, but he had nothing. (Service user)*

> *Intervention missed. (CDC clinician)*
>
> *Yeah. So, he had none of that, you know, that window was missed. (Service user)*

Limitations in the ability to access therapeutic supports can increase pressure on the school to fill the gap, however, school staff often don't have the capacity, knowledge, or expertise to respond to therapeutic needs:

> *A lot of kids miss out. If I'm going to be completely honest. And it is all reliant and dependent on an individual school's capacities in those particular areas… we can refer for physio and for occupational therapy for some children that meet criteria, but it's a pretty, it's a bare-bones intervention… And especially our cohort of children with ASD, they're not eligible for any MOE supports, which leaves it reliant on school capacity. (Frontline education professional)*

The limitations regarding access to therapeutic support can result in issues of equity between those who are able to self-fund access to private support and those who are unable to do this. Even for those who can privately fund support, there are also limitations regarding the number of providers in the private sector:

> *So, then we end up with a two-tier system of our families who can afford to pay for it privately, and our other families just miss out. (Frontline education professional)*

Participants recognised the need for increased provision of therapeutic support and the importance of early access to therapeutic support:

> *Really getting in there as early as possible. (Service user)*
>
> *And I think that makes quite a lot of us sad. Because I think we can see the need for therapy, we can see that, we know the benefits of therapy. And we can do a little bit of therapy, but we can't do ongoing endless therapy. (CDC clinician)*

7.1.3 Focus Group One Category Three: Key Worker Model

Participants commented that the idea of a key worker model may be beneficial, however, they felt that this was something that sat outside of the role of CDC, possibly within the role of EGL:

> *And the key worker model, I think is great, but CDC doesn't have the capacity to have a role with every child that's diagnosed with say an intellectual disability, so is CDC the right place to be a key worker model for that population?... They're probably the kids that, and I could be wrong here, are going to benefit from being under EGL. And that's probably a goal for them, and to bring us all together as well. So, I don't want to defer that as something that might be our work on to someone else. But my kind of working so far with EGL is that they would be that person. (CDC clinician)*

> *I like that idea that it sits with EGL. I just imagine EGL being from, let's talk about the connector, being that umbrella for that whānau. And, you know, because they're monitoring and they're keeping up to date with that whānau, and just making sure that everything's okay, and whatever was going on. So, I imagine that the whole umbrella, they'll cover a whole range of things. (Service user)*

Participants queried what the criteria for a key worker model would look like; whether it would be required for all neurodivergent children and how long a key worker would be involved. It was thought that the crucial point of involvement for a key worker would be at the point of diagnosis:

> *Yeah, and when I say key worker, like I wouldn't say, expect a keyworker like all the way up till he's, however old, it's mainly that first stage where there's that little gap, there might be that gap where you're just waiting on that waiting list to get to that next pathway. (Service user)*

> *The key worker model… I wondered, from a zero-resource perspective, whether that would be necessary for all. I wonder about the idea of identifying complex cases early… Because I've seen quite a few students who, you know, they might have five or six or seven agencies working with them all in silos, and often it ends up being the*

> *school that is the one that takes that lead agency role, and I'm not sure whether we're the right people to do that. (Frontline education professional)*

Focus Group One Category Four: Silos

Participants agreed that siloed working and the lack of collaboration between services are major obstacles in making changes and providing services for neurodivergent children. The current siloed way of working impacts the ability to provide service users with a definitive pathway of support:

> *I think the definitive pathway, like, I mean, like, you know, of all these silos and all that kind of stuff, it's, there's not really anything concrete. (Service user)*
>
> *We're all working in silos. So that's why we're not able to say, here you go, this is the pathway, this is what you can expect in the next couple of years. Because at CDC, we can tell you what we do, we can give you pamphlets of services, but we can't actually connect because that is their service. Same with MOE, we can't actually tell you, your school has to provide you this service because that's MOE. So, it's really the silos, we're coming back to that silos make the biggest problem. There is no connection, and therefore we can't give our families a pathway. (Te Whatu Ora manager)*

Participants emphasised the significance of bridging silos between CDS and education and expressed that prioritising the bridging of these silos is necessary for implementing changes:

> *I think, I mean, just saying bridging silos alone, it sounds amazing. (Service user)*

The idea of implementing shared IT platforms to enable channels of communication was corroborated:

> *I really like the mention of information sharing via IT systems, because I think we need to have a platform for MOE and CDC to be able to touch base with each other because we need that communication, right from the referral stage through to the implementation stage. (Te Whatu Ora manager)*

Not only did participants emphasise the importance of bridging silos between child development and education, they also stressed the need for a stronger connection between CDC and EGL. They suggested that EGL could serve as the central figure to fulfil a key worker role and assist in bridging the gap between disconnected services. The importance of clarifying EGL's role and ensuring all relevant stakeholder groups are informed of their responsibilities was also highlighted:

> *I was just wondering where, with bridging silos, if Enabling Good Lives sort of plays a big part in sort of the bridging?... I guess, some sort of maybe collaboration with CDC and Enabling Good Lives. Because I guess that Enabling Good Lives, you know, it's going to be quite a main entity in everybody's lives, and all those families. (Service user)*
>
> *... it'll be really important that schools are aware of EGL's role, as well, because I'm not sure, I mean, I understand that some people with EGL, get the lead worker, but my understanding of even that service, and I think most schools, it would be pretty limited to be honest. (Frontline education professional)*

7.1.5 Focus Group One Category Five: Provision of a Community-focussed CDC

Participants corroborated the importance of improving the collaboration and integration between CDC, schools, and MOE. Some participants were relieved to see that the concept of CDC being more community-based and integrated with schools had come through as a key finding:

> *And it's part of something I was relived is in there as well, is CDC being more community-based and more integrated with schools. Because the reports and the assessments that we receive from CDC are only as good as their implementation. And so, for there to be dialogue, and for there to be a better integration both with schools as well as Ministry of Education, I think that's really key here. (Frontline education professional)*

In consideration of the literature evidence referring to examples of health professionals providing support within school environments, participants favoured the concept of the P4C model with OTs going into schools to provide support. Participants felt that a system similar to P4C would support the process of referrals and triaging, ensuring services are receiving referrals that are relevant to the services they provide.

> *I really like the concept of Partnering for Change. And it was, I didn't know about it, but it was something that I talked about in my interview was that I felt that there's probably a role for people like occupational therapists to be in the school environment, and helping schools to put strategies in place. And then, so that tertiary services, or even secondary services, are getting the referrals that they should be getting. (CDC clinician)*

The frontline education professional highlighted the current difficulties around accessing an OT to provide support in school. During conversations about the P4C model and the integration of CDC with schools, participants suggested using the RTLB framework, where each school has a liaison RTLB, as inspiration for CDC's integration with schools. Using this framework, each school could have a designated CDC clinician. Alternatively, participants proposed that at the very least, there is a need for CDC to have a designated contact person for schools to reach out to with any queries or concerns:

> *... currently the only way we can get occupational therapy unless it's funded is through OTRS [rehabilitation services] for disability, and so, I have an OT in the school, who comes to consult on maybe, like, five kids, but it's quite a strict criteria there. I wonder whether the framework that RTLB currently use where each school has a liaison RTLB. (Frontline education professional)*
>
> *That's what I think should be happening. (CDC clinician)*
>
> *... but even if each school had a contact person, that they were able to contact with a query, you know. (Frontline education professional)*

> *100%. (CDC clinician)*

> *They can both provide advice and guidance, raise capacity, but also triage, you know, like, so CDC aren't getting referrals they don't need. (Frontline education professional)*

A further strength identified within the P4C model was that it was perceived as a proactive response for providing support rather than reactive:

> *I guess that's probably why I like the Partnering for Change, because I see that as being proactive. (CDC clinician)*

7.1.6 Focus Group One Output: Draft CDC Service Delivery Model

Following consideration of the data collected from the first phase of the project and the first focus group, a drafted model of service delivery for improving the provision of CDC services was developed (see Figure 4). Birks and Mills (2015) discuss that a model is a strategy for the presentation of grounded theory. The use of illustrative modelling allows for a visual representation of the components of a grounded theory. As such, it is essential to provide an accompanying explanation to fully comprehend the meaning represented by the model (Table 6). Within the context of the current project, the model is a summative visual representation of the findings.

The model of service delivery aims to provide the essential support to improve the health and social outcomes of children facing developmental challenges to enable them to participate positively in community and family life. Through the multi-agency integration of CDC and education services and the provision of tiered support, neurodivergent children will have prompt access to equipment and modification services (EMS), comprehensive assessment for diagnosis, and therapeutic support. Families will experience equitable, well-coordinated, inclusive, proactive, evidence-based service that is easily accessible, person-centred, and responsive to their goals and evolving needs.

Figure 4

Draft Service Delivery Model for Improved Provision of CDC Services

Note. Refer to Table 6 for the storyline to accompany the draft service delivery model for improved provision of CDC services

Table 6

Storyline to Accompany Draft Service Delivery Model for Improved Provision of CDC Services

Main issues identified within phase one of the project

A. Insufficient support within the education setting.
B. Inadequate training and support for education staff.
C. Untimely provision of CDC service.
D. You don't know what you don't know (difficulty navigating services/pathways).
E. The current CDC service setting is a barrier.
F. Stigma around neurodivergence.
G. Insufficient support for the family network around the child.
H. Working in silos.
I. Lack of adequate resources.
J. Different professional ideologies and a lack of understanding of each other's roles.
K. Lack of access to therapeutic support.
L. Lack of support across ages and stages.

Illustrative representation in the model	Storyline	Primary issue(s) targeted for addressing	Enabling Good Lives focus
1. Children and whānau on their journey.	The provision of CDC services begins with children and their whānau commencing their journey to access support for children who face additional challenges to achieving expected developmental milestones.	N/A	• Self-determination
2. Gatekeepers are removed and children and whānau are welcomed to access CDC.	The open gate and the welcome sign represent the removal of gatekeepers to create open access to CDC services which is straightforward for families to navigate. Having clearer pathways will assist in making the system easier for families to navigate and reduce the chances of children getting passed back and forth between services, or missing out on services altogether. A strategy that may be beneficial for creating easier access to care and support is the implementation of a centralised triage/referral system such as CHIRP (Bay of Plenty District Health Board, 2021, October 29).	D. You don't know what you don't know.	• Beginning early • Mainstream first • Easy to use

Table 6 (continued).

3. CDC service provision is rooted within EGL principles.	Just as tree roots are interconnected and firmly implanted, the provision of CDC services should be ingrained and connected to the principles of EGL (Appendix A). Policy representatives highlighted that the future direction of CDS includes being led by the EGL principles, therefore the principles must be incorporated within the enhanced delivery of CDC. Using the EGL principles as a foundation for improving service delivery will help maintain focus on achieving the goals and objectives of enhanced service delivery and assist in overcoming the main issues identified within the current project.	All	All
4. Bridging services working in silos.	The goal of the bridge is to symbolise the connecting of siloed services, such as child development and education, to enable increased collaboration and a multi-agency approach to supporting children with developmental differences to meet goals and live their best lives. This is supported by the findings of the current project, which suggest that bridging silos could be achieved through various means, including the implementation of a shared IT platform, increased opportunity to develop relationships and build connections between services, the establishment of a designated contact person at CDC for referrers to communicate with, and the creation of a centralised referral/triage system. An additional way of bridging silos included creating a system where a child has one therapist that supports their needs across all contexts, rather than different therapists that support them at home or at school. The benefits of adopting such strategies include the reduction of redundant information gathering, elimination of repetitive storytelling for families, minimisation of confusion for families, the ability to respond more effectively to the needs of families, and enhancement of service efficiency.	C. Untimely provision of CDC services. D. You don't know what you don't know. G. Insufficient support for the family network around the child. H. Working in silos. I. Lack of adequate resources. J. Different professional ideologies.	• Person-centred • Easy to use • Relationship building
5. Community-based CDC providing outreach services to community settings.	The model proposes that CDC should be based within the community in a fit-for-purpose building that is child-friendly and accessible for disabled people. The model includes CDC providing outreach services to early education centres and schools. A range of benefits associated with the integration of CDC within education were highlighted. CDC could actively support the delivery of tiered support in schools which would contribute to increased provision of support, including therapy input, within the education setting. Integrating CDC clinicians within schools would allow for increased opportunities to develop relationships across services, and build the capacity of education staff and families. CDC clinicians would be available to provide prompt on-the-spot assistance and recommendations for teaching staff and would gain an increased understanding of what disability means for a child within the learning environment.	All	All

Table 6 (continued).

	Having CDC clinicians available within schools, may alleviate some issues of equity as schools are an accessible environment for children and families, and the familiarity of the school setting may decrease the possibility of a child not participating in the assessment process because of an unfamiliar setting (such as at CDC). Observing children within their natural environments may provide richer information and allows for the contextual triangulation of information required for diagnostic criteria. Within the school setting, CDC clinicians could screen the extent and severity of a child's developmental concerns and make a preliminary clinical judgment regarding the appropriate pathway of care for meeting the child's needs. This may assist with the flow of referrals, ensuring CDC is seeing the most appropriate children for their service.		
6. Two-way street to allow service users to access support as required.	To be flexible and responsive to children's changing needs across different ages and stages, the concept of a two-way street signifies that children can remain fluid within CDC services depending on their differing support needs throughout their development and transition circumstances.	C. Untimely provision of CDC service. D. You don't know what you don't know. L. Lack of support across ages and stages.	• Self-determination • Person-centred • Ordinary life outcomes • Easy to use
7. Services are positioned at the top of the cliff to ensure a proactive rather than reactive response.	Placing services at the top of a cliff, surrounded by a safety fence stems from the belief that relying on an 'ambulance at the bottom of the cliff' is ineffective. This analogy highlights the importance of addressing the root cause of issues rather than treating their consequences. Unlike a reactive approach, where an ambulance aids those who have already fallen, a proactive strategy involves installing a fence at the top for greater preventive benefits (Farlex, 2022). Therefore, the services are based at the top of the cliff to emphasise the delivery of CDC services that are proactive in response rather than reactive, and support is provided in a timely manner.	C. Untimely provision of CDC service. G. Insufficient support for the family network around the child. K. Lack of access to therapeutic support. L. Lack of support across ages and stages.	• Beginning early • Person-centred • Ordinary life outcomes
8. Hei matau (fishhook) to represent needs-based funding.	In Māori culture, the hei matau (fishhook) represents prosperity and abundance. The hei matau finds its origin in Māori legend which holds that the North Island of New Zealand was once a large fish that was caught by Maui. It is considered that one who has the means to catch fish will prosper (Ministry of Business, n.d.). The hei matau is used to represent an abundance of needs-based funding regarding a whole-life approach rather than funding that is compartmentalised across services.	G. Insufficient support for the family network around the child. H. Working in silos. L. Lack of support across ages and stages.	All

Table 6 (continued).

9. The waka represents unity in a shared purpose.	The waka, a traditional Māori canoe, is often used as a metaphor for a journey. Building a waka and paddling a waka requires teamwork and collaboration. In relation to healthcare, the metaphor of a waka can represent a team of paddlers, such as whānau and health professionals, working side by side, bringing both worlds of knowledge together to work towards a goal (Elder, 2017). The Māori proverb "He waka eke noa" highlights the importance of unity and collective effort, with a reminder that we are all in this canoe together; we rise together, fall together, work together, and keep going together (McCaffery, 2018, August 13; Te kupu o te ra, n.d.). The waka is used to emphasise a client-centred approach to the delivery of CDC where service users are viewed as partners and their expertise are collaboratively incorporated alongside that of associated professionals, such as CDC clinicians and education professionals, to work towards a client-centred goal. This also aligns with 'ako', a traditional Māori value, which refers to both teaching and learning, encompassed by a reciprocal relationship of equal value (Ministry of Education, n.d.).	D. You don't know what you don't know. F. Stigma around neurodivergence.	• Self-determination • Person-centred • Ordinary life outcomes • Mana enhancing • Relationship building

7.2 Phase Two Part Two: Focus Group Two

The four participants who represented service users and professionals from the education and health sectors in the first focus group were involved in a second focus group. The preliminary service delivery model (Figure 4) was presented for review and feedback. The insights gathered during this second focus group served as the foundation for refining the initial model to create a proposed model of service delivery for improved provision of CDC services. Three main categories were generated from the data collected during the second focus group: ‘strengths of the model’, ‘the role of MOE and CDC’, and ‘missing pieces’.

Numerous strengths of the drafted model of service delivery were identified including CDC being located within the community and working with schools, and placing services at the top of a cliff to represent a proactive response. Having CDC involved in the community and providing outreach support to schools was perceived to have various advantages including increased accessibility and efficiency of services, thereby promoting equity.

Participants highlighted the need for more clarity regarding the role of MOE and CDC within the education setting. They acknowledged that while there may be some overlapping areas of responsibility between these two entities in an integrated approach, regardless of any potential overlap, it was agreed that CDC should provide support to schools. An inquiry was raised as to whether one service (i.e. merging CDC and MOE) could provide the input instead of separate roles for CDC and MOE.

Regarding ‘missing pieces’ of the drafted model, suggestions were made to include EGL as they are a key service to collaborate with and to represent the age range of the journey to manage expectations about the duration of support.

7.2.1 Focus Group Two Category One: Strengths of the Model

Participants were provided the opportunity to contribute their ideas around what they perceived as strengths of the model. CDC being based within the community and providing an outreach service involving more integration with schools was identified as a strength within the model:

> *See, that's why the little car which says CDC outreach is going to be very valuable… CDC needs to be in school, because that's a safe space for families, and that car is your winner. I think that that is a strength. The car is a strength. (Te Whatu Ora manager)*
>
> *Yeah, that car's my favourite bit… In the ideal world, I think it would be amazing to have, have somebody live on-site to give us advice and guidance. (Frontline education professional)*

Several advantages of CDC's presence in the community and provision of outreach support in schools were identified. One key benefit was the promotion of equity as conducting screenings in schools would increase the accessibility and efficiency of services:

> *... the equity that we talked about, of getting out into the community. (CDC clinician)*
>
> *I thought that was kind of a strength because I'm sure there's a lot of growth in that. I'm just thinking out loud, like, does that make it more efficient? In terms of, I'm not saying let's get everyone diagnosed or anything like that, but it would wouldn't it, it would sort of like maybe get a bit of a head start with being integrated, by having that bridge to schools in that flow, there might be that opportunity to, screen or see a child or tamariki quicker. (Service user)*

The benefits gained when utilising schools as a platform for health promotion were identified:

> *We also know of benefits gained when utilising schools as a platform for health promotion e.g. Waikids at school for immunisations, dental, audiology etcetera. (Te Whatu Ora manager)*

The positioning of services at the top of the cliff to represent a proactive rather than reactive approach was recognised as an additional strength of the model:

> *I like the fence. (Service user)*

> *…we don't need an ambulance we just need, just need services who don't let it to get to that stage. (Te Whatu Ora manager)*

7.2.2 Focus Group Two Category Two: The Role of MOE and CDC

Regarding suggested improvements for the drafted model of service delivery, participants expressed that the draft model required further clarification regarding the roles of CDC and MOE within the education setting:

> *I'm just wondering also is the roles again, just where does that, it doesn't really jump out to me like the role? (Service user)*

> *Where does someone like the Ministry of Education, sit in amongst all of this?... Just how those MOE specialist services, and CDC might link together maybe? (CDC clinician)*

When discussing the role differentiation between CDC and MOE, it was acknowledged that there would be overlap. However, regardless of the potential crossover of roles, it was still thought that there is a need for CDC to be involved in providing support within schools:

> *So, there'd be a little bit of crossover, perhaps between the Ministry of Education early intervention teachers. But I think for them, it would be incredibly helpful, even if there was somebody at CDC who was the kind of, a liaison person for the Ministry of Education, early intervention teachers. (Frontline education professional)*

In consideration of the differentiation between the roles of CDC and MOE, it was also queried whether they could combine as one service to provide the input:

> *Or do you see that, actually, if the funding was to sit with CDC, and CDC was out there in the schools, that actually maybe that that service would all be one, and you wouldn't need two different services that say, 'that's yours and that's mine', you'd actually just have one service, and then it's just that one service's work? (CDC clinician)*

7.2.3 Focus Group Two Category Three: Missing Pieces

Participants were invited to identify gaps missing from the model and propose ideas for adjustments. In acknowledgement of bridging silos, suggestions were made regarding representing EGL in the model as EGL has been identified as a key service to collaborate with and it has been proposed that establishing a key worker model within EGL could be a fitting approach:

> *Oh, to be nit-picky, I wonder if, you know, you've got school and ECE there, I wonder if, and I know you've got EGL principles there, I wondered if that bridge also, on the other side of the bridge, where the school is, that you would have, that you would have EGL, actual EGL building there. (Service user)*

To assist with managing expectations about the duration of support from CDC, it was suggested that the age range for the journey be represented in the model:

> *I'm just thinking about the journey, and I'm thinking about the road, and I'm just thinking, this is the journey from this part to this part, it's not, you know the whole journey. And I just wondering, if I saw that, I might be like, oh, sweet, they're gonna be here for the whole time. (Service user)*

In recognition of the emphasis the model places on the collaboration between CDC and schools, a conversation occurred regarding the role of primary health and capturing children who are not currently attending, or are yet to start attending school:

> *… it's around capturing high-risk families early. And I'm wondering about information sharing or referrals that are coming from either primary GP, your Plunket nurse all of those, primary health… the ones that potentially haven't been to ECE or, you know, can't really wait until they're six before they get in the system, you know? (Frontline education professional)*

In acknowledgement that not all children will attend early childhood centres, and may not start attending school until they turn 6, it was emphasised that it will be important for CDC to continue to develop and maintain relationships with community services, such as GPs, to ensure children with developmental differences who may be missed by ECE are still captured and supported.

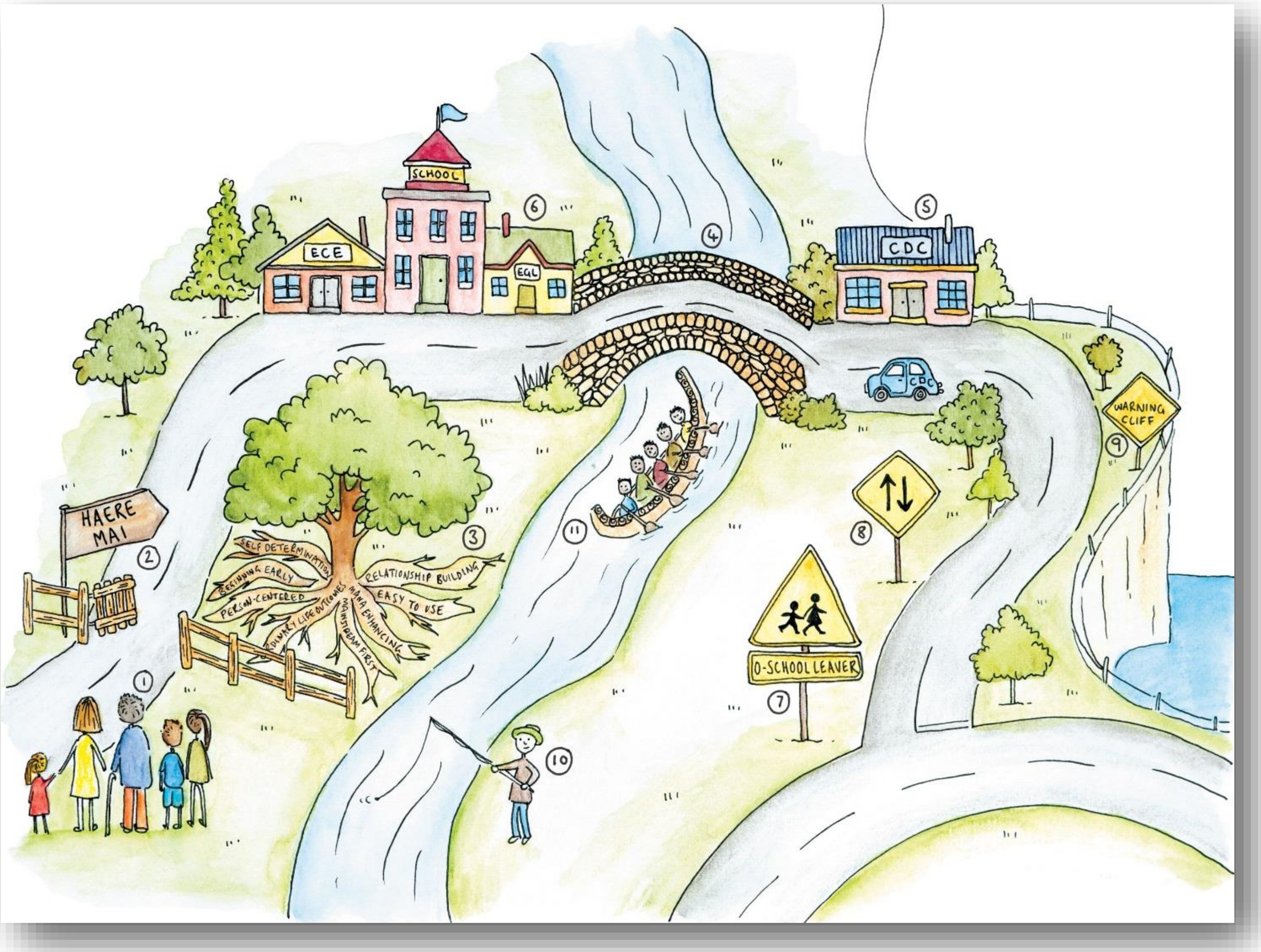
7.2.4 Focus Group Two Output: Proposed CDC Service Delivery Model

The proposed service delivery model for CDC represents a framework designed to enhance the provision of CDC services. This model, presented in Figure 5, integrates participant insights and relevant literature, and is fundamentally guided by the principles of EGL. Serving as a visual representation, the model encapsulates the key findings from the two phases of the study.

Based on the feedback discussed during the second focus group, two main amendments were made to the drafted model of service delivery. These include the addition of the EGL service and representation of the age range of the CDC journey. CDC will be accessible for children and youth from birth through until school leaving age. For some children, this will be around 18 years of age, however, those receiving ORS funding can attend school until 21 years (Ministry of Education, 2021, March 30). Equipment and Modification Services are provided within CDS for children under the age of 16 years (Claridge, 2023). Refer to Appendix Q for the storyline to accompany the proposed model of service delivery.

Figure 5

Proposed Service Delivery Model for Improved Provision of CDC Services



Note. Refer to Appendix Q for the storyline (representing key findings) to accompany the proposed service delivery model for improved provision of CDC services. Illustration completed by Sophie Stevens and Pete Oswald at Little Difference.

While the study acknowledges the significance of clarifying the roles of both CDC and MOE within the education environment, the specific details of their responsibilities within the proposed model remain outside the scope of the current project. This matter necessitates input from policymakers to delineate the responsibilities. The model underscores the importance of increased collaboration between CDS and the education sector and advocates for a funding and support system that is needs-based rather than contingent on rigid sector-specific criteria.

The proposed model suggests that a single therapist serving across different contexts, such as home and school, is more advantageous than having separate therapists in each setting. While the model envisions increased support from CDC within schools, implementing this vision requires substantial system changes, necessitating agreement and co-design between MOE and CDS. As explained by Craig and colleagues (2008), the implementation of a model in practice can be understood as a complex process involving various components that interact with each other. It requires organisational and procedural changes across different systems. Furthermore, it requires changes in behaviour from both the providers and recipients of the service.

Although not explicitly represented in the model, access to CDC would require ongoing collaboration with primary health services, such as GPs, to ensure that children outside the educational setting receive the necessary support for their developmental challenges. The open gate to accessing the service provides alternative entry points beyond the school environment, however, by integrating CDC clinicians into educational settings it is anticipated that most children would be captured through this particular pathway. The model envisions a holistic approach, acknowledging the interconnectedness of various systems and emphasises collaboration to better address the diverse needs of children facing developmental challenges.

7.3 Phase Two Findings Summary

Two focus groups were carried out and analysed using principles of grounded theory. Analyses of the first focus group’s contributions generated five main categories; ‘clarification regarding the roles and responsibilities of CDC’, ‘missed opportunities for therapeutic support', 'key worker model', 'silos', and 'provision of a community-focused CDC'. After analysing the data from phase one of the project and conducting the first focus group, a preliminary model of service delivery for improving the provision of CDC services was developed. In the second focus group, valuable feedback was shared by participants regarding the drafted service delivery model. Data analysis of the focus group data generated three main categories: 'strengths of the model', 'the role of MOE and CDC', and 'missing pieces'. These insights were instrumental in refining the model, contributing to the development of a proposed service delivery model for improved provision of CDC services.

Based on participant feedback, relevant literature, and the guiding principles of EGL, the proposed CDC service delivery model offers a recommended framework for enhancing the provision of CDC services. The model serves as a visual representation that captures the key findings derived from the two phases of the project. The service delivery model aims to provide the necessary support to improve the health and social outcomes of children with developmental challenges, by integrating CDC and education services. A goal of the model is to ensure that neurodivergent children can easily access equipment, assessments, and therapeutic support as needed.

To implement the proposed model effectively, it would be necessary to undertake a significant restructuring process that incorporates MOE and CDS agreements. This restructuring would also require extensive collaboration in terms of policymaking and design efforts.

Chapter 8: Discussion

Through the application of a qualitative approach, guided by principles of grounded theory and co-design, this research sought to develop a proposed service delivery model aimed at improving the provision of CDC services in Waikato. This process involved gathering and understanding insights from a range of stakeholders regarding the access to and provision of support for neurodivergent children, as well as ideas for service delivery improvement. Stakeholder perspectives were combined with existing literature to inform the development of a proposed service delivery model that ultimately aims to improve health and social outcomes for neurodivergent children.

This final chapter discusses the results that have been presented in the preceding findings chapters and contextualises them alongside existing literature. The chapter begins with a summary of the key findings. Following this, further in-depth discussion of the findings is presented in relation to the two primary research questions:

1. What are the current perspectives of stakeholders regarding the access to and provision of support for neurodivergent children in the Waikato region?
2. How can the delivery of CDC be enhanced to ensure improved health and social outcomes for neurodivergent children in the Waikato region?

The chapter concludes with a discussion regarding the implications of the research findings, limitations of the current project, and opportunities and recommendations for future research.

8.1 Summary of Findings

The findings are derived from a range of stakeholders, including CDC service users, CDC clinicians, managers from Te Whatu Ora Waikato, education professionals within Waikato, and nationwide policy representatives from the Ministry of Disabled People and MOE. Participants in the study highlighted several issues associated with the provision of support for neurodivergent children within both the education and health sectors, including a lack of adequate support, delays in receiving services, challenges in finding appropriate support pathways, and inadequate CDC service settings. They expressed a desire for improved collaboration between services, increased access to therapeutic support, support across different ages and stages, and a community-focused CDC that is integrated with schools. These insights enabled the development of a proposed service delivery model that is grounded in both the valuable insights of participants and relevant literature.

The project's visual summary of the findings, presented as a proposed service delivery model, offers a recommended framework for enhancing the provision of CDC services. To provide enhanced CDC services, the model proposes that CDC needs to be straightforward for families to access and navigate without long waitlists and children with disabilities or those facing challenges in meeting developmental milestones need to be able to easily access equipment, assessments, and therapeutic support. Access to CDC should be based on individual needs and accessible across ages and stages, with needs-based funding that considers the person's entire life rather than being divided among different sectors. The provision of CDC services should align with the principles of EGL. To improve collaboration and support for children with developmental differences, there is a need to bridge the gap between separate services and promote a multi-agency approach. There is a need for CDC to be located in a community setting with a facility that is easily accessible. Outreach services should be provided by CDC to schools and other community settings to offer diagnostic screening and assist in the provision of tiered therapeutic support within the education setting. By establishing a more integrated approach between CDC and education services, the service delivery model provides a framework to deliver the necessary support to improve the health and social outcomes of children with developmental challenges.

8.2 Research Question One: What are the Current Perspectives of Stakeholders Regarding the Access to and Provision of Support for Neurodivergent Children?

The perspectives of stakeholders regarding the access to and provision of support for neurodivergent children were focussed around three key concepts: access to and provision of support within the education setting, access to and provision of support within CDS, and barriers to making change and adopting multi-agency collaboration. Participants commented that there is insufficient support within the education setting and inadequate training and support for staff working within the area. Regarding access to and provision of CDS, participants spoke of the untimely provision of CDS services, difficulty navigating appropriate pathways for support, and that the current CDC service setting is a barrier. In terms of barriers that impact the ability to make changes to the provision of support for neurodivergent children, participants emphasised issues such as working in silos, lack of adequate resources, and differing professional ideologies and a lack of understanding of each other’s roles.

8.2.1 Access to and Provision of Support with the Education Setting

As the school setting plays a significant role in a child’s daily life, it was important to gain insight into stakeholders’ perspectives on the accessibility and availability of support for neurodivergent children within this context. It was anticipated that gaining these perspectives would assist in identifying gaps that require attention which may be addressed or supported through an alternative provision of CDC services.

Insufficient Support within the Education Setting. Data analysis showed participants identified the access to and provision of support within the education setting as insufficient. This finding is corroborated by an IHC[3] press release from July 2022 (Grant, 2022, July 07). The press release highlights that a recent study carried out by Russell and colleagues (2022) with 6,109 mother-child dyads showed that one in four of all New Zealand preschool children have developmental difficulties. Based on this data, Trish Grant, the Inclusive Education Consultant at IHC, highlights the need to address the issues around the education system's ineffectiveness in providing resources and funding that benefit both children and schools. Disabled students are not receiving adequate funding and assistance to have an equal opportunity in education compared to their non-disabled peers. IHC advocates for a system that offers appropriate support so these students are able to fully participate in all aspects of school life, rather than being limited to basic activities, such as colouring in, or being sent home (Grant, 2022, July 07). A recent survey conducted by IHC showed that 95% of family members of disabled children, 100% of health, and 99% of education professionals believe that the current education system is ineffective in meeting the needs of disabled children (IHC, 2022). IHC have been campaigning and taking legal action since 2008 to advocate for the necessary changes needed for the education system. However, after 14 years, new students continue to enter a system that is not suitable for them (Grant, 2022, July 07).

In the current project, data highlighted that ORS funding is difficult to obtain and successful applicants may still not receive adequate support. In New Zealand, approximately 15% of students in each school are listed on the school's special needs register (NZEI Te Riu Roa, 2018); however, only 1.2% of children and youth in school qualify for ORS funding (Ministry of Education, 2020, December). The level of support required for neurodivergent children has been highlighted in previous research. Within Eggleston and colleagues (2019)

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[3] IHC originated as the Intellectually Handicapped Children’s Parents’ Association (IHCPA) in the 1950’s. The organisation changed its name to Intellectually Handicapped Children’s Society in 1962, New Zealand Society for the Intellectually Handicapped in 1975, and IHC New Zealand Inc. in 1994. The initials no longer stand for ‘intellectually handicapped children’ but have continued to be used due to their wide-spread familiarity.

research on ASD diagnosis and support, caregivers (n = 516) of children and adolescents with ASD in New Zealand highlighted the level of support their child requires in day-to-day life. They identified 40.7% of children requiring mild support, 36.0% needing moderate support, and 13.6% needing very substantial support. Only 7.8% of children require little or no support. This example within the literature, as also suggested in the findings of the current project, highlights the disparity between the number of children who require support and the number of children who actually receive support. Participant perspectives regarding challenges associated with ORS funding are consistent with the recent IHC inclusive education survey which states that 86% of health and education professionals reported increased difficulties with the ORS policy and accessing the specialist support disabled students needed to participate and achieve (IHC, 2022).

In comparison to children who require a high level of support to access education, participants emphasised that children who experience moderate learning needs tend to miss out on receiving support within the education setting. The support within the education setting appears to be variable between different schools and the lack of support available within education settings may see children moving schools to find the right fit and/or children being excluded from attending full-time school hours. This may result in families having to make sacrifices, such as giving up work, to support their child’s access to education. These findings are confirmed within a recent report carried out by the Education Review Office (ERO; 2022) highlighting that education in New Zealand is failing disabled learners. The ERO, in partnership with the Human Rights Commission (HRC) and the Office for Disability Issues (ODI), explored how well the education system is supporting disabled learners in schools. The review showed that disabled learners continue to experience exclusion including being discouraged from attending local schools (experienced by one-fifth of disabled learners), being asked to stay home due to lack of resources (one-quarter of disabled learners), being stood down, and having to change schools.

Under the Education and Training Act 2020, people with special education requirements, regardless of their disability or other factors, are entitled to the same opportunities to enrol and receive education at mainstream schools as those without such needs (Ministry of Education, 2020b). Despite this remit, in line with the current findings, some students with learning needs are not given equal access to the entire curriculum and some students have experienced schools limiting their attendance to part-time (Community Law, n.d.; Grant, 2022, July 07). Findings within the IHC inclusive education survey showed that over a third of families reported that their children were frequently dismissed from school for a portion of the day and were unable to participate in school events. Forty-seven percent of education professionals confirmed having to send disabled students home due to inadequate funding to support their full-day attendance at school (IHC, 2022).

The support available for children within the classroom setting was thought to be influenced by classroom environments that may be disabling for neurodivergent children. Participants raised concerns about the classroom being an overwhelming environment for neurodivergent children, particularly in the context of modern learning environments (larger classroom spaces with more students than traditional classrooms), which may impact their ability to successfully participate and engage in learning.

Johnston's (2022) report, focused on the MOE modern learning environment experiment, supports the participants' perspective that modern learning environments are not suitable for the learning needs of neurodivergent children. In 2011, MOE adopted a 10-year plan to refresh New Zealand's outdated classrooms. This involved creating larger, open-plan classrooms that could accommodate more students than traditional classrooms. The

Innovative Learning Environment (ILE) model was introduced, commonly employing ‘team teaching’ methods involving multiple teachers and larger groups of children, often 60 or more students. Johnston (2022) revealed that there is no reliable evidence in the research literature that supports these environments. Evidence is not available to support the concept that team teaching is better than individual teaching or that children learn more in open-plan classrooms. However, there is evidence to suggest that children with learning disabilities, such as auditory processing disorder, ASD, and ADHD, are negatively impacted by ILEs (Goodall, 2017; Keith et al., 2019; Page & Davis, 2016). The effects of challenges associated with neurodivergent conditions are likely to be exacerbated in large, open-plan classrooms (Goodall, 2017; Johnston, 2022). The ERO (2022) report on education support for disabled learners further highlights families' concerns regarding modern learning environments and the associated impact of sensory overload and overwhelm on the adverse learning experiences for neurodivergent children. To assist schools that have been set up with ILEs, Johnston (2022) has urged MOE to support schools in addressing the challenges that ILEs present to students with learning disabilities.

Based on their experiences, participants had different views regarding the criteria for accessing learning support in the education setting. Some participants were aware that education supports and resources are provided based on need rather than diagnosis. The Ministry of Education (2012) stipulates that most students with special education needs/disabilities are not required to have a specific diagnosis, and often those with the same diagnosis may have different needs. Therefore, the type and level of education support varies depending on the severity and impact of a disabled learner’s impairment(s) and the level of support they require to enable them to join in and learn alongside other children in their class. With the exception of children who have particularly high needs, schools receive a Special Education Grant as part of their overall funding to help them provide support for children with special education needs. The school can use the money to fund a SENCO and teacher aides, and/or provide time for teachers to plan and adapt their teaching to meet students' needs or implement intervention programmes. For students who have moderate needs, the school can request additional support from specialists such as RTLBs, hearing and vision services, and physical disability services (Education Review Office, 2022; Ministry of Education, 2010).

In contrast to the understanding that education support is provided from needs-based criteria, some participants perceived that a diagnosis is required to be able to apply for education support. This perception appears to have evolved from situations where education professionals have been more successful in receiving extra learning support for a child when they have a diagnosis while facing a higher likelihood of being denied additional support when a child does not have a confirmed diagnosis, regardless of their needs. Although not definitive, the data within the current project suggests that the lack of clarity and consistency regarding access to learning support may be contributing to a variety of challenges within the systems responsible for providing disability services. It is possible that schools may be referring children to CDC for diagnostic assessment, purely in the hopes that the outcome of a diagnosis will increase their ability to access learning support. This may contribute to a higher number of referrals to CDC, causing larger waitlists and longer wait times for assessments, resulting in children being placed on a waitlist without receiving any support or input in the meantime. Pursuing a diagnosis under these pretences can lead to misunderstandings and skewed expectations for families regarding the assessment process and the confirmation of a diagnosis. Families may mistakenly believe that getting a diagnosis for their child will automatically lead to support at school. This may cause conflicts when families were hoping their child would meet the criteria for a diagnosis but the child does not meet diagnostic criteria. In some cases, because of the pressure to seek a diagnosis to be able to access support, schools may refer children for diagnostic assessments without the family being aware that the outcome could be a diagnosis. This is further potential for conflict when families do not wish to consider the possibility of their child having an underlying diagnosis.

The recognition of both positive and negative implications associated with diagnostic labels has been highlighted in the literature. For some, a diagnosis can provide comfort by showing that a child's situation is not unexplainable and alleviating caregiver feelings of guilt, such as parents blaming themselves for their child’s differences. Diagnosis can enable an individual’s understanding of their uniqueness and help them avoid feelings of shame, loneliness, and low self-esteem that may arise if they are simply labelled or perceived as strange or abnormal. Stigma can also be minimised with the recognition of a medical explanation for a person’s presentation. Diagnosis allows for communication between professionals and the public, and provides access to support groups and relevant resources including connecting with others facing similar challenges through support groups (Craddock & Mynors-Wallis, 2014). On the negative side, receiving a diagnosis for a child implies that they may never fully achieve a state of being considered ‘normal’, which may cause significant concern about their future. Additionally, others may lack understanding about the condition, resulting in negative reactions or treatment towards both the child and their families. It can be difficult for caregivers to differentiate whether their child’s challenging behaviours are associated with their diagnosis or not. Furthermore, particularly in the case of ASD, the diagnosis itself does not offer clear information about a specific cause for the condition, as the causes have yet to be definitively determined and are likely to involve multiple factors. This lack of clarity can lead to feelings of frustration and confusion (Mansell & Morris, 2004).

The misunderstandings around accessing learning support are partly discussed by ERO (2022) in their review of how well the education system is supporting disabled learners in schools. Regarding disabled learners, school leaders are reported to lack a comprehensive understanding of what is expected. Most schools have a strong commitment to include disabled students and provide support for them, however, almost half (43%) of school leaders and School Boards are not fully aware of their legal obligations towards disabled students, and not all schools have policies in place to support them. Additionally, there is no national system for monitoring the progress of disabled students.

Providing other diagnostic criteria are met, the diagnosis of an ID is typically made when a child's cognitive abilities fall below an average full-scale IQ cut-off of 70 on a standardised measure such as the Wechsler Intelligence Scale for Children (WISC-V) (Boat & Wu, 2015; Pearson, 2016). The WISC-V utilises a bell-shaped curve to represent IQ scores, with different percentages of cases falling within different ranges. Approximately 25% of cases are categorised as above average, 50% of cases fall within the average range, 16.1% are considered to be in the low average range, 6.7% of cases are categorised in the very low range, and 2.2% of cases fall below the full-scale IQ score of 70 in the extremely low range (Pearson, 2016). This highlights that 22.8% (the 'low average' and 'very low' ranges) of cases fall into a category above the cutoff point for an ID diagnosis, yet they remain below the range of what is considered average. This is suggestive that there will always be a portion of the population, likely representative of the 'moderate group', who do not meet the requirements for a formal diagnosis but are still prone to encountering challenges in their cognitive abilities and may require extra support in their learning. This reinforces the need to provide support based on need rather than a diagnosis.

Inadequate Training and Support for Education Staff. The current study revealed the viewpoint that teachers receive little to no training regarding working with neurodivergent children during their initial teacher education. This may impact their ability to provide adequate support in the classroom. Schools have trouble accessing formal support for these children, therefore teachers are often left to provide support themselves. This pattern of results is consistent with pre-existing literature that acknowledges that teachers who work with children who have a neurodevelopmental disorder may not have strong knowledge of the diagnoses they are dealing with. Various studies have found that both parents and teachers have concerns about the level of knowledge and understanding of mainstream school staff, and they believe that more training is needed to effectively support children with neurodevelopmental disorders in the classroom (Kendall, 2019; Reilly et al., 2015; Roberts & Simpson, 2016). An ERO review showed that over half of teachers also lack confidence in teaching disabled students. One-third of disabled students feel they are not supported to learn in ways that best meet their needs, and a similar proportion of their families are dissatisfied with the quality of their child's education. (Education Review Office, 2022).

The finding of limited provision of support and special needs training for education professionals is further corroborated by the IHC inclusive education survey. Findings within this survey showed that both experts and families noted there has been a decline in teacher capacity to effectively teach diverse learners over the past three years. This decline in teacher assurance and skills is thought to potentially be associated with various factors such as excessive work demands, insufficient support systems, and persistent issues stemming from inadequate training and ongoing professional development within the teaching profession (IHC, 2022). An immense responsibility is placed upon teachers in facilitating the process of teaching and learning, therefore it is essential that they are provided with additional support to enable them to consistently deliver inclusive education environments that prioritise the education of every student (Mayes & Wall, 2023).

The ERO have made several recommendations to improve the sense of belonging and acceptance of disabled learners in schools, as well as enhance teachers’ ability to teach them. The recommendations include improving the training and education of principals and new teachers, providing better support and mentoring for beginner teachers, clarifying professional expectations for the inclusion of disabled learners, prioritising professional development on disability, evaluating the quality of disability professional development, and providing guidelines, resources, and support for teachers of disabled students (Education Review Office, 2022).

In promoting progress towards inclusive schools, the importance of special needs training for educational personnel has long been highlighted. In 1994, more than 300 representatives from 92 governments and 25 international organisations met at the World Conference on Special Needs Education. The purpose of the conference was to reaffirm a commitment to Education for All by considering the necessary changes in policies to promote inclusive education, which involves ensuring that schools can cater to all students, including those with special needs. In recognition of every child's right to an education, one outcome of the conference was the 'framework for action on special needs education'. One guiding principle included the recruitment and training of education personnel. The framework suggests that training programmes for student teachers should teach them to have a positive attitude towards disabilities and understand what support services are available in their local schools. There is a need for teachers to have knowledge and skills in teaching, including assessing special needs, adapting curriculum, using assistive technology, and individualising teaching methods. Training needs to prepare teachers to use their skills to adapt their teaching to meet the needs of students, collaborate with specialists, and work with parents. During the assessment and certification of student teachers, their skills in responding to special educational needs should be taken into account (United Nations Educational Scientific and Cultural Organization, 1994).

Overall, the findings within the current project show that stakeholders perceive the access to and provision of support in schools for neurodivergent children as inadequate. This lack of support within the education system may be contributing towards and exacerbating the demand for CDS, particularly for diagnostic assessments. Disappointingly, the need to address the shortcomings of the education system in supporting disabled children and providing equal opportunities compared to their non-disabled peers, as well as provide teachers with training to work with neurodivergent children, has been long recognised (Grant, 2022, July 07; United Nations Educational Scientific and Cultural Organization, 1994). However, the current project findings, supported by literature, indicate that the education system continues to present with numerous gaps in addressing these issues.

8.2.2 Access to and Provision of Support within Child Development Services

Regarding the access to and provision of support within CDS, the perspectives of participants showed that access to CDC services was not timely, it is difficult to navigate the appropriate pathways to access developmental and disability support ('you don't know what you don't know'), and the current CDC service setting is a barrier to access.

Untimely Provision of CDC Services. Over recent years, referrals to CDC have increased, resulting in larger waitlists and increased waiting times for children to be seen for diagnostic assessments. Many factors may be contributing to an increased number of referrals for neurodevelopmental disorder diagnostic assessments, such as increases in the needs and the population of families seeking access to CDC for support and a lack of other services available within the community. Concerns about equity were raised in situations where children are unable to access CDC due to not meeting criteria or when timely access to services is required. In such cases, caregivers may have to pay privately for support, however, for those who are unable to fund private support, children may end up not receiving the necessary support.

While not explicitly referring to how child development services are provided in New Zealand, existing literature demonstrates a similar pattern of findings regarding delayed access to rehabilitation support for children with or at risk of disability. In Shannon and colleagues' (2021) exploratory research, they employed a constructivist interpretive approach to investigate how leaders in district school boards, children's treatment centres, and the community envision effective collaboration in rehabilitation therapy services. In their study, participants expressed a shared concern about the need for enhancing timely access to services for children and families. Participants recognised the significance of improving service timeliness to prevent further disparities in access based on a parent's capacity to advocate effectively or afford the services.

As discussed in the preceding section, it is possible that challenges accessing support within the education setting may be contributing to increased referrals to CDC for diagnostic assessment. Although the population and needs of neurodivergent children have increased, the funding of CDS has not been adjusted to meet the increased demands (Claridge, 2023; Thabrew & Eggleston, 2018). Research in the United Kingdom aimed at understanding the cost of assessing childhood ASD shows a similar pattern of challenges regarding the diagnostic processes for ASD. The increasing prevalence of ASD has created a greater need for diagnostic services, resulting in delays in assessments. Additionally, the traditional method of funding child development services through block contracts has been unable to keep up with the growing demand for these services. To alleviate the increasing wait times for diagnostic assessment, it is suggested that funding allocated for child development services needs to match the cost of carrying out a diagnostic assessment and the staffing resources required to fulfil the demand (Galliver et al., 2017). When a diagnosis is delayed or missed, it becomes harder for individuals to receive the necessary support, resulting in a detrimental effect on their well-being, participation in activities, and overall quality of life (Chamberlain et al., 2017; Kentrou et al., 2019; Rutherford et al., 2018).

Findings suggested that a lack of clarity around service criteria and challenges regarding the referral processes to access CDC may result in children missing out on support, children being passed back and forth between different services, and/or not receiving access to service in a timely manner. Referrals to CDC may be declined if they lack sufficient information or fail to demonstrate that the child meets the service criteria. The referral process and ability to access CDC are often dependent on the referrer's knowledge and ability to effectively communicate the child's needs and the purpose of seeking support from CDC. It can be difficult to accurately convey concerns through written information, especially for those from an education background, and the information provided in the referral could determine whether a child is accepted or declined for access to CDC. The lack of clarity around service provision may be further impacted by limited funding and resources. This has resulted in many CDS in New Zealand, including CDC, focusing primarily on conducting diagnostic assessments, rather than providing longer-term support, even though this is only a small part of their overall service responsibilities (Claridge, 2023; Thabrew & Eggleston, 2018). The current CDS service specifications are not congruent with how CDC services are being provided, therefore, the limitations around the ability of CDS to operate in a way that adequately reflects the service specifications may be contributing to confusion and lack of clarity regarding the entry to service criteria. The current focus on diagnostic assessments has contributed towards external stakeholders perceiving assessment as the main role of CDC rather than having awareness of CDC’s responsibility to provide therapeutic support. This emphasises the need for clarification regarding the roles and responsibilities of CDC.

Limited knowledge and understanding of health and disability issues among education professionals may hinder their ability to determine if CDC is the most suitable service for a child, potentially affecting a child’s access to timely support. If education professionals do not make the appropriate referral in the first instance, this may cause delays in children receiving the support they need. There are challenges in differentiating symptoms of mental health and disability conditions, such as ADHD and ASD, as they often have similar characteristics and can coexist. This uncertainty can lead to confusion among referrers about whether to refer a child to mental health services or development/disability services. Additionally, there can be different opinions and/or inflexibility in service provision between mental health and disability service providers about which criteria the referral meets, and which service is more suitable for the child. This may also be influenced by the referrer’s ability to effectively communicate their concerns in a written referral. If people are not aware of the services provided by CDC or do not know about other suitable services, CDC may spend valuable time and resources triaging referrals that are not relevant to their service. Consequently, this can lead to a further burden on an already overworked and under-resourced CDC, resulting in increased time constraints and workload pressures.

You don’t know what you don’t know. The findings showed that people experience challenges when trying to navigate the appropriate pathways to access developmental and disability support. Although not limited to the access to CDC, the lack of clear roles and responsibilities for services can create confusion for families and referrers in determining the most suitable services and pathways to seek support. Families faced difficulties in accessing necessary services if they lacked guidance or knowledge about where to seek support. It is not only difficult for families and referrers to navigate the system, clinicians and healthcare professionals can also have difficulty finding the appropriate pathways of support for neurodivergent children. A key factor contributing to the challenges around navigating the appropriate pathways for disability support included the division between the disability support provided by CDC from a healthcare perspective and the disability support provided by MOE for education purposes. This siloed approach creates confusion about who is responsible for fulfilling certain tasks or roles.

Evidence within the literature reinforces the current findings showing that families of children with illness and/or disability have a hard time finding and accessing the services they need, and it can be stressful and difficult to navigate through complicated and disconnected systems (Freedman & Boyer, 2000; Ray, 2002; Tehee et al., 2009; Valentine, 2010; Wiart et al., 2010). Caregivers find it challenging and isolating to coordinate their child's services, as they must spend significant time and effort on it. They also struggle to obtain information and are confused about the best way to navigate through different systems with varying access and eligibility criteria (Schurgin et al., 2021). Eggleston and colleagues (2019) explored caregiver perspectives in New Zealand regarding obtaining an ASD diagnosis for their child. Many parents found the process to be stressful, with 40.4% saying it was quite stressful and 37.2% saying it was very stressful. On average, children saw 4.5 professionals before getting diagnosed at a mean age of 6.6 years old, and the average wait time for an assessment was 5.3 months. Consistent with the findings presented in the current study, Eggletson and colleagues (2019) comment that there is a need for improvements in the referral process and shorter wait times for assessments. If these changes are made, parents are more likely to have better access to early intervention services, experience less stress, and be more satisfied with the overall process.

Further research corroborates the current findings by highlighting that caregivers often feel uninformed about the relevant services and supports for their children and service providers are not always able to bridge this gap as they are also often unaware of available supports. Caregivers frequently rely on their own research and word-of-mouth from other caregivers to discover services and entitlements. One area where caregivers particularly feel they require assistance is finding and accessing services related to supporting their child's transitions, such as from pre-school to school-aged services or from paediatric to adult care. Pozniak and colleagues' (2023) qualitative descriptive study exploring parents' experiences of paediatric service delivery reported that caregivers greatly appreciate when service providers provide them with connections to services that are specifically suited to their child's needs, rather than generic resources that they have to research the suitability of for themselves.

In 2021, a provincial Summit on navigation for children and youth with neurodevelopmental differences, disabilities, and special needs was carried out in British Columbia (BC), Canada (hereafter referred to as the 'Navigation Summit'). The Navigation Summit consisted of more than 120 people, including researchers, government officials, service providers, educators, healthcare professionals, and advocates for families. As a part of the Navigation Summit, research findings relating to the nature, purpose, and terminology of navigation for children with neurodisabilities and their families were presented. The synthesis of the relevant research highlighted barriers families experience as they navigate neurodisability-related supports including waitlists, finances, institutional/systemic barriers, lack of awareness, family capacity and circumstances, and siloed services. It was highlighted that children and families will see improvements in their capacity, health, and overall well-being when services can be accessed as required, obstacles to access are removed, and integrated and coordinated support is offered based on principles of safety, strengths, individuality, and collaboration. During the Navigation Summit, personal stories from individuals who had experience navigating service systems in BC to support their children with neurodisabilities were shared and used to facilitate discussion. In response to the shared stories from caregivers, the attendees were asked to reflect and share their thoughts on the wisdom within the family stories that need to be carried forward. A major highlighted theme was the need to simplify the systems that families navigate (Gardiner et al., 2022).

Due to the difficulties in navigating the complex processes involved in obtaining the necessary support, families, particularly Māori and Pasifika families, may disengage from services, resulting in issues of equity and children missing out on necessary support. Although not specific to accessing child development services, research on the persistent health inequities between young Māori and other young people within New Zealand suggests there may be deliberate under-resourcing, institutional racism, and Eurocentric practices within the health and social service sectors which have detrimental effects on the overall well-being of Māori youth. These detrimental effects leave young Māori and their whānau in vulnerable positions, with limited options for support. As a result of these unfavourable conditions, it is common for young Māori and their whānau to disengage or avoid accessing services and agencies to protect themselves. Unless social and healthcare services can effectively meet the unique requirements of young Māori individuals and allow for opportunities to establish connections and find culturally focused and empowering solutions, the ability to adequately support young Māori and their whānau will continue to be compromised (Department of the Prime Minister and Cabinet, 2019b; Lindsay Latimer et al., 2022). The concept of using schools and marae as community hubs to support Māori children and their families has been suggested to improve the well-being of children and young people. Schools and marae are viewed as important community centres and centralising government services in these locations would be more convenient and accessible for people (Department of the Prime Minister and Cabinet, 2019b).

A range of barriers to accessing healthcare for Pasifika children and their families has been identified in previous literature including the cost of GP consultations, cost of and/or lack of transport to attend appointments, inability of caregivers to get time off work, difficulty enrolling in healthcare services, and lack of childcare (Tukuitonga et al., 2023). Research also suggests that Pasifika people may experience stigma, lack of cultural responsiveness, mistrust, and lack of knowledge of services when seeking professional healthcare, creating further barriers to accessing services (Fa’alogo-Lilo & Cartwright, 2021). With specific consideration of disability services for children, there is a scarcity and lack of funding for services specifically designed for Pasifika families. Furthermore, young Pasifika individuals with disabilities or chronic conditions experience more discrimination from healthcare providers compared to other groups (Tukuitonga et al., 2023). The identification of Māori and Pasifika families as groups that face higher rates of inequities in terms of accessing healthcare services underscores the prompt need for the provision of culturally responsive services.

The Current CDC Service Setting is a Barrier. The current service setting of CDC poses difficulties for disabled individuals to access and receive support. Despite being a service provider for disabled children, the building itself is not easily accessible for disabled individuals. Additionally, the location of CDC within the hospital campus creates further obstacles to access, such as difficulties with parking and the overwhelm, particularly for neurodivergent children, associated with walking through the hospital. These challenges lead to issues of inequity as they may prevent some children from accessing the necessary support they need. These issues suggest that CDC is not currently providing adequate access to service.

The main access to CDC is via a small lift. Participants highlighted that for some children with larger wheelchairs, it can be difficult and sometimes not possible to fit the wheelchair as well as any caregivers into the lift. A minimum internal lift dimension of 1800mm by 1800mm is recommended (Auckland Council, n.d.), however, the current size of the lift to access CDC is 1380mm by 1380mm. Additionally, participants highlighted that for neurodivergent children, the requirement to access the service via a lift may be intimidating and the stairwell is not signposted or easy for service users to find. According to the design for access and mobility standards in New Zealand (NZS 4121:2001), buildings with more than one floor must have at least one accessible stairway connected to an accessible route, regardless of whether there are elevators. Additionally, accessible entrances and stairways must be clearly marked with signs (Access 2000 Committee, 2001). The inappropriateness of a physical environment can present as a significant barrier to access to care for disabled people. Previous research stresses the need to address and understand the barriers disabled people encounter and the impact this has on them and their families, to ensure they have access to high-quality healthcare (Hashemi et al., 2022). The lack of accordance with recommended standards emphasises that the current issues around the physical environment and access to services for disabled people at CDC require prompt addressing.

Participants highlighted that having children attend a child development appointment within the hospital setting is not a typical or comfortable setting for them. Requiring children to participate in assessments with unfamiliar staff and surroundings can hinder their engagement and the ability to observe them accurately. Due to the wide geographical area covered by CDC, the distance children have to travel to access on-site appointments may also affect their engagement with the assessment.

The hospital setting is recognised as an environment that can be particularly stressful for children with ASD. Although CDC is not directly attached to the main hospital building, it is based on the hospital campus and due to challenges associated with parking, many families are required to access CDC by walking through the main hospital building. In support of the current findings, research has shown that children with ASD often experience high levels of anxiety when faced with unfamiliar situations, including being in a hospital. The sensory, communication, and social challenges associated with ASD make it particularly challenging for these children to cope with the hospital environment, which may potentially heighten their behavioural responses and impact their engagement and cooperation in hospital-based processes (Johnson & Rodriguez, 2013; Muskat et al., 2015; Straus et al., 2019; Thom et al., 2019). Within the processes of multidisciplinary assessment and diagnosis of neurodevelopmental conditions, it is recommended that pre-screening and assessment involve naturalistic observation in typical environments such as the home and/or the classroom setting including the involvement of education staff (DuPaul & Stoner, 2014; Moore et al., 1998; Rutherford et al., 2021). Although not specific to assessment, research shows that interventions for children with disabilities that are provided in natural environments such as schools, daycares, and community settings are more meaningful to children and families and enhance the participation of children with disabilities in their schools and communities (Dunst & Bruder, 2002).

The patterns of results in the current project regarding the access to and provision of CDS are consistent with recent qualitative descriptive research carried out by Pozniak and colleagues (2023) which explored parent experiences of paediatric service delivery for their children with disabilities and developmental challenges. Caregivers highlighted a range of widespread issues within the system of the delivery of paediatric disability services. These issues included a lack of services and qualified providers, a lack of coordination between different sectors (particularly between healthcare and education), unequal distribution of services across geographical locations, long wait times (resulting in some children outgrowing services before being able to access them), and a decrease in available services as children grow older. Caregivers expressed that services appear to prioritise diagnoses rather than addressing the unique needs of the child and family. They also comment that these services lack flexibility because alternative options are often not provided when a particular service is not suitable for the child or family. Ultimately, parents believe that the system does not prioritise the values of families and call for a substantial change in service delivery. The research conducted by Pozniak and colleagues exclusively focused on gathering insights from parents. The current project expands upon their work by presenting a similar pattern of findings representative of a broader range of perspectives from various stakeholders, in addition to caregivers.

8.3 Research Question Two: How can the Delivery of CDC be Enhanced to Ensure Improved Health and Social Outcomes for Neurodivergent Children in the Waikato Region?

To obtain a comprehensive understanding of how the delivery of CDC could be enhanced to ensure improved health and social outcomes for neurodivergent children in the Waikato region, barriers to making changes and adopting multi-agency collaboration were explored. The study also explored factors perceived by participants as contributors to improved health and social outcomes for neurodivergent children and ideas for enhancing the delivery of CDC.

8.3.1 Barriers to Making Change and Adopting Multi-agency Collaboration

When considering ways of making improvements to service delivery, it is important to understand perspectives regarding the barriers that may be influencing the current access to and provision of support for neurodivergent children. Understanding the obstacles hindering the implementation of a multi-agency approach is important to comprehend why services have not yet adopted such changes. Within the current project, working in silos, lack of adequate resources, and different professional ideologies and a lack of understanding of each other's roles were identified as key barriers to making change and adopting multi-agency collaboration.

Working in Silos. Depending on their needs, it is common for disabled children to be in contact with many different agencies and services (Beattie, 1999; Cass et al., 1999; Wiart et al., 2010). Sloper's (2004) literature review on facilitators and barriers to co-ordinated multi-agency services highlights that research consistently shows there is a lack of multi-agency collaboration, a lack of availability of key workers within many services, and a continued lack of integration between children's services. Barriers to multi-agency collaboration associated with siloed services and systems include poor communication and information sharing, inadequate or incompatible IT systems, and lack of joint budgets. Consistent with the literature, the current research showed that participants perceived services working in silos as a major obstacle to making service changes and implementing a multi-agency approach. This issue is particularly noticeable in the separation between the Ministry of Health (and more recently the Ministry of Disabled People) and MOE, including their respective budgets. In addition to the siloed working between the health and education sectors, there was a noticeable divide within the health sector itself, specifically in the areas of child disability, child health, and child mental health services. The siloed systems and blurred specifications within the systems add to the confusion around who holds the responsibility for fulfilling particular roles, contributing to challenges in navigating support systems.

Children with physical and behavioural health conditions may present with a variety of complexities regarding their challenges. Therefore, it is unrealistic for a single provider to have all the necessary information to provide adequate care and intervention for children with complex needs. Additionally, many of these children and youth have co-occurring conditions, which further complicates the assessment, diagnosis, and treatment processes (Forman et al., 2018; Williams & Salmon, 2002; Winters et al., 2016). A lack of integration between services often leads to delays in accessing services and a decrease in the quality of patient satisfaction (Glasby & Dickinson, 2014; Kodner & Spreeuwenberg, 2002).

The detriments of services working in silos and the fatigue of having to repeatedly share their stories have been referred to by caregivers in previous research. Caregivers have expressed a strong desire for paediatric disability service providers and organisations to improve their coordination of care. Existing communication gaps among providers, resulting in information not being efficiently shared between the various individuals, departments, and organisations responsible for the child's care have been identified. Additionally, caregivers have highlighted the lack of a designated person overseeing the child's overall care, leading caregivers to take on the roles of messengers and care coordinators. As a result, caregivers often adopt the role of ensuring the timely and effective transfer of relevant information among the different parties involved. Caregivers want to see improved communication and coordination among the different service providers and organisations involved in their child's care (Pozniak et al., 2023).

Lack of Adequate Resources. Alongside services working in silos and separate Ministries and funding streams, lack of time, workload pressures, frequent staff vacancies, and lack of adequate staffing resources were highlighted by participants as barriers that impact the ability to create change and work collaboratively between child development and education services. Extended periods of staff vacancies can contribute to delays in seeing children and lengthier waitlists. These findings are supported by the work of Sloper (2004) who highlights that inadequate resources, frequent staff turnover, lack of qualified staff, and lack of time for joint working are barriers to multi-agency working. When services and staff members are focused on trying to keep up with the demands of lengthy waitlists, they are less likely to be able to prioritise initiating and engaging in collaboration with other services.

Different Professional Ideologies and Lack of Understanding each other's Roles. Differences in professional ideologies and deficits in understanding each other's roles were identified as obstacles that hinder the ability to work collaboratively among sectors and services. The ethos underpinning child development and education differ, and the specific vocabulary and terminology employed within these distinct sectors create a limitation in effective communication. These findings reflect those of Sloper (2004) who also discussed that various professional beliefs and organisational cultures, negative professional stereotypes, and a lack of trust and understanding among individuals and organisations may hinder the effectiveness of collaborative efforts across multiple agencies. The cultures within individual professions and agency settings are important for encouraging collaboration. Multi-agency collaboration is more successful when professionals and agencies have a mutual understanding and respect for each other's roles, which can be achieved through collaborative training.

Previous research also emphasises the potential obstacle of unclear roles and responsibilities, and the absence of guidelines and standards for service delivery in hindering coordinated multi-agency collaboration. This underscores the importance of explicitly outlining roles and responsibilities to establish a shared understanding of expectations and promote clear lines of accountability. Clearly defined roles and responsibilities are considered advantageous in facilitating multi-agency collaboration and enhancing transparency (Shannon et al., 2021; Sloper, 2004).

In line with the current findings, the importance of addressing the barriers associated with different professional ideologies and lack of understanding of each other’s roles has been recognised within the literature. To ensure effective collaboration among child-serving systems it is important to acknowledge and address differences in philosophies, organisational cultures, and attitudes towards healthcare and professional practices (Forman et al., 2018; Wiart et al., 2010). To promote effective communication among providers, it is important to have a common professional language and terminology, so that providers can avoid confusion and not be disempowered by unfamiliar jargon (C. Cheminais, 2009; Robinson et al., 2005). There is not only a need for an improved understanding of professional roles between different sectors such as education and health, but there is also a need for improved understanding within healthcare providers. For effective collaboration among healthcare providers, it is crucial to have a mutual understanding and trust among professionals. Trust is built on the belief that each provider is competent and genuinely cares about supporting the needs of the client and their families, and the referrer (Lee et al., 2011).

To aid the navigation of support systems and services for neurodivergent children, research has highlighted the desire for improved understanding amongst different professionals and providers. In consideration of possible improvements to be made for the navigation of neurodisability-related services for children, attendees at the Navigation Summit were hopeful for better connectivity among service providers including improving communication, understanding each other's responsibilities, and promoting opportunities for knowledge exchange and collaboration (Gardiner et al., 2022).

Overall, the current research findings are consistent with what has been previously discussed in the literature about the obstacles to collaboration between different agencies in children's services. These obstacles include siloed services, sectors, and budgets, limited time and heavy workloads, insufficient staffing resources, and differing professional beliefs and a lack of understanding about each other's roles and responsibilities.

8.3.2 Factors that may Contribute Towards Improved Health and Social Outcomes for Neurodivergent Children

In the current study, increased understanding and reduction of stigma around neurodivergence, support for the family network around the child, and increased support in schools were identified as three main factors that may contribute to improved health and social outcomes for neurodivergent children.

Increased Understanding and Reduction of Stigma Around Neurodivergence. Participants acknowledged the existence of stigma regarding neurodivergence and examples were provided where families with neurodivergent children experience unwanted attention in public settings and children being excluded from accessing particular groups and activities as a result of differences associated with their neurodivergence.

When discussing how to promote positive health and social outcomes for neurodivergent children, there was a strong emphasis on the significance of enhancing knowledge and awareness about neurodivergence while working towards reducing the negative connotations and stereotypes attached to it. Neurodivergent children may face social exclusion which may negatively affect their emotional well-being. The importance of educating other children and peers about neurodivergence to promote acceptance and understanding of individuals with different needs was emphasised within the current findings. Overall, the findings expressed a desire for neurodivergent children to be accepted without judgment or prejudice, irrespective of any differences or distinct characteristics they may exhibit.

These findings align with previous research, showing that neurodivergent children experience stigma, which negatively impacts their well-being. Reducing the stigma surrounding neurodivergence may potentially lead to improved outcomes for these children. Regarding the school context, research shows that over 25% of disabled children in New Zealand do not feel accepted for who they are, almost a third do not feel a sense of belonging in the school environment, and a third of caregivers report that their disabled child lacks friendships at school. Disabled children who attend lower decile schools report better outcomes and increased feelings of belonging compared to those who attend higher decile schools (Education Review Office, 2022). This corroborates the perspective in the current study that wealthier school communities appear less diverse and less accepting of difference.

Turnock and colleagues (2022) completed a synthesised review of the literature relating to the stigma associated with autism, summarising their findings in a model of autism stigma. They highlighted that autistic people often encounter stigma, which includes being subjected to ignorance, prejudice, and discrimination. The authors presented a range of variables that play a role in perpetuating the stigma surrounding autism, including the way the general public and professionals perceive autistic traits and how individuals with autism express those traits. The level of understanding people have about autism has a significant impact on the development of stigma. Additionally, the way autistic individuals demonstrate their unique characteristics, such as unusual patterns of eye contact or reduced facial expression, also contributes to the stigma, as society tends to detect and label these differences based on cultural norms. It is at the junction of understanding and observing autism that other elements of stigma arise. Several factors may influence the strength or direction of the relationship between the variables and stigma, including the quality and quantity of contact between individuals, the act of disclosing one's diagnosis, cultural influences, as well as sex and gender differences.

Turnock and colleagues (2022) also highlight the harmful effects of stigma on the well-being of autistic individuals, such as their mental and physical health as well as their social connections. Furthermore, as a result of stigma, autistic individuals may feel the need to hide or suppress their autistic traits, further contributing to negative impacts on their mental health and sense of self. Parents of autistic children may also face affiliate stigma, such as being asked not to bring their child to certain gatherings or feeling embarrassed in public when their child's behaviour does not meet societal expectations (Farrugia, 2009; Ryan, 2010). These experiences can negatively impact the caregivers' overall well-being. Various interventions and approaches to reduce stigma are suggested, including creating ‘autism-friendly’ spaces, promoting positive media representation, providing education and training to the public and professionals, and promoting inclusivity and acceptance of different neurological abilities. Through the reduction of stigma, there is potential for significant improvement in the lives of autistic people (Turnock et al., 2022).

The proposed service delivery model within the current project aims to reduce stigma through the integration of allied health clinicians visiting schools. This approach not only includes providing opportunities for training and education around diversity and acceptance to school staff and students but also extends to offering support and recommendations to education staff around creating more inclusive and suitable learning environments for neurodivergent children.

Support for the Family Network around the Child. Participants in the current study pointed out that the impact on the family system is frequently overlooked when accessing support regarding their neurodivergent child. The significance of providing support to the extended family network surrounding a child was highlighted as an element that may enhance the overall well-being of neurodivergent children. Previous research also highlights that caregivers may face multiple challenges when raising a child with long-term health or developmental difficulties, such as financial strain, insufficient social support, concerns about the future, and limited knowledge about accessing funding and relevant services (Daniels et al., 2017; Parsons et al., 2020; Vaz et al., 2021). These challenges can adversely impact the overall well-being and functioning of the neurodivergent child as well as their family (Hayes & Watson, 2013; Hsiao, 2018; Scherer et al., 2019; Valicenti-McDermott et al., 2015). The current study emphasised the importance of caregivers being able to connect with other families going through similar situations, for example by participating in group sessions or intensive therapy programmes. Previous research, particularly the Navigation Summit, has also underscored the significance of peer-to-peer connections for families and caregivers. The Navigation Summit research highlighted that families possess invaluable knowledge and unique perspectives, thereby making their support for one another particularly meaningful (Gardiner et al., 2022). In Parsons and colleagues' (2020) cross-sectional survey completed with 278 families living in Western Australia who have a child or adolescent with ASD, results showed that meaningful connections and social support from others are considered crucial for caregivers, as they play a significant role in mitigating mental health issues, alleviating psychological stress, and enhancing caregivers' belief in their own abilities.

In line with the findings of the current project, Pozniak and colleagues’ (2023) qualitative descriptive research highlighted that caregivers often feel forced into playing multiple roles, described as acting like a CEO, of their child’s care. These roles include coordinating care, advocating for their needs, implementing medical and therapy programmes, and researching relevant services and their child's condition. Insufficient funding and support contribute to caregivers feeling obligated to provide this support, often making significant sacrifices such as having to leave their jobs. Caregivers assume these responsibilities because they believe they are the ones most dedicated to their child's well-being and often lack confidence in the follow-through of service providers to effectively fulfil their obligations. Caregivers expressed that they wanted service providers to adopt a holistic approach and take into account the entire family context, including other family members such as siblings or grandparents. They also pointed out the need for support for caregivers’ own health issues, including mental health. Caregivers highlighted the high levels of stress they often experience and did not always feel that their own needs were recognised or acknowledged by service providers. They appreciated situations where service providers acknowledged and validated their emotions and concerns, such as recognising when the family was experiencing a tough time.

Findings in the current study did not specifically mention the significance of providing support to Māori families, but instead discussed the need for support for the broader family network of the child in general. Previous literature emphasises the cultural importance of providing services that are more responsive to the needs of the wider family network around the child for Māori and Pasifika families (Reweti, 2023). Recent research has emphasised the positive outcomes associated with whānau-centred initiatives that encompass the broader family and community as a foundation for health promotion. An extensive literature review that explored 110 publications from various literature including reports, journal publications, and books, highlighted that effective delivery of whānau-centred initiatives enables self-determination and empowerment of Māori and Pasifika families, leading to better health and well-being outcomes (Savage et al., 2020). This further reinforces the significance of adopting a more holistic approach to care that takes the wider family unit into account.

Although participants in the current study did not explicitly state experiences of financial hardship associated with having a neurodivergent child, these challenges were indirectly hinted towards as participants noted that caregivers often have to make sacrifices that affect their finances. For example, some caregivers are unable to work because they need to be available for their child, particularly when the child is not receiving sufficient support at school. Additionally, families may have to self-fund equipment or therapy if they are unable to access these services through public funding. The likelihood of families of neurodivergent children experiencing financial hardship is also prevalent in other research which shows that caregivers of neurodivergent children are twice as likely to face financial difficulties compared to caregivers of children who are typically developing (Trentacosta et al., 2018). Studies indicate that the severity of a child's disability plays a significant role in the financial struggles experienced by families, as it hinders their ability to work and incurs additional expenses for therapy, adaptive equipment, and assistive technology (Mohd Nordin et al., 2019; Nuri et al., 2019). These financial challenges contribute to increased stress among caregivers, negatively impacting their overall quality of life and mental well-being (Vaz et al., 2021).

Collectively, the findings of the current project and literature suggest that there are significant gaps in meeting caregivers’ support and well-being needs. While supporting the child's family network was mentioned in participant interviews as a way of contributing towards improved health and social outcomes for neurodivergent children, it was not a main theme in the focus groups. As a result, the proposed service delivery model does not place a significant emphasis on extensively addressing this area for improvement. However, it does propose various approaches that may support avenues towards addressing this issue, such as bridging siloed services and integrating CDC with the education setting.

Increased Support in Schools. The importance of enhancing the support provided in schools for neurodivergent children was emphasised as it was perceived to contribute towards positive effects on the overall well-being of these children. The impact of engagement in the school setting for disabled learners on their well-being is also highlighted in other research which shows that disabled learners who are enabled to access the entire school curriculum, including physical and outdoor education, are more likely to experience improved well-being and social outcomes, as well as achieve greater success in their learning (Education Review Office, 2022).

Within the current project, various strategies were discussed to increase the support available in schools, such as establishing smaller class sizes and increasing teacher aide resources. The expectation for neurodivergent children to conform to the education curriculum was not always thought to be practical or beneficial for their learning. Providing more support in schools, such as additional staff or resources, may allow for more flexibility in fostering a child’s strengths rather than requiring them to conform to a curriculum. Having additional staff may also help support children who require a break from the classroom due to sensory overload or other needs.

Additional research supports the current findings emphasising the significance of providing sufficient support in the education setting for neurodivergent children including the provision of teacher aide support and smaller class sizes. Jones and colleagues (2020) conducted an explorative study in the United Kingdom which involved the completion of an online questionnaire with 57 parents and 70 teachers regarding the various sensory experiences encountered by autistic students in school and the subsequent impact on their learning and overall school life. One finding of this study revealed that both parents and teachers highlighted the significance of small class sizes, a high staff-to-student ratio, and the provision of one-on-one support in facilitating the fulfilment of autistic students' potential within the school environment. Additional evidence is provided by a literature review carried out by Roberts and Simpson (2016) that aimed to investigate the viewpoints of stakeholders concerning the factors that enable or hinder the success of autistic students in mainstream schools. This review emphasised that the main factor contributing to school failure for these students was the absence of essential support systems at the individual, classroom, and school-wide levels. Support that was identified as essential at a school level included reducing class sizes, allocating more teacher time, and providing additional support personnel such as teacher aides and expert consultants or mentors. The review proposed that the implementation of these support systems has the potential to positively benefit a wide range of diverse learners within the school community, beyond just autistic children.

The New Zealand MOE compiled an ‘implementing an inclusive curriculum’ resource as a part of the ‘inclusive practice and the school curriculum’ professional development for education professionals. This resource acknowledges that the official policy for teaching and learning in English-medium schools in New Zealand is the New Zealand curriculum. It aligns with the expectations of the New Zealand curriculum for early childhood education (Te Whāriki) and the New Zealand Qualifications Framework, aiming to help young people become confident, connected, and engaged learners throughout their lives. The New Zealand curriculum is reported to be designed to cater to the needs of every student without any form of discrimination. It emphasises the importance of acknowledging and respecting the unique identities, languages, cultures, abilities, and talents of all students. In any given classroom, there will be a diverse range of learners, each operating at varying levels of achievement in relation to their respective year levels. Consequently, the classroom curriculum needs to be flexible and adaptable to effectively address the individual learning needs of all students, regardless of their abilities (Ministry of Education, 2015). Despite stipulations that the New Zealand curriculum is flexible and can be tailored to suit the diverse needs of students and their communities, the results of this study suggest that neurodivergent children are not receiving the necessary adjustments to the curriculum that address their specific learning priorities and needs, and instead are expected to conform to the expectations of a non-adjusted curriculum.

An ERO review looking into the education for disabled learners highlighted similar results showing that one-third of disabled learners feel unsupported to learn in a way that is responsive to their learning needs and a similar proportion of their whānau are dissatisfied with the quality of education their child receives. It is suggested that teacher confidence may be one contributing factor including teachers lacking confidence in adapting the curriculum and teaching disabled learners. Over half of teachers are reported to lack confidence in their ability to effectively teach disabled students, particularly those with complex needs that necessitate significant adaptations. The existing guidelines and resources for supporting these learners are often not well-aligned or easily accessible, resulting in teachers rarely utilising them. The ERO report highlights that quality education for disabled learners requires making adjustments to the curriculum, teaching methods, and the physical environment (Education Review Office, 2022). Additionally, successful inclusive education requires a strong partnership and active involvement with whānau in the planning of their child's learning (Education Review Office, 2022; Ministry of Education, 2015).

Taking into account the potential for flexibility in the curriculum, the findings in the current project are in favour of strategies being put in place that enable education professionals to build their confidence in adapting the curriculum and working with disabled students. Additionally, there is a need for these strategies to foster a more collaborative relationship between educators and families. The current project's findings also prompt further contemplation regarding the objectives of the education curriculum and whether those objectives should differ for disabled learners compared to non-disabled children. One aspect to consider is whether it is necessary for education to prioritise learning opportunities that may have little relevance to their lives, or whether it would be more advantageous to adopt an approach that promotes joyful engagement. For example, some caregivers in the current project emphasised that their primary concern was their child's happiness and involvement in tasks and activities that bring them joy, rather than focusing on academically oriented skills that may not provide long-term benefits to the child.

The three main factors identified in the current project that may contribute towards improved health and social outcomes for neurodivergent children relate primarily to three indicators of well-being as documented in the Children and Young People: Indicators of Wellbeing in New Zealand report (Ministry of Social Development, 2008). Increasing understanding and reducing the stigma associated with neurodivergence relates to the 'safety' indicator, providing increased support for the wider network around the child relates to the 'economic security' indicator, and providing increased support in schools is relative to the 'education' indicator of well-being. Considering that the factors identified in the present project are connected to indicators of well-being in New Zealand, this substantiates the significance of these factors in improving overall well-being.

While the primary objective of the current project was not focused on altering the education sector, it has highlighted potential methods through which CDC may become involved in supporting these children in their education environment. Within the proposed service delivery model, CDC would play an active role in aiding the provision of tiered support in schools, leading to greater availability of support, such as therapeutic support, within the education environment. Integrating CDC clinicians into schools would enhance opportunities to develop relationships and establish connections as well as strengthen the skills and knowledge of education staff and families. The presence of CDC clinicians in schools would enable them to offer immediate assistance and guidance to teaching staff, while also gaining a deeper understanding of how disabilities are impacted by a child's learning environment, ensuring that their recommendations align with the specific needs of the educational context.

8.3.3 Improving the Provision of Child Development Services

Within the current study, ideas for improving the provision of CDC included bridging silos, provision of a community-focused CDC integrated with schools, increased provision of therapeutic support, and access to support across ages and stages.

Bridge Silos. Participants in the current study emphasised the importance of establishing structured practices that promote collaboration between various sectors and services, highlighting the importance of bridging silos. Prioritising this bridging process was seen as essential to bring about necessary changes.

The importance of bridging silos within the healthcare sector, including CDS, child health (paediatrics), and child mental health services (CAMHS) was emphasised. A centralised triage process was suggested as one strategy for collaborative working and responding to the needs of the child. Due to the complexities and overlapping neurodevelopmental and mental health traits that children may present with, it may be difficult to differentiate their symptoms to determine the most appropriate pathway of support for a child. From the perspective of someone making a referral, having multiple pathways for referrals can be confusing, especially when a child presents with multiple complexities, or it is unclear which service is best suited to address a child's needs. Implementing a central triage process may help to mitigate children being passed back and forth between services, minimise unnecessary delays in receiving care, and alleviate the burden on referrers in determining the most appropriate referral pathway.

The concept of establishing a centralised triage system for children's health services is being put into action through various approaches that involve a single point of access process. These initiatives aim to address problems associated with inadequate communication and coordination among different services, which often result in duplicated work and uncertainty regarding who is responsible for meeting a child’s needs. Different countries are implementing referral processes that have a centralised point of access, showing that the demand for more efficient referral processes is widespread and not unique to New Zealand (Brighter Futures for Children, n.d.; DPV Health and Northern Health, 2023, March 26; NHS, n.d.; NHS Sussex Partnership, 2022, June 01; Support Staffordshire, 2023, April 24).

Within New Zealand, the Child Health Integrated Response Pathway (CHIRP) is a single point-of-entry referral and triage system being trialled in Te Whatu Ora Bay of Plenty. It aims to streamline access to healthcare services for children aged 0-13 years old with developmental, behavioural, and mental health concerns. The model brings together different teams, such as CDS, CAMHS, and child health (paediatric) services, to provide coordinated and efficient care. Previously, children with these needs had to navigate multiple services and be placed on several waiting lists. CHIRP aims to prioritise the needs of children and provide them with the most appropriate care, reducing waiting times and improving access to services. Some children may only require support from one team, while others with more complex needs will benefit from collaboration between multiple services (Bay Navigator, 2021, October 29). Within the proposed service delivery model the implementation of a centralised referral system is recommended as an avenue towards bridging silos.

Due to the complexities in the presentation of some children, one step further to a centralised triage system was the idea that all the necessary support for neurodivergent children could be provided from one service. Suggestions were made to bridge the existing gaps between different funding sources, particularly between CDS and MOE, to ensure that the provision of support for neurodivergent children is determined by their overall needs rather than whether they require support at school or home. In line with this notion, an evaluation report on the United Kingdom Health Act 1999 carried out by Glendinning and colleagues (2002) emphasises that the incorporation of pooled budgets to promote collaboration and minimise duplication in commissioning and contracting has been recognised as an advantageous approach to enhance multi-agency collaboration.

Acknowledging the often intertwined symptoms of ADHD and other mental health issues, along with the conventional practice of addressing them through separate pathways, an increasing body of research is exploring the potential benefits and opportunities associated with integrating the services offered by Child Development Teams (CDTs) and CAMHS (Male et al., 2023; Male et al., 2020). To demonstrate the potential suitability of an integrated pathway approach (CDTs integrated with CAMHS) versus a non-integrated approach (CDTs in isolation), some case scenarios are presented within the literature. For a child exhibiting challenging behaviour, difficulties in social interaction and communication, repetitive behaviours, and sensory issues, an assessment through a non-integrated pathway required 20.75 hours of professional time. This publicly funded assessment incurred a cost of £1,357 (equivalent to NZ$2,743 as of December 2023) and involved a waiting period of up to two years from the referral to the completion of a diagnostic formulation. In comparison, an integrated approach for a child presenting with similar symptomology took 13 hours of professional time, costing £817 (NZ$1,651 as of December 2023), and had a waiting time of around 26 weeks (Male et al., 2020). The emerging literature suggests that implementing an integrated neurodevelopmental service approach that can assess and treat children with ASD, ADHD, and related conditions may improve efficiency. This includes reducing frequent duplication of assessment processes, preventing referrals going back and forth between different services, reducing costs, decreasing wait times, optimising staffing resources, and enhancing the overall experience for the child and their family (Male et al., 2023; Male et al., 2020).

A similar suggestion has been presented in Canadian research which aimed to understand the impact of Ministerial cultures, processes, and structures on collaboration among different Ministries to improve care for disabled children and their families. Wiart and colleagues (2010) conducted interviews with key informants from the Ministries primarily responsible for funding rehabilitation services for children, including Health, Education, and Social Services, and analysed provincial policy documents. They found that collaborative programmes between the health and education sectors can help address the gaps in service delivery for disabled children. Having a system where the same service providers can assist a child in various environments is thought to be beneficial. Currently, limitations in the continuity of care arise when service integration is restricted by boundaries within a single Ministry. However, establishing structured frameworks for service integration across multiple Ministries may enable children and families to have easier access to holistic care across settings including their homes and schools. In their discussion paper, Kodner and Spreeuwenberg (2002) indicate that cross-sector service provision can facilitate less duplication, more flexible service provision, and better coordination and continuity.

In line with the findings presented in the current research, prior research has noted the need for and importance of agencies working together around the needs of the child and that children and youth should be provided with integrated and coordinated care that addresses their specific needs as well as the needs of their family (Department for Education and Skills, 2003; Department of Health, 2003). Children and their families have diverse needs that cannot be easily met in isolation within separate agencies (Greco & Sloper, 2004). Multiple studies have emphasised the importance of collaboration between health, education, and social services. These studies have focused on various groups, such as children in care, children excluded from school, child protection, child mental health, and services for disabled or chronically ill children. The studies have documented the challenges faced by families in dealing with multiple professionals and agencies, including accessing information regarding the different roles of different services, conflicting advice, and gaps in service provision (Biehal et al., 1995; Hallett & Birchall, 1992; Mental Health Foundation, 1999; Sloper, 1999; Watson et al., 2002; Webb & Vulliamy, 2001).

Similar to the suggestions presented in the current project, attendees at the Navigation Summit emphasised the need for a simplified system of services and support for children with neurodisabilities such as through the provision of a centralised resource like a ‘one-stop shop’. It was also suggested that access to support should not be limited to specific diagnoses. The importance of enhancing communication between professionals and fostering collaboration and transparency among various government Ministries and agencies to improve the navigation of neurodisability-related services was highlighted. These recommendations aim to alleviate the burden on families by reducing the necessity for them to coordinate fragmented services (Gardiner et al., 2022).

The findings in the current project suggested it would be beneficial to have more opportunity for either direct integration between education and health for disability supports or at least more flexibility with structured overlap between CDC and MOE. Similar recommendations have been presented in previous literature such as the findings from

Shannon and colleagues’ (2021) research on leaders' perspectives regarding rehabilitation services for children in schools. Their research advocates for inter-ministerial directives and suggest these directives should include standards specifying the services to be provided by children's treatment centres and district school boards, along with guiding principles to aid decision-making. Findings in the current project highlight that the present system of separate services and waitlists makes it challenging for children and families to navigate and find the appropriate support. It would be beneficial if families were able to get the answers they were seeking by accessing one single service rather than being passed between different services. This may reduce the chances of children not receiving the support they need, ensure a more seamless journey for children and their families, and minimise the possibilities of miscommunication and the need for repetition of information.

One suggestion for overcoming the division between CDC and education was to improve avenues for sharing information which could be achieved through shared data platforms. By making information readily available in this manner, it may be easier to provide continuity of support for neurodivergent children and minimise the chances of relevant information not being passed on. The concept of shared data platforms is consistent with research showing that effective communication and information sharing through data systems is advantageous for collaborative work among multiple agencies and helps patients and their families share information with their healthcare teams and other providers (Sloper, 2004; Turchi et al., 2014). This is likely to improve the efficient sharing of information and communication between healthcare teams and community partners, including education. Sharing IT platforms allows professionals to access the data they need to provide prompt advice and support to children, young people, and their families and encourages collaboration among professionals to coordinate support and plan for future transitions (Allard et al., 2019; Turchi et al., 2014).

The information presented in the literature underscores a longstanding suggestion regarding the importance of collaborative service provision across different sectors to more effectively meet the needs of service users. However, both the findings from the current project and existing literature indicate an ongoing need for the adoption of strategies aimed at bridging gaps between different sectors and facilitating a collaborative approach involving multiple agencies in working with neurodivergent children and their families. The proposed service delivery model offers a variety of suggestions to overcome the division between different sectors and services, including implementing a shared IT platform, creating opportunities for service providers to build relationships with one another, designating a specific contact person at CDC for referrers to communicate with, and developing a centralised system for managing referrals. Additionally, the model proposes having a single therapist to address a child's needs across all environments, rather than having separate therapists for their home and school settings.

Provision of a Community-focused CDC Integrated with Schools. Alongside the other mentioned suggestions for bridging silos, participants suggested an additional avenue for linking segregated services by creating more opportunities for connection between CDC and schools. This could be achieved by CDC providing a community-focused service integrated with schools through the provision of outreach support. It was perceived to be beneficial if CDC was based in the community in a more purposeful space rather than on a hospital campus, ideally in a shared space or close to other related services.

Although research does not explicitly highlight the advantages of placing child development services within the community, it does underscore the negative impact of a hospital environment on neurodivergent children. This implies that it is beneficial to avoid having CDS situated on hospital campuses. As mentioned in previous examples, children with ASD face difficulties in dealing with the hospital environment due to their sensory, communication, and social challenges. This makes it particularly challenging for them to adapt and cope with the hospital setting, potentially leading to increased behavioural reactions and hindering their involvement and cooperation in hospital-related procedures (Johnson & Rodriguez, 2013; Muskat et al., 2015; Straus et al., 2019; Thom et al., 2019).

The notion of providing CDC services from a purposeful and accessible space is not a new recommendation. The CDS service specifications state that the provider of CDS will offer services in a location that is convenient for the child and their family. Efforts should be made to minimise the need for families to travel long distances to access services, and services may be provided at a central facility or in the family home, a marae, a pre-school or school setting, or another community-based location. The CDS provider must ensure that any facilities used for service delivery are fully accessible. The specific location should be determined through negotiation with the family and other support services to ensure that no one is disadvantaged in accessing services (Ministry of Health, 2012). Despite shortcomings in the current delivery of the service specifications, in general, the specifications of CDS support the idea of providing a community-oriented service that offers accessible facilities. Research has shown that inaccessible environments can prevent people from accessing healthcare. Conversely, creating accessible environments can facilitate individuals in accessing healthcare services. This ultimately leads to improved health outcomes, as people can access care without facing obstacles (Lagu et al., 2014; World Health Organization, 2023, March 07). The proposed service delivery model aims to address accessibility issues by situating CDC within a community setting in a fit-for-purpose building that is child-friendly and accessible for disabled people.

The suggestion of having CDC based in a community setting either close to or alongside other related services is also presented in other research as a facilitator towards multi-agency collaboration. In a review of the literature on multi-agency working, Sloper

(2004) points out that when relevant agencies are located close to each other, such as sharing offices or being situated in the same building, it is easier for staff members to communicate with each other and exchange information. This physical proximity creates a conducive environment for effective collaboration and enhances the overall productivity of the organisations involved in the child’s care. The use of schools as community hubs was suggested in the research by Shannon and colleagues (2021). In their research, participants discussed the idea of schools functioning as service hubs, envisioning the provision of health services for children within the school premises during the school day. This integration of health and education services was perceived as an approach that would offer multiple benefits for families. A prevalent premise in envisioning schools as community hubs involved the design of services based on the child’s life and surroundings.

The project’s findings suggested that locating CDC in the community and collaborating with schools had several advantages that may reduce barriers to accessing CDC and may facilitate better results when working with children. These included schools being easily accessible for children and families, being able to observe children in their natural environments, triangulation of information, building relationships with school staff, gaining a better understanding of the impact of disability in the learning environment, minimising the power dynamics that may occur with on-site assessments at CDC, and reducing the chances of children not participating in assessments due to being in an unfamiliar setting. Having CDC clinicians in schools would enable them to offer immediate help and advice to teachers regarding supporting neurodivergent students. They could also differentiate between those children who would benefit from universal recommendations versus those who require individualised assessments and intervention. This may also improve the appropriateness of referrals to CDC. The convenience of conducting assessments at CDC may be preferred by clinicians and funders, but it may not be the most client-centred approach for meeting the needs of service users. The findings also highlighted that it is considered best practice to observe children in their natural environments.

Participants did not discuss the positioning of CDC in the community and offering support in schools from a cultural perspective. However, the Māori engagement report on New Zealand's First Child and Youth Wellbeing Strategy, presented by the Department of the Prime Minister and Cabinet (2019b), emphasises the benefits of using schools and marae as community hubs to enhance the well-being of Māori children and their families. Designating schools and marae as community centres is seen as a practical and accessible approach to facilitating the engagement of Māori in healthcare initiatives. This reinforces the idea of implementing CDC with a community-focused approach, facilitating a more culturally responsive process.

When participants had the opportunity to consider the interview data alongside the literature during the focus group, participants expressed a favourable response to the P4C model, which involves OTs providing support in schools (CanChild, 2015). The P4C model was perceived as a positive proactive response for providing support rather than reactive. It was thought that implementing a similar approach in the New Zealand context would help assist the referral and triage processes, ensuring that CDC is receiving referrals relevant to the services they provide and appropriately prioritising children.

As discussed in the literature review, P4C is an evidence-informed, population-based service delivery model, developed to provide rehabilitation services for children with special needs in school environments. The P4C model offers numerous key benefits that could also be highly advantageous in addressing many of the issues highlighted within the current project. One of these benefits is the significant reduction in both time and costs associated with the involvement of individuals in the referral process. The implementation of P4C has seen a decrease in the number of steps required in the process, resulting in more streamlined and efficient procedures. This not only saves valuable time but also eliminates unnecessary costs. Moreover, P4C ensures that each step in the referral process adds value for the family, ultimately enhancing their overall experience and satisfaction. P4C has proven to be effective in streamlining administrative processes, leading to improved system efficiencies and reduced paperwork. Additionally, this innovative approach can reach a significant number of children, enabling early identification of those with special needs and facilitation of equal access to services. The prompt identification of these children allows for immediate intervention and support, which has contributed towards the elimination of wait lists for services. Furthermore, one of the notable advantages of the P4C model is its shift from a reactive system, where children are referred for rehabilitation services after an issue arises, to a proactive approach that prioritises prevention. The P4C model facilitates a collaborative partnership among educators, therapists, caregivers, and children, with a strong emphasis on relationship building and enhancing the skills and knowledge of all involved. P4C is designed to empower educators and caregivers by equipping them with evidence-based information and strategies provided by therapists. This information helps educators effectively support students in the education setting, while also enabling caregivers to provide optimal support for their children at home (CanChild, 2015).

Although not formally documented, the policy group of participants referred to a successful project where the Ministry of Health and MOE worked together to collaborate in schools. The project allowed facilitators to work with teachers, observe and screen children on the CDS waitlist, and reach out to families who were difficult to access. The existing relationship between school staff and families was used to support families’ engagement with CDS. Given the beneficial outcomes evident within the P4C model, it is encouraging to hear about initiatives underpinned by a similar approach to P4C being trialled in New Zealand.

The findings within the current project may provide additional evidence to support the continued adoption of similar programmes in New Zealand.

Increased Provision of Therapeutic Support. Findings in the current project emphasised the need for increased provision of therapeutic support and highlighted the current lack of access to such support. This deficit has also been highlighted by CDS which acknowledges that although providing therapeutic input is stipulated in the CDS service specifications (Ministry of Health, 2012), the current availability of allied health support for children is not enough to meet the increasing demand. This has contributed to service rationing and prioritisation of diagnostic assessments over therapeutic input (Claridge, 2023).

This issue extends beyond New Zealand as research conducted in the United Kingdom has also indicated a similar outcome. Beresford and colleagues (2018) carried out qualitative interviews with parents of children with neurodisabilities, aiming to gain insight into their perspectives on the effects of therapy interventions on their children's lives. The findings revealed that parents hold a strong belief in the essentiality and significance of therapy interventions. However, the primary issue that parents consistently emphasised is the insufficiency of therapy services, which frequently prompts them to pursue alternative options such as seeking private providers or implementing self-researched techniques that are often lacking in empirical support.

The benefits of therapeutic support for neurodivergent children are widespread. The primary objectives for therapeutic input are to assist children in acquiring developmentally appropriate functional abilities, prevent any negative consequences, reduce the impact of impairments on the child's activities and participation, offer adaptive strategies to lessen functional deficits, and ensure that these skills are transferred to various environments through family training, support, and community integration strategies (Palisano et al., 2012).

The opportunity to engage in allied health therapeutic support with a focus on enhancing participation has been shown to result in inadvertent positive outcomes such as improved quality of life, physical and emotional well-being, confidence and self-esteem, and resilience and self-management (Beresford et al., 2018).

When it comes to the provision of therapeutic support, participants advocated for a single therapist to provide support to the child in all settings, rather than having multiple therapists working separately in different settings. There is frequently a perceived insufficiency of resources and staffing, leading individuals to question the necessity of having separate therapists for home and education support. If resources were reallocated to enable one therapist to work with the child in all settings, it is likely to alleviate some of the strain on available resources and create enhanced continuity of care.

While there is limited evidence regarding the benefits and practicalities of shifting from a system previously fragmented by separate Ministry contracts and funding to a more cohesive approach, where a single therapist operates across multiple settings relevant to the child, recommendations exist for creating organised agreements for joint commissioning. This is aimed at enabling a comprehensive therapeutic approach across different settings. One example is provided by the United Kingdom's Department for Education and Department of Health (2015) special educational needs and disability code of practice, which outlines a legal framework for working together across education and health for joint outcomes.

Previous research highlights the significance of integrating therapy interventions into everyday life, thereby supporting the concept of clinicians working in collaboration with schools to provide therapeutic support. To maximise the effectiveness of therapeutic interventions that promote participation and goal-oriented approaches, allied health therapists have emphasised the importance of extending therapeutic support beyond the confines of the clinic space and the importance of providing therapy in environments where the child typically spends their time (Beresford et al., 2018).

Access to Support across Ages and Stages. The findings in the current project emphasised the importance of providing support to neurodivergent children at different ages and stages of development. Children go through different transitions and it would be beneficial if there was more support available for them as they navigate these. The suggestion was made to have a designated key person who provides comprehensive support to the child and their family, including coordinating access to necessary resources.

The need for and recommendation of a key worker or navigator-type role for families with children who have special care needs has also been highlighted in previous research. Parents of children with developmental disabilities frequently struggle to find and access appropriate healthcare services for their child. Additionally, children with an array of health or developmental issues tend to be under the care of multiple services (Halfon et al., 1993; Law et al., 2003). As mentioned in the literature review, the key worker model is a way to support families by assigning a person to guide them and be a central point of contact. This person helps families coordinate their care across different systems and aims to provide personalised support and information (Bruder et al., 2005; Drennan et al., 2005; Gardiner & Miller, 2023; Reid et al., 2020). The effectiveness of key worker models continues to be explored (Drennan et al., 2005), however, research that highlights the favourable outcomes of key worker models suggests that having key worker support and care coordination can have positive effects on children and families. These effects include receiving family-centred care, forming partnerships with professionals, being satisfied with services, easily accessing referrals, reducing expenses and financial burden, spending less time coordinating care, experiencing less impact on parental employment, and having fewer school absences and emergency department visits. Families with key worker support report a better quality of life, improved relationships with services, easier access to necessary services, and reduced levels of stress compared to families without key workers (Liabo et al., 2001; Turchi et al., 2014).

As recognised in the present research, prior research has also emphasised that monitoring, following, and addressing needs and changes over time and assisting with transitions between different entities and time periods for children with special healthcare needs are crucial (Turchi et al., 2014). One major transition for children is the transition from pre-school services into formal schooling. This transition can be challenging for all children, but those with a neurodevelopmental disorder are at a greater risk of facing disadvantages due to a lack of sufficient support. Furthermore, their unique developmental needs or preparedness for school may not be fully acknowledged or understood (Jiang et al., 2021; McIntyre et al., 2010; Rous et al., 2007). Educational disadvantages at the time of transition to school predispose a child to ongoing disadvantages throughout their schooling journey, therefore, it becomes imperative to create an inclusive and supportive transition environment for children with disabilities to ensure these children have a strong foundation from which they can fully engage in and succeed in their future education (Then & Pohlmann-Rother, 2022).

Another important milestone in the transition process occurs when individuals move from paediatric health services and the education system to adult healthcare services and other systems relevant to their functional abilities. This includes access to opportunities for additional education, vocational training, and independent living arrangements. The findings in the current study suggest that young people are not receiving adequate support from either the education or health sectors to effectively navigate through this significant transition period. Previous research has also highlighted the issue of inadequate continuity of care experienced by young people with neurodevelopmental disorders as they transition from paediatric to adult healthcare services (Campbell et al., 2016; Shanahan et al., 2021). Various recurring barriers have been identified in the literature that hinder a smooth transition from paediatric to adult healthcare services. These include ineffective communication between paediatric and adult care providers, scarcity of resources, insufficient understanding of transition practices among adult care practitioners, inadequate planning for the transition process, and the apprehension young adults may feel towards unfamiliar healthcare systems (Campbell et al., 2016). The challenges faced during the transition period are exacerbated by shortcomings in healthcare, social services, and disability systems, as well as a lack of collaboration among these services. This ultimately leads to young individuals and their caregivers feeling disconnected from the support systems that are meant to assist them (Thanalingam et al., 2022). The negative consequences of a poorly supported transition experience may have a detrimental impact on a young person's overall health, social interactions, and education outcomes. A lack of adequate planning, consistency, and accessibility of adult services may lead to a range of problems. These include heightened levels of anxiety, lack of holistic care, lack of awareness of relevant services, an elevated risk of preventable complications, unnecessary dependence on emergency health services, increased hospitalisations, poorer long-term clinical outcomes, disrupted psychological well-being, and reduced quality of life (Clarke et al., 2011; Shanahan et al., 2021; Shogren & Plotner, 2012; Singh & Tuomainen, 2015; Sonneveld et al., 2013). Consistent with previous literature, the current project also emphasises the need for improving support and processes for young individuals transitioning from paediatric to adult healthcare services.

Within the current project, the concept of implementing a key worker model was thought to be advantageous, however, participants commented that this role was likely to be more suited to an organisation such as EGL, rather than within the role of CDC. A client's personal EGL budget can include funding from the Ministries of Health, Social Development, and Education (Enabling Good Lives, n.d.). Having the ability to access funding from various Ministries could be beneficial when considering the implementation of a key worker role. It may help bridge some of the gaps that exist between segregated funding approaches that are solely focused on specific aspects of CDS or education. Additionally, this approach may facilitate a more holistic and well-rounded approach to supporting young people in navigating through different transition stages of their development. Within the data generated in the current study, questions remain about the potential implementation of a key worker model such as whether it is something that is required for all neurodivergent children seen at CDC and for how long the child or young person may require the support. However, when envisioning the introduction of a key worker framework, it prompts contemplation on its continued relevance if substantial improvements are achieved in both CDS and education systems, fostering clearer and more accessible support pathways for families.

Within the context of CDS, some initiatives targeted towards providing support across ages and stages have been implemented, however, they continue to present with shortcomings in the adequacy of the support. In 2011, the New Zealand government provided extra funding to DHBs to employ ASD coordinators in light of the release of the New Zealand Autism Spectrum Disorder Guidelines (Ministries of Health and Education, 2016b; Thabrew & Eggleston, 2018). The main goal of the coordinator role is to ensure efficient coordination of ASD assessments and support services after diagnosis (Thabrew & Eggleston, 2018). While the ASD coordinator position has brought about certain advantages, a study exploring the viewpoints of caregivers in New Zealand regarding their experiences of and satisfaction regarding the ASD diagnosis and support procedure revealed that only 27.2% of parents were satisfied with the assistance they received following their child's diagnosis. This underscores the pressing need to enhance and broaden these services in New Zealand, as emphasised by Eggleston and colleagues (2019). Additionally, there is a need to extend support to children with various neurodevelopmental disorders, beyond the scope of just autistic children.

8.4 Implications

This project is the first to provide comprehensive data on the perspectives of stakeholders from both the health and education sectors in New Zealand concerning the accessibility and quality of care and support provided for neurodivergent children. The project also provides a novel understanding of stakeholder perspectives regarding ways to enhance the delivery of services tailored to the specific needs of these children within the New Zealand context. This includes data highlighting perceived factors that may contribute towards improved health and social outcomes for neurodivergent children and barriers to making change and adopting multi-agency collaboration.

Health services research has increasingly acknowledged the importance of considering the perspectives and experiences of various stakeholders. Recognising these perspectives is seen as an essential component in enhancing the delivery of healthcare services, as it ensures the outcomes align with the needs of individuals and can be effectively implemented in real-world settings (Eyles et al., 2016; Maher et al., 2017; McKercher, 2020). Therefore, the exploration of stakeholder perspectives within the current project contributes essential knowledge towards informing research-based practices which can be used in conjunction with other relevant evidence to improve the delivery of CDS.

Furthermore, the exploration and presentation of different stakeholder perspectives within the current project may contribute towards an increased level of understanding between different stakeholder groups. For example, if frontline education professionals are able to access the current perspectives of CDC clinicians, and vice versa, this may support their understanding of the challenges and pressures faced within the different sectors of the system or increase their knowledge in regard to accessing certain pathways or support for children. The current findings highlight the issue of working in silos and a lack of communication, indicating there may be a lack of awareness of the perspectives and experiences of other stakeholder groups. Sharing the perspectives of the different stakeholder groups may assist in understanding situations from others' beliefs and experiences, increase understanding and empathy, improve communication, and reduce misunderstandings and distortions of information. In my combined capacity as a researcher and clinician, the process of collecting qualitative data provided a unique opportunity to listen to the diverse narratives shared by various stakeholder groups from the distinct vantage points of both a researcher and clinician. Although the primary focus was the research interpretation of the data, this process also yielded valuable clinical insights by increasing my understanding and empathy towards the experiences of different stakeholders in accessing disability-related services and systems. As a result, this enhanced my ability to connect and relate to other stakeholders, particularly service users, within the context of clinical practice. Overall, the opportunity for exposure to various perspectives had a positive impact on my clinical practice, therefore it is hoped that other stakeholders will benefit from access to a variety of perspectives from different stakeholder groups.

The current project is timely as New Zealand implements the initial phases of a comprehensive reform of the healthcare system. This has included the disestablishment of DHBs and the introduction of a more streamlined nationwide healthcare system called Te Whatu Ora – Health New Zealand (Department of the Prime Minister and Cabinet, 2022, September 06). Te Whatu Ora seeks to establish an equitable, accessible, cohesive, and people-centred system that facilitates the improved health and well-being of all New Zealanders (Te Whatu Ora Health New Zealand, 2023, September 22).

Linked to the timing of the national healthcare reform and persistent challenges exacerbated by insufficient resourcing and funding, CDS are striving to develop and implement a nationally consistent approach for delivering CDS throughout New Zealand (Claridge, 2023). Although focusing on a regional perspective, the creation of a suggested service delivery model in this project has yielded significant insights. These findings may contribute to the development of best practice policies, ultimately leading to the establishment of efficient and consistent care for neurodivergent children and children experiencing developmental differences throughout the entirety of New Zealand.

The proposed service delivery model aims to create a comprehensive, collaborative, and user-friendly system for families seeking CDS by establishing a more integrated approach between child development and education services. It seeks to bridge the gap between separate services and promote a multi-agency approach. By bringing together different organisations and professionals, the model aims to provide a more holistic and cohesive support system for children and their families. In terms of physical infrastructure, the model suggests that CDC is located in a community setting with a suitable facility. This ensures easy accessibility for families and enables the provision of outreach services in various community settings, such as schools. These outreach services can include diagnostic screening and tiered therapeutic support within the education setting.

Unlike the current system, which compartmentalises funding based on different sectors, this model proposes a needs-based funding system that considers the individual's entire life. This allows children and young people to access appropriate care as they transition through different ages, stages, and needs. The model also incorporates the EGL principles to ensure alignment with the future trajectory of CDS, which aims to more effectively embody the EGL principles in future modifications to service delivery (Claridge, 2023).

The model is a tool that can be used to support policymaking and decision-making for the design of evidence-based initiatives to improve service delivery and provide coordinated care. To put the proposed model into practice and ensure shared ownership and accountability, considerable restructuring that involves MOE and CDS agreement, as well as collaborative policymaking and co-design efforts involving commitment and participation of senior staff, frontline staff, and service users is required. The establishment of policy and procedure to enable joint commissioning is also necessary. If policy alignment is not achieved, barriers are likely to persist. Refining and establishing a more in-depth design process and concrete implementation plan will take time as the process will require transforming mindset, forming partnerships, altering system processes, and establishing a shared language for effective multi-agency communication.

The design and implementation of a service delivery based on the proposed model is likely to lead to quicker assistance for children facing developmental challenges. This approach aims to provide enhanced support, ensuring that children and families can easily access and navigate various supports and services throughout different stages of development, fostering a sense of continuity in care. Through a collaborative approach, frontline education staff may gain increased knowledge, capacity, and confidence in working with neurodivergent children. The stigma around neurodivergence may be reduced by providing education around understanding and acceptance with classroom peers, and child development clinicians will have increased opportunities to observe children in naturalistic settings and learn more about what an individual’s challenges mean for them within the learning context. By removing segregated funding for education and health disability support, and instead implementing a system that integrates disability supports, or allows for increased structured overlap between education and health services, the allocation and utilisation of resources could be more efficient. Having one therapist who works with children across various settings, such as their home and school, rather than having different therapists for each context has the potential to alleviate a number of the challenges currently faced by the system associated with inadequate funding and limited resources.

The findings also provide data that emphasises the need for improved clarification regarding the roles and responsibilities of different health and disability services. Of particular importance is the need for policymakers to clarify which neurodevelopmental disorders fall within the scope of which particular contracts and services, and whether a separation should exist. As discussed in the introduction, ADHD is considered a neurodevelopmental disorder (American Psychiatric Association, 2013) but it is usually diagnosed and treated by psychiatrists in CAMHS (Bradley, 2021, December 06), rather than child development teams or paediatricians. However, due to the common occurrence of comorbidity between neurodevelopmental disorders and difficulty separating overlapping symptoms, the findings in the project highlight the need for more flexibility in supporting children with variable neurodivergent symptomology. Furthermore, the findings indicate that there is a need for CDC to evaluate the suitability of their name, as the existing name may lead to misconceptions and influence assumptions about the services offered. Consequently, CDC should consider whether to align their service delivery with the implications of their name, or to adopt an alternative name that more accurately represents the services they provide.

The MOE Learning Support Action Plan 2019 – 2025 recognises the need to enhance support for disabled children and those with additional learning needs. One of the priorities in the plan is to provide flexible support for neurodivergent children, particularly those with moderate needs who do not qualify for ORS support (Ministry of Education, 2019). The literature review carried out by Mirfin-Veitch and colleagues (2020) as one response to this priority suggests that successful inclusion for neurodivergent students requires collaboration between educators and other service providers. The proposed service delivery model in the current project provides a bridge between CDS and education for children with developmental differences. This approach may serve as a suitable way to contribute towards addressing the highlighted learning priority and recommendations aimed at enhancing support for neurodivergent children and young individuals.

Although not explicitly evidenced in the current findings, they imply that the deficits of a particular system, be it education or CDS, in fulfilling its intended roles and responsibilities may potentially impact other interconnected systems and services. For instance, despite MOE promoting a needs-based approach to learning support (Ministry of Education, 2022, October 13), education professionals face difficulties in accessing such support and have experienced more success accessing support when a child has a formal diagnosis. This may be a contributing factor towards the growing number of referrals and longer waitlists at CDC for diagnostic assessments, as education professionals may be seeking a diagnosis to increase their chances of obtaining support in the learning environment. This emphasises the interconnectedness of different systems and underscores the need for collaborative solutions to address shared issues.

While acknowledging the New Zealand-specific context of the proposed service delivery model, the design and process of formulating this model provide insights that may resonate with international readership. The presence of other international models such as P4C (CanChild, 2015), the keyworker model (Bruder et al., 2005; Drennan et al., 2005), and transdisciplinary and collaborative care approaches (Lyon et al., 2016), highlights the need for strategies that overcome common challenges faced in child development service delivery, such as lengthy waitlists and siloed services. Continuous mutual learning and knowledge exchange are integral across various research domains. Although certain challenges and content discussed in this thesis may be unique to New Zealand, the acknowledgment of globally shared issues underscores the benefits of collaborative exploration and innovation. It is anticipated that this research provides insights that may encourage a re-evaluation or offer a fresh perspective on policies and practices in international contexts.

As mentioned throughout the discussion, this research contributes to the international literature and initiatives by corroborating several key findings and recommendations. The pre-existing literature often reflects the perspectives of a limited number of stakeholder groups and/or only represents the viewpoint of one child-serving sector such as health or education. For example, Pozniak and colleagues (2023) only included parents of children with neurodevelopmental disabilities in their focus groups on healthcare services. Shannon and colleagues (2021) carried out focus groups with participants from both health and education sectors to explore how they envision effective collaboration in school-based rehabilitation services, however limited their inclusion to leadership-level stakeholders including superintendents, directors of children's treatment centres, and members of Special Education Advisory Committees. The current research is unique for its inclusion of the viewpoints of six diverse stakeholder groups across both the education and health sectors. These perspectives involve service users and span various levels of involvement with neurodivergent children, encompassing frontline staff, management, and policy representatives. Unlike many studies with limited stakeholder representation, this research provides a unique understanding by capturing similar patterns of meaning across a broader range of stakeholders, revealing shared perspectives on the same issue among different stakeholder groups.

8.5 Limitations

Although the current project has generated a novel proposed service delivery model for CDC, limitations within the study are present and need to be acknowledged. One limitation of the project is the sampling of participants. With the application of purposive sampling, it is recognised that the likelihood of researcher bias is high because personal judgment is applied to selecting participants to recruit for the study. Regardless of the chances of researcher bias occurring, purposive sampling was the most appropriate technique to underpin a grounded theory methodological approach and ensure data pertinent to the research questions could be generated. Some naturally occurring confinements on who was able to be recruited for the project may have assisted in reducing the impact of researcher bias. In some cases, there was a restricted pool from which to recruit, such as the CDC clinicians and Te Whatu Ora managers groups. As a result, these individuals were purposively recruited for the study as they were the only ones meeting the criteria within their respective groups, and not selected based on subjective researcher judgement. In other cases, the potential impact of researcher bias may have been further mitigated through the availability of a more extensive pool of potential participants who could adequately represent a particular group, such as education professionals and principals. This approach eliminated the need for the researcher to selectively focus on specific individuals and instead facilitated the ability to approach participants based on their respective roles. Within the sampling approach, it is also important to acknowledge that participation in the project may have attracted individuals who were passionate about the topic, which may have resulted in a narrower range of responses during the data collection process.

Limitations occurred regarding the inability to apply a theoretical sampling approach to phase one of the project. The first phase of the project used a grounded theory approach, however, the participant criteria and recruitment processes were more aligned with a co-design approach. This was necessary due to limitations in using theoretical sampling and the anticipation of the requirements for phase two of the project. In the current project, the ability to use theoretical sampling was limited by a capped number of people in specific roles, such as in the disability sector, and the response rate during recruitment efforts. The ability to apply a theoretical sampling approach was further hindered when suitable individuals within groups that had a restricted pool of appropriate stakeholders to recruit either did not respond or declined to participate in the study. This was particularly relevant to the difficulties associated with recruitment for the Te Whatu Ora management group of participants.

Although the current project was unable to use the grounded theory method of theoretical sampling, this did not appear to impact the overall quality or outcomes of the data. The participants made valuable contributions that allowed for the exploration of leads in the data and the development of a model based on participant insights and literature.

Despite deliberate attempts to recruit up to 10 participants to represent each stakeholder group, this was unable to be achieved within the given timeline of the project. Challenges in sampling and recruiting particular participant groups resulted in a limited number of participants within some specific groups (only five individuals). This small sample size within groups makes it difficult to directly compare the perspectives between different stakeholder groups, such as comparing the perspectives of five service users versus ten CDC clinicians. However, when considering all participant groups together, the total sample size of 41 participants is considered sufficient for comprehensive qualitative findings.

There were also difficulties in recruiting participants to represent all of the stakeholder groups for the second phase of the project. As a result, there was no representation from the leadership level in education. Difficulties recruiting a principal or deputy principal to participate in the focus groups may be attributed to the various complexities and time demands involved in their role. Furthermore, the overall context of the project was from a health lens rather than an education lens which may have impacted motivation to participate. Encountering difficulties in achieving the desired type and amount of participant engagement is not uncommon in research. Recruiting for qualitative research poses challenges due to the inherent complexity of human behaviour. Research highlights that the ideals in selecting participants may not always match the realities of human variability, making it challenging to consistently achieve the desired sample characteristics and participant engagement (Hudson et al., 2017; Jessiman, 2012).

Another limitation of the study's sampling is the exclusion of neurodivergent children as participants. Neurodivergent children are considered vulnerable participants, which raises the level of risk associated with the research. Due to the scope of the current project and the ethical considerations involved in conducting research with vulnerable participants, the current study did not include neurodivergent children. There is a need for future research regarding services and supports for neurodivergent children to strive to involve children and youth to gain a better understanding of their needs in terms of service delivery. Due to the primary aims of the project, an additional group of participants that were not included in the current study were mental health clinicians. However, considering the results of this study, which indicate a necessity for increased collaboration between child development and mental health services, future research should consider the perspectives of mental health clinicians in collaboration with other key stakeholders.

The context under which the current study was carried out presents some limitations. The current study utilised CDC in the Waikato region as a case study to contribute towards a better understanding of the issues and suggestions for future directions of CDS across all of New Zealand. Therefore, further research may be necessary to ensure the applicability of the findings to other regions around New Zealand. The current project has been carried out within the context of the New Zealand education and healthcare systems, therefore adaptations may be required when considering the research within the context of different countries.

Within qualitative research, limitations are present regarding the role of the researcher, particularly in the context of the current project where I held a dual role as a researcher and a clinician. The evolved and constructive approaches to grounded theory acknowledge that researchers are unable to achieve complete objectivity. Instead, the subjective contributions of the researcher help to enhance understanding of the subject being studied by building on the information contributed by participants (Birks & Mills, 2015; Charmaz, 1995, 2014; Strauss

& Corbin, 1990). To manage the impact of subjective influence and biases on the study, a continual process of reflexivity occurred throughout the duration of the project. I acknowledged and reflected on my own life experiences relevant to and beyond the context of the project and how the cultural groups I identify with (age, gender, ethnicity) shape and influence perceptions and interpretations of the research phenomena. My experience as a clinician and firsthand exposure to several of the issues raised by participants helped in building rapport as I was able to empathise with their challenges and frustrations, and validate their experiences of the system which had not been favourable.

The potential ethical issues regarding my clinical role at CDC were taken into account. To prevent any bias linked to my existing connections associated with CDC, interviews with CDC clinicians were carried out by my supervisors (MP and AB) and service users were recruited from families with whom I had no prior involvement. Using a semi-structured interview guide for completing the interviews minimised the chances of unintentionally asking leading questions that could sway the participants' responses. Additionally, the use of these interview guides ensured that the focus of the interviews remained aligned with the research questions and the ultimate purpose of the project. This prevented any potential deviation or digression from the main objectives, allowing for a more streamlined and coherent data collection process.

8.6 Future Direction

The current project provides a building block upon which to construct future studies. The findings of this study support the notion that there is a need for CDC to be based within a community setting, closely integrated with schools through the provision of outreach services. As mentioned throughout this thesis, the P4C model is a framework that involves clinicians going into schools to provide rehabilitation support (CanChild, 2015). In light of the confirmation provided by the current findings, one way of bringing the proposed model of service delivery to life could involve conducting co-design research that specifically investigates the applicability of the P4C model within the unique context of New Zealand. This could involve exploring stakeholder perspectives regarding the suitability of the P4C model and whether the model could work in the context of the New Zealand health and education systems. This could also involve the consideration of the cultural context of New Zealand and whether adaptations of the model would be required to ensure the model was culturally appropriate and inclusive of Māori. Originally, the P4C model was primarily centred around OTs delivering rehabilitation support in education settings specifically focusing on children presenting with DCD. However, following two years of implementation it was acknowledged that the P4C model could apply to a broader range of children with special needs or developmental challenges. Additionally, insights from interviews indicated the potential for P4C to extend beyond OTs and encompass other rehabilitation professionals (CanChild, 2015). Therefore, when carrying out research in relation to the New Zealand context, it would be beneficial to further explore the expansion of P4C to include a more generic population of neurodivergent children and the involvement of allied health staff beyond OTs. Ideally, the outcome of this process would be a co-designed intervention plan that enables the establishment of implementation strategies to guide trial implementation and an implementation evaluation process.

Collectively, the findings of the current project and literature suggest there are significant deficits in meeting the support and well-being needs of caregivers' of neurodivergent children (Parsons et al., 2020; Pozniak et al., 2023). Although participant interviews highlighted the importance of supporting the family network to enhance the well-being of neurodivergent children, this did not evolve as a prominent discussion point in the focus groups. As a result, there remains an unaddressed gap in understanding and addressing the support and well-being requirements of caregivers, indicating the need for additional investigation.

The current project's findings provide a comprehensive overview of potential solutions by bringing together the ideas of those who are affected by the issue at hand. The study participants contributed a wide range of ideas and solutions to address the flaws in the system. This project has given the participants a platform to share their ideas, for which many expressed gratitude. The significance of involving those directly affected by the situation in generating valuable data emphasises the continual necessity to allocate time and opportunities to facilitate such conversations among different groups and individuals. This approach enables them to collaboratively develop and implement solutions. As mentioned within the limitations, there is a need for future research to strive to involve neurodivergent children and young people as well as representatives from CAMHS. Furthermore, the current project emphasises the importance of more integration between CDS and schools. However, additional research is required to explore the integration among child development/disability, child health (paediatrics), and CAMHS.

Due to the limitations of small sample sizes within particular participant groups in the current study, it is important to address this by carrying out future research with a larger sample size for individual stakeholder groups. This will facilitate the ability to elicit direct comparisons of perspectives among different stakeholder groups, allowing for the validation and/or expansion of the current findings.

8.7 Conclusion

Utilising a qualitative research design inspired by principles of grounded theory and co-design, the study revealed several issues associated with the current provision of support for neurodivergent children within both the education and health sectors. These include insufficient support, delays in accessing services, difficulties in navigating suitable support options, and unsatisfactory CDC service environments. The participants expressed a desire and need for enhanced collaboration among child-serving services, greater availability of therapeutic support, support that caters to individuals across different age groups and life stages, and the establishment of a community-focussed CDC that is integrated with schools.

Grounded in participant insights and existing literature, a proposed model of service delivery has been developed. This model is intended to address the specific issues identified and offers a recommended framework for improving CDS. The goal of this model is to establish a comprehensive, collaborative, and easily accessible system that caters to the needs of families seeking assistance with their child's developmental needs. To achieve this, the model emphasises the importance of integrating CDS with education services, thus fostering a more holistic approach. Additionally, the model takes into account the principles of EGL, ensuring that it aligns with the future direction of CDS.

With the increasing prevalence of neurodivergent diagnoses (Boyle et al., 2011; Centers for Disease Control and Prevention, 2023, April 04; G. Russell et al., 2022; Zablotsky et al., 2019), it has become evident that the current approach to delivering CDS in New Zealand is unable to adequately meet the growing demand for support. This calls for urgent attention for significant improvements in the delivery of services. The proposed model of service delivery is able to serve as a valuable tool to guide policy and decision-making to develop evidence-based initiatives that will improve service delivery and ensure coordinated care. To implement the suggested model, substantial changes are required. These include restructuring through agreements between MOE and CDS, as well as engaging in collaborative policymaking and co-design initiatives. The success of these processes will be reliant on the active involvement and commitment of senior staff, frontline staff, and service users.

There is a need for subsequent research to engage in co-design to explore the potential adoption and adaptation of the P4C model for use in the specific context of New Zealand. Future research relevant to the context of the current study should prioritise the inclusion and involvement of key stakeholders, including service users, in the co-creation of solutions. This means facilitating opportunities for them to express their opinions, share their experiences, and actively contribute to the decision-making and problem-solving processes. By doing so, researchers can ensure the derived solutions are more comprehensive, effective, and tailored to the needs and preferences of the individuals who will ultimately benefit from them.

To realise the vision articulated in the New Zealand Disability Strategy, aiming to establish an inclusive and supportive society for individuals with disabilities, ensuring equal opportunities for the pursuit of their aspirations and dreams (Office for Disability Issues, 2016), it is fundamental to implement substantive and evidence-based reforms to the existing CDS healthcare model. This is particularly necessary in response to the increasing demand for services among the neurodivergent child population in New Zealand. The key to enhancing the experiences and outcomes of neurodivergent children and their whānau lies in collaborative efforts to deliver integrated care. As emphasised by the present study, achieving this goal necessitates a concerted collaboration between the healthcare and education sectors. The research underscores the interconnected challenges faced by these sectors, highlighting the need for collective and shared solutions.

> *No matter what the barriers are, the opportunities are too big to ignore.*
> *(Principal and deputy principal 01)*

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Appendix A: Enabling Good Lives Principles

Self-determination	• Disabled people are in control of their lives.
Beginning early	• Invest early in families and whānau to support them to be ambitious for their disabled child. • To build community and natural supports. • To support disabled children to become independent.
Person-centred	• Disabled people have supports that are custom-made to their individual needs and goals. • A whole life approach rather than being split across programmes.
Ordinary life outcomes	• Disabled people are supported to live an everyday life in everyday places. • Disabled people are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life.
Mainstream first	• Disabled people are supported to access mainstream services before specialist disability services.
Mana enhancing	• The abilities and contribution of disabled people and their families are recognised and respected.
Easy to use	• Disabled people have supports that are simple to use and flexible.
Relationship building	• Supports build and strengthen relationships between disabled people, their whānau and community.

Source: (Enabling Good Lives, n.d.)

Appendix B: Advertisement for Service User Participant Recruitment

ENHANCING CHILD DEVELOPMENT SERVICES FOR NEURODIVERGENT CHILDREN IN WAIKATO:

A QUALITATIVE STUDY

Waikato District Health Board

THE UNIVERSITY OF WAIKATO
Te Whare Wānanga o Waikato

PARTICIPANTS REQUIRED

Who are we looking for?

Parent/s or primary care giver/s of children aged between 4 - 12 years of age who have a diagnosis of autism, intellectual disability, and/or global developmental delay.

Aim of the study

We want to better understand your viewpoints on the access to and provision of support for neurodivergent children and ways to improve the delivery of Child Development Centre services.

What will you need to do?

You will be required to answer a range of interview questions to discuss your thoughts on the services and support that you and your child have received. You will also be asked to complete a brief questionnaire about your child's age, gender, and ethnicity. Interviews will be carried out online using Zoom, and should take no longer than one hour.

Interested?

If you would like to register for the study or for further information, please contact Ashlie Nobilo via phone 021 183 5321 or email ashlie.nobilo@waikatodhb.health.nz

Appendix C: Phase One Semi-Structured Interview Schedule

		EXAMPLE QUESTIONS					
		FRONTLINE STAFF		MANAGEMENT		POLICY	
Question Categories	**Service Users**	**Child Development Centre (CDC) Clinicians**	**Frontline Education Professionals**	**DHB Managers**	**School Principals and Deputy Principals**	**Whaikaha**	**Ministry of Education**
Introduction	Tell me a little bit about your child.	Tell me about your role and the work you do at CDC. How long have you been in your current role?	Tell me about your role and how long you have been in your current role. Talk me through the involvement you have had with neurodivergent children.	Tell me about your role and your involvement with CDC. How long have you been in your current role?	Tell me about your role and how long you have been in your current role. Talk me through the involvement you have had with neurodivergent children.	Tell me about your role and your involvement with CDS. How long have you been in your current role?	Tell me about your role and how long you have been in your current role. Talk me through your involvement with CDS.
Referral and Assessment	When did you or others first have concerns regarding your child's development? Can you explain your level of involvement with services for your child?	How do you feel about CDC's current referral process? What are your thoughts about how assessment clinics are currently delivered at CDC?	What is your understanding of what CDC does? What is your experience of referring children to CDC? If any children you have worked with have had an assessment at CDC, were you involved with that process at all?	What do you think CDC does well? What are your thoughts about CDC's current referral process? What are your thoughts about how assessment clinics are currently delivered at CDC?	What is your understanding of what CDC does? What are your views about children's access to child disability services i.e. the process of referral and access to a diagnostic assessment for neurodevelopmental disorders?	What are your views about children's access to child disability services i.e. the process of referral and access to a diagnostic assessment for neurodevelopmental disorders?	What are your views about children's access to child disability services i.e. the process of referral and access to a diagnostic assessment for neurodevelopmental disorders?
School Environment	Does your child attend mainstream education? Does your child receive any support at school e.g. ORS funding, RTLB, teacher aide?	What is your view on access to support within the school setting for neurodivergent children?	Have you had any specific training to prepare you for working with neurodivergent children? If, so, what? What is your view on access to support within the school setting for neurodivergent children?	What is your view on access to support within the school setting for neurodivergent children?	Does the staff at your school have access to any additional training around working with neurodivergent children? What is your view on access to support within the school setting for neurodivergent children?	What is your view on access to support within the school setting for neurodivergent children?	What is your view on access to support within the school setting for neurodivergent children?
Well-being	Photo of the child's ideal state (happy or a place etc) or ask the parent to imagine that state… What would need to be put in place to support your child to be like that most of the time / more often?	Thinking of overall well-being, if there were no time or resource limitations, what do you think should be put in place to better support neurodivergent children in their day-to-day life (e.g. at home, at school, other services, leisure activities etc)?	Thinking of overall well-being, if there were no time or resource limitations, what do you think should be put in place to better support neurodivergent children in their day-to-day life (e.g. at home, at school, other services, leisure activities etc)?	Thinking of overall well-being, if there were no time or resource limitations, what do you think should be put in place to better support neurodivergent children in their day-to-day life (e.g. at home, at school, other services, leisure activities etc)?	Thinking of overall well-being, if there were no time or resource limitations, what do you think should be put in place to better support neurodivergent children in their day-to-day life (e.g. at home, at school, other services, leisure activities etc)?	Thinking of overall well-being, if there were no time or resource limitations, what do you think should be put in place to better support neurodivergent children in their day-to-day life (e.g. at home, at school, other services, leisure activities etc)?	Thinking of overall well-being, if there were no time or resource limitations, what do you think should be put in place to better support neurodivergent children in their day-to-day life (e.g. at home, at school, other services, leisure activities etc)?

Appendix C: Phase One Semi-Structured Interview Schedule (continued).

Collaboration	Can you tell me about a time when two or more services you have been connected to worked well together? How do you think different services could work better together?	Do you have any examples of a time when collaboration between CDC and schools was effective? What may be some barriers to CDC and schools working together? What may be some facilitators for CDC and schools working together? How do you think CDC and schools could work better together?	Do you have any examples of a time when collaboration between CDC and either yourself or the school was effective? What may be some barriers to CDC and schools working together? What may be some facilitators for CDC and schools working together? How do you think CDC and schools could work better together?	Do you have any examples of a time when collaboration between CDC and schools was effective? What may be some barriers to CDC and schools working together? What may be some facilitators for CDC and schools working together? How do you think CDC and schools could work better together?	Do you have any examples of a time when collaboration between CDC and either yourself or the school was effective? What may be some barriers to CDC and schools working together? What may be some facilitators for CDC and schools working together? How do you think CDC and schools could work better together?	Do you have any examples of times when collaboration between CDS and schools was effective? What may be some barriers to CDS and schools working together? What may be some facilitators to CDS and schools working together? Picture the ideal future vision of collaboration between CDS and schools – describe what that would look like.	Do you have any examples of times when collaboration between CDS and schools was effective? What may be some barriers to CDS and schools working together? What may be some facilitators to CDS and schools working together? Picture the ideal future vision of collaboration between CDS and schools – describe what that would look like.
Dream	If you could develop something for the journey you've been on for other parents/caregivers, what would it look like? If you could change one main thing about your experience at CDC, what would it be?	What would you like to see done differently at CDC / if you could change one main thing about CDC, what would it be?	What would you like to see done differently at CDC / if you could change one main thing about CDC, what would it be?	What would you like to see done differently at CDC / if you could change one main thing about CDC, what would it be?	What would you like to see done differently at CDC / if you could change one main thing about CDC, what would it be?	What would you like to see done differently at CDS / if you could change one main thing about CDS, what would it be?	What would you like to see done differently at CDS / if you could change one main thing about CDS, what would it be?
Final thoughts	Is there anything else you would like to share that you think is important that hasn't come up in anything else we have discussed?	Is there anything else you would like to share that you think is important that hasn't come up in anything else we have discussed?	Is there anything else you would like to share that you think is important that hasn't come up in anything else we have discussed?	Is there anything else you would like to share that you think is important that hasn't come up in anything else we have discussed?	Is there anything else you would like to share that you think is important that hasn't come up in anything else we have discussed?	Is there anything else you would like to share that you think is important that hasn't come up in anything else we have discussed?	Is there anything else you would like to share that you think is important that hasn't come up in anything else we have discussed?

Appendix D: Phase One Participant Information Sheet

Ethics Committee Approval Number: HREC(Health)2021#37

Participant Information Sheet

School of Health
Te Huataki Waiora

Enhancing Child Development Services for Neurodivergent Children in Waikato: A Qualitative Study

PARTICIPANT INFORMATION SHEET

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate, we thank you. If you decide not to take part, there will be no disadvantage to you and we thank you for considering our request.

What is the aim of the project?

The aim of this PhD project is to develop recommendations for improved delivery of services for children experiencing neurodevelopmental disorders. Examples of neurodevelopmental disorders include intellectual disabilities, communication disorders, autism spectrum disorder, attention-deficit/hyperactivity disorder, and motor disorders. For the initial phase of this project, we are interested in exploring the current perspectives of service users and stakeholders regarding the access to and provision of support for neurodivergent children and ideas for improving the delivery of Child Development Centre services.

What will participants be asked to do?

As part of this research, we are interviewing a range of service users and stakeholders who are associated with the Waikato DHB Child Development Centre, and/or education. Should you agree to take part in this project, you will be interviewed to discuss your thoughts on the access to and provision of care for neurodivergent children. Interviews should take no longer than one hour. All information you provide is confidential and your name will not be used unless indicated by yourself. We would like to record the interview on audio tape in order to develop clear and full transcripts of the interview. Service user participants will also be requested to complete a brief demographics questionnaire.

What data or information will be collected and what use will be made of it?

The information gathered from each interview will be transcribed and analysed using general inductive approach for qualitative data. You will be given the option to choose transcription by PhD student only, or transcription by PhD student with Otter.ai. Otter.ai (https://otter.ai) is a third-party speech-to-text automatic transcription application. Recordings will be deleted from Otter.ai immediately after transcription, removing them permanently from the transcription service files.

Data will be stored under password protection on the Waikato DHB and University of Waikato computer system to maintain confidentiality. Access to this information will only be available to those mentioned at the end of this document. Data obtained as a result of this research will be retained for at least 5 years in

Appendix D: Phase One Participant Information Sheet (continued).

secure storage as per requirements of the University of Waikato. You will be able to receive a summary of the transcript of your interview with an opportunity to comment or request changes.

Findings from the study will be published in a student thesis, DHB report, and research publications. Confidentiality is assured and you will not be identified in any reports or presentations connected with the study. Any excerpts from interviews will have identifying information changed.

Possible risks and inconveniences.

The interview is designed to understand your experiences of a health service, and is not expected to be distressing. If you do feel distressed or have any questions or concerns during or after the interview, please let us know.

You can take your time in considering whether you would like to participate in this research and can consult with any support people and ask any questions of the researchers before making this decision.

Access to your information and results.

No individual results will be provided to you. However, the results from you and other participants may provide valuable information on the health of the community and advance scientific discoveries. We will produce a brief summary of the findings, which we will send to you.

Withdrawal from the study.

Your involvement in the study is voluntary and you may decline to answer any particular question or withdraw your consent to participate at any time during the interview without providing a reason. You may also withdraw at any time up until one month after the end of your participation by emailing one of the researchers. If you withdraw from this study, your data will be confidentially disposed of. Choosing not to participate in the study will not affect your relationship with the University of Waikato, the Waikato DHB or your current or future health provision or employment.

Funding and benefits of the study.

This research is aimed at improving future health and well-being of families and is not designed to benefit the individual in the short-term. However, the study may provide important information concerning well-being, and how services can best meet the needs of children with neurodevelopmental disorders. Participants and the wider community may benefit directly from improved health guidelines and policy resulting from scientific discoveries made by this study.

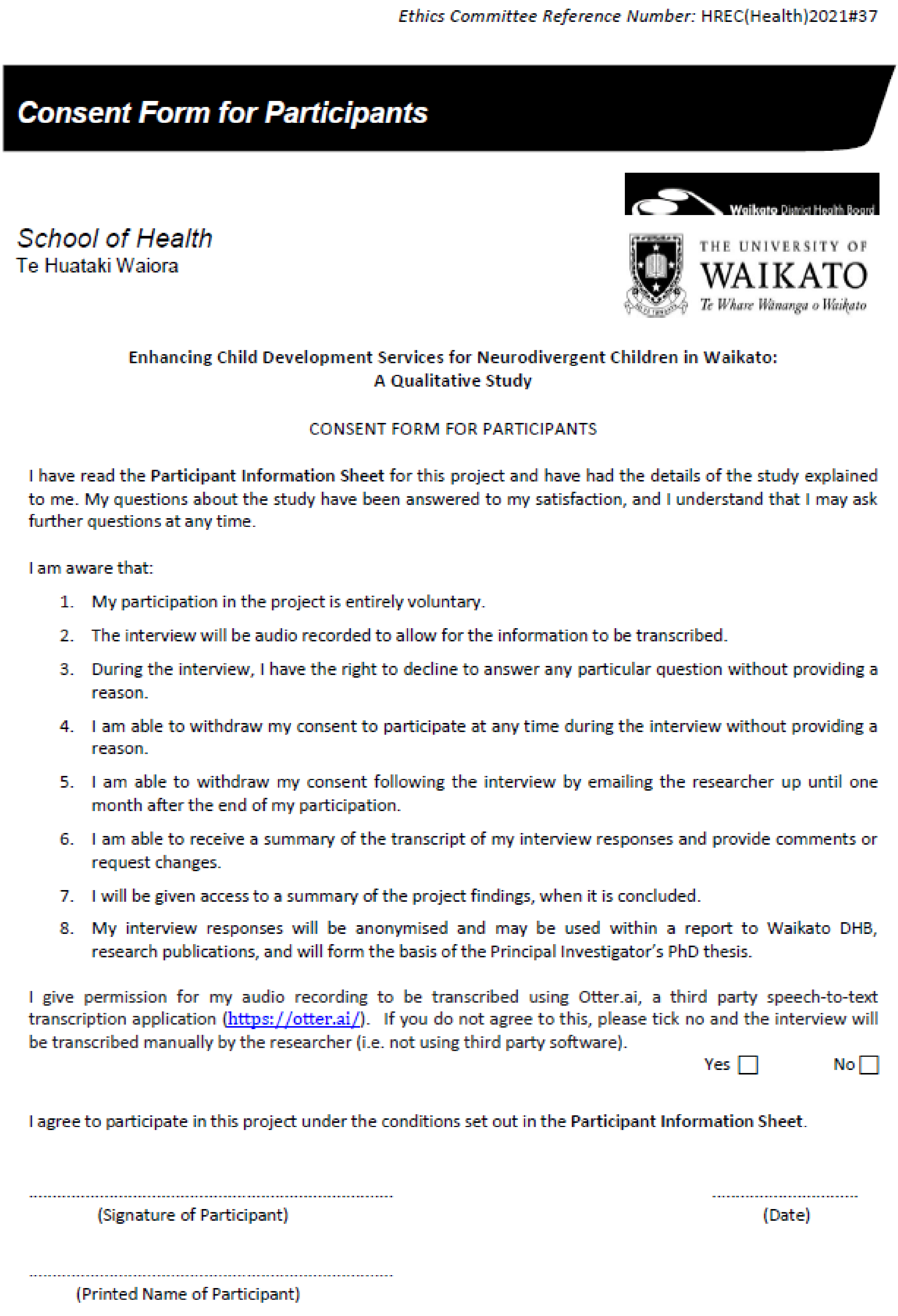
What if participants have any questions?

If you have any questions about this research project, either now or in the future, please feel free to contact either:

Ashlie Nobilo (PhD Student)	Dr Amy Bird	Professor Matthew Parsons
School of Health	School of Psychology	School of Health
021 183 5321	(07) 837 9226	021 753 204
an213@students.waikato.ac.nz	abird@waikato.ac.nz	mparsons@waikato.ac.nz

Please note: This PhD study has been approved by the University of Waikato Human Research Ethics Committee. The ethics committee approval number is: HREC(Health)2021#37

Appendix E: Phase One Consent Form



Ethics Committee Reference Number: HREC(Health)2021#37

Consent Form for Participants

Waikato District Health Board

School of Health
Te Huataki Waiora

THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

Enhancing Child Development Services for Neurodivergent Children in Waikato:
A Qualitative Study

CONSENT FORM FOR PARTICIPANTS

I have read the **Participant Information Sheet** for this project and have had the details of the study explained to me. My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I am aware that:

1. My participation in the project is entirely voluntary.
2. The interview will be audio recorded to allow for the information to be transcribed.
3. During the interview, I have the right to decline to answer any particular question without providing a reason.
4. I am able to withdraw my consent to participate at any time during the interview without providing a reason.
5. I am able to withdraw my consent following the interview by emailing the researcher up until one month after the end of my participation.
6. I am able to receive a summary of the transcript of my interview responses and provide comments or request changes.
7. I will be given access to a summary of the project findings, when it is concluded.
8. My interview responses will be anonymised and may be used within a report to Waikato DHB, research publications, and will form the basis of the Principal Investigator's PhD thesis.

I give permission for my audio recording to be transcribed using Otter.ai, a third party speech-to-text transcription application (https://otter.ai/). If you do not agree to this, please tick no and the interview will be transcribed manually by the researcher (i.e. not using third party software).

Yes ☐ No ☐

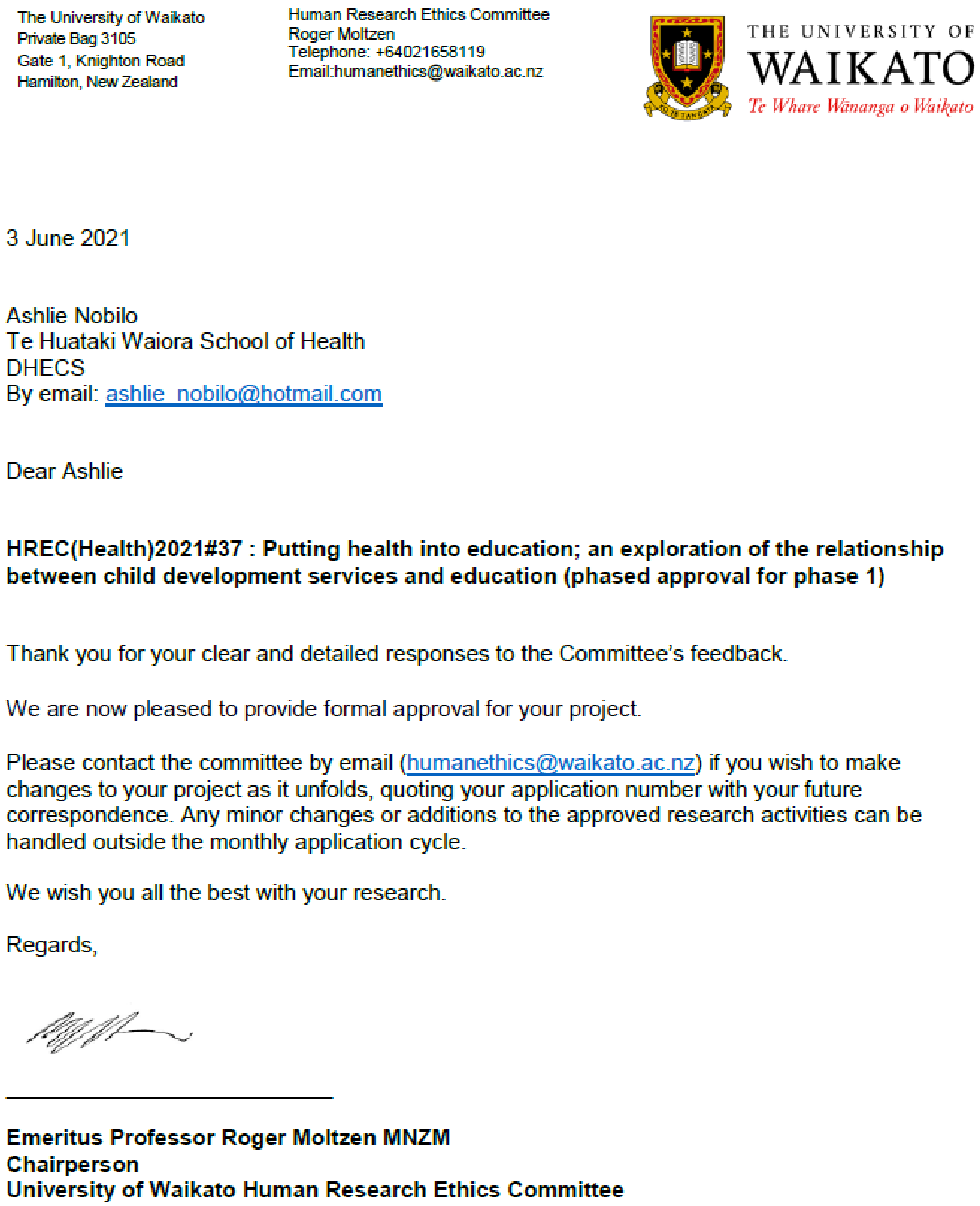
I agree to participate in this project under the conditions set out in the **Participant Information Sheet**.

.... (Signature of Participant)

.... (Date)

.... (Printed Name of Participant)

Appendix F: Phase One University of Waikato Ethics Approval



The University of Waikato
Private Bag 3105
Gate 1, Knighton Road
Hamilton, New Zealand

Human Research Ethics Committee
Roger Moltzen
Telephone: +64021658119
Email:humanethics@waikato.ac.nz

THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

3 June 2021

Ashlie Nobilo
Te Huataki Waiora School of Health
DHECS
By email: ashlie_nobilo@hotmail.com

Dear Ashlie

HREC(Health)2021#37 : Putting health into education; an exploration of the relationship between child development services and education (phased approval for phase 1)

Thank you for your clear and detailed responses to the Committee's feedback.

We are now pleased to provide formal approval for your project.

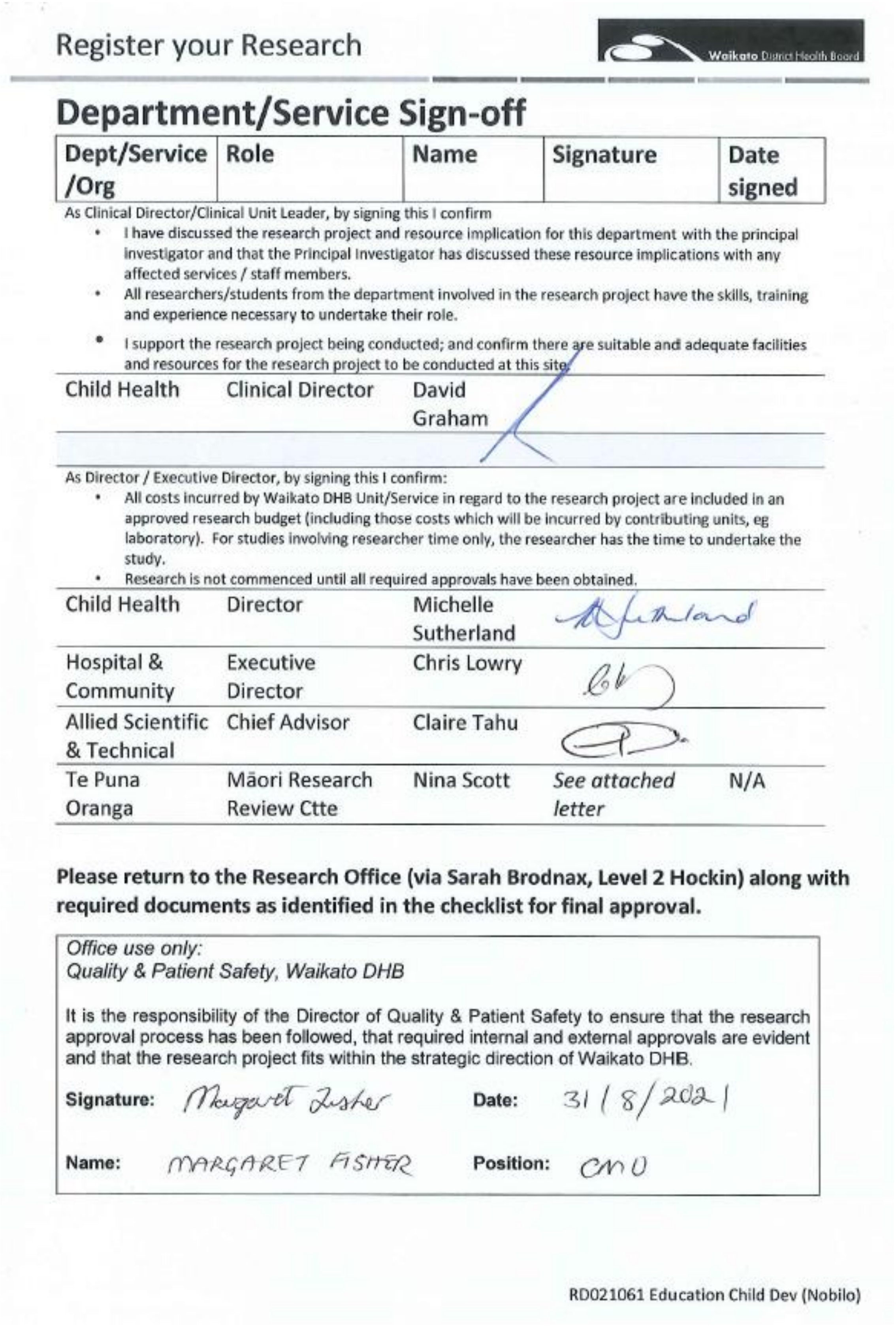
Please contact the committee by email (humanethics@waikato.ac.nz) if you wish to make changes to your project as it unfolds, quoting your application number with your future correspondence. Any minor changes or additions to the approved research activities can be handled outside the monthly application cycle.

We wish you all the best with your research.

Regards,

Emeritus Professor Roger Moltzen MNZM
Chairperson
University of Waikato Human Research Ethics Committee

Appendix G: Waikato DHB Project Registration Approval



Register your Research

Waikato District Health Board

Department/Service Sign-off

Dept/Service /Org	Role	Name	Signature	Date signed

As Clinical Director/Clinical Unit Leader, by signing this I confirm

- I have discussed the research project and resource implication for this department with the principal investigator and that the Principal Investigator has discussed these resource implications with any affected services / staff members.
- All researchers/students from the department involved in the research project have the skills, training and experience necessary to undertake their role.
- I support the research project being conducted; and confirm there are suitable and adequate facilities and resources for the research project to be conducted at this site.

Child Health	Clinical Director	David Graham		

As Director / Executive Director, by signing this I confirm:

- All costs incurred by Waikato DHB Unit/Service in regard to the research project are included in an approved research budget (including those costs which will be incurred by contributing units, eg laboratory). For studies involving researcher time only, the researcher has the time to undertake the study.
- Research is not commenced until all required approvals have been obtained.

Child Health	Director	Michelle Sutherland	M Sutherland	
Hospital & Community	Executive Director	Chris Lowry		
Allied Scientific & Technical	Chief Advisor	Claire Tahu		
Te Puna Oranga	Māori Research Review Ctte	Nina Scott	*See attached letter*	N/A

Please return to the Research Office (via Sarah Brodnax, Level 2 Hockin) along with required documents as identified in the checklist for final approval.

Office use only:
Quality & Patient Safety, Waikato DHB

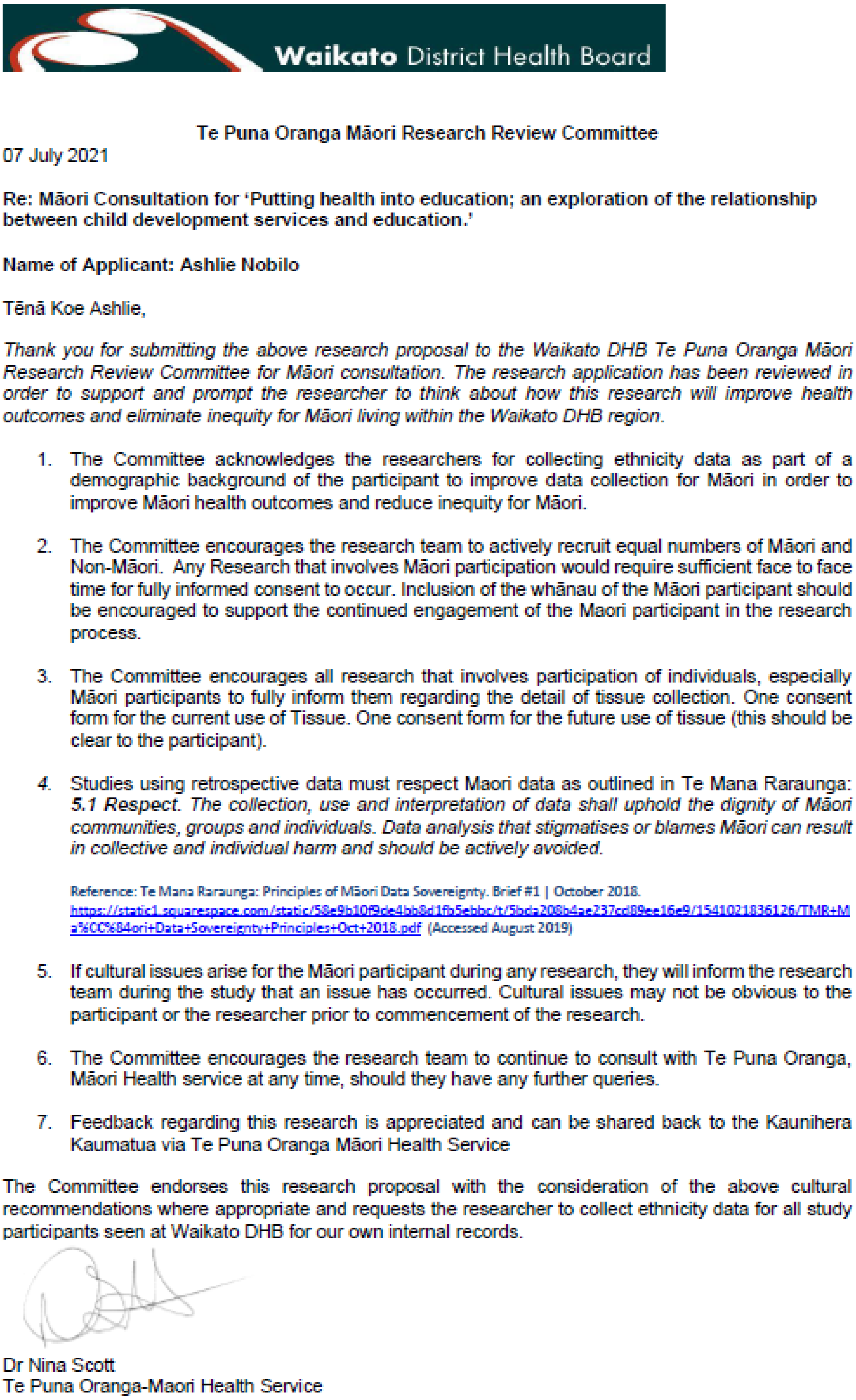
It is the responsibility of the Director of Quality & Patient Safety to ensure that the research approval process has been followed, that required internal and external approvals are evident and that the research project fits within the strategic direction of Waikato DHB.

Signature: Margaret Fisher **Date:** 31/8/2021

Name: MARGARET FISHER **Position:** CMO

RD021061 Education Child Dev (Nobilo)

Appendix H: Te Puna Oranga Māori Research Review Committee Approval



Waikato District Health Board

Te Puna Oranga Māori Research Review Committee

07 July 2021

Re: Māori Consultation for 'Putting health into education; an exploration of the relationship between child development services and education.'

Name of Applicant: Ashlie Nobilo

Tēnā Koe Ashlie,

Thank you for submitting the above research proposal to the Waikato DHB Te Puna Oranga Māori Research Review Committee for Māori consultation. The research application has been reviewed in order to support and prompt the researcher to think about how this research will improve health outcomes and eliminate inequity for Māori living within the Waikato DHB region.

1. The Committee acknowledges the researchers for collecting ethnicity data as part of a demographic background of the participant to improve data collection for Māori in order to improve Māori health outcomes and reduce inequity for Māori.

2. The Committee encourages the research team to actively recruit equal numbers of Māori and Non-Māori. Any Research that involves Māori participation would require sufficient face to face time for fully informed consent to occur. Inclusion of the whānau of the Māori participant should be encouraged to support the continued engagement of the Maori participant in the research process.

3. The Committee encourages all research that involves participation of individuals, especially Māori participants to fully inform them regarding the detail of tissue collection. One consent form for the current use of Tissue. One consent form for the future use of tissue (this should be clear to the participant).

4. Studies using retrospective data must respect Maori data as outlined in Te Mana Raraunga: *5.1 Respect. The collection, use and interpretation of data shall uphold the dignity of Māori communities, groups and individuals. Data analysis that stigmatises or blames Māori can result in collective and individual harm and should be actively avoided.*

   Reference: Te Mana Raraunga: Principles of Māori Data Sovereignty. Brief #1 | October 2018. https://static1.squarespace.com/static/58e9b10f9de4bb8d1fb5ebbc/t/5bda208b4ae237cd89ee16e9/1541021836126/TMR+Ma%CC%84ori+Data+Sovereignty+Principles+Oct+2018.pdf (Accessed August 2019)

5. If cultural issues arise for the Māori participant during any research, they will inform the research team during the study that an issue has occurred. Cultural issues may not be obvious to the participant or the researcher prior to commencement of the research.

6. The Committee encourages the research team to continue to consult with Te Puna Oranga, Māori Health service at any time, should they have any further queries.

7. Feedback regarding this research is appreciated and can be shared back to the Kaunihera Kaumatua via Te Puna Oranga Māori Health Service

The Committee endorses this research proposal with the consideration of the above cultural recommendations where appropriate and requests the researcher to collect ethnicity data for all study participants seen at Waikato DHB for our own internal records.

Dr Nina Scott
Te Puna Oranga-Maori Health Service

Appendix I: Phase Two University of Waikato Ethics Approval

The University of Waikato
Private Bag 3105
Gate 1, Knighton Road
Hamilton, New Zealand

Human Research Ethics Committee
Roger Moltzen
Telephone: +64021658119
Email:humanethics@waikato.ac.nz

17 August 2022

Ashlie Nobilo
Te Huataki Waiora School of Health
DHECS
By email: an213@students.waikato.ac.nz

Dear Ashlie

HREC(Health)2021#37 : Putting health into education; an exploration of the relationship between child development services and education

Thank you for your request to amend your application to include Phase 2. We understand that this will involve the combination of major themes arising from the stakeholder interviews and evidence arising from the literature to inform the development of a model of service delivery that best meets the needs of children with neurodiverse needs in the Waikato region. The model will be presented and discussed through a series of focus groups with key stakeholders.

We are pleased to provide the formal approval for this inclusion.

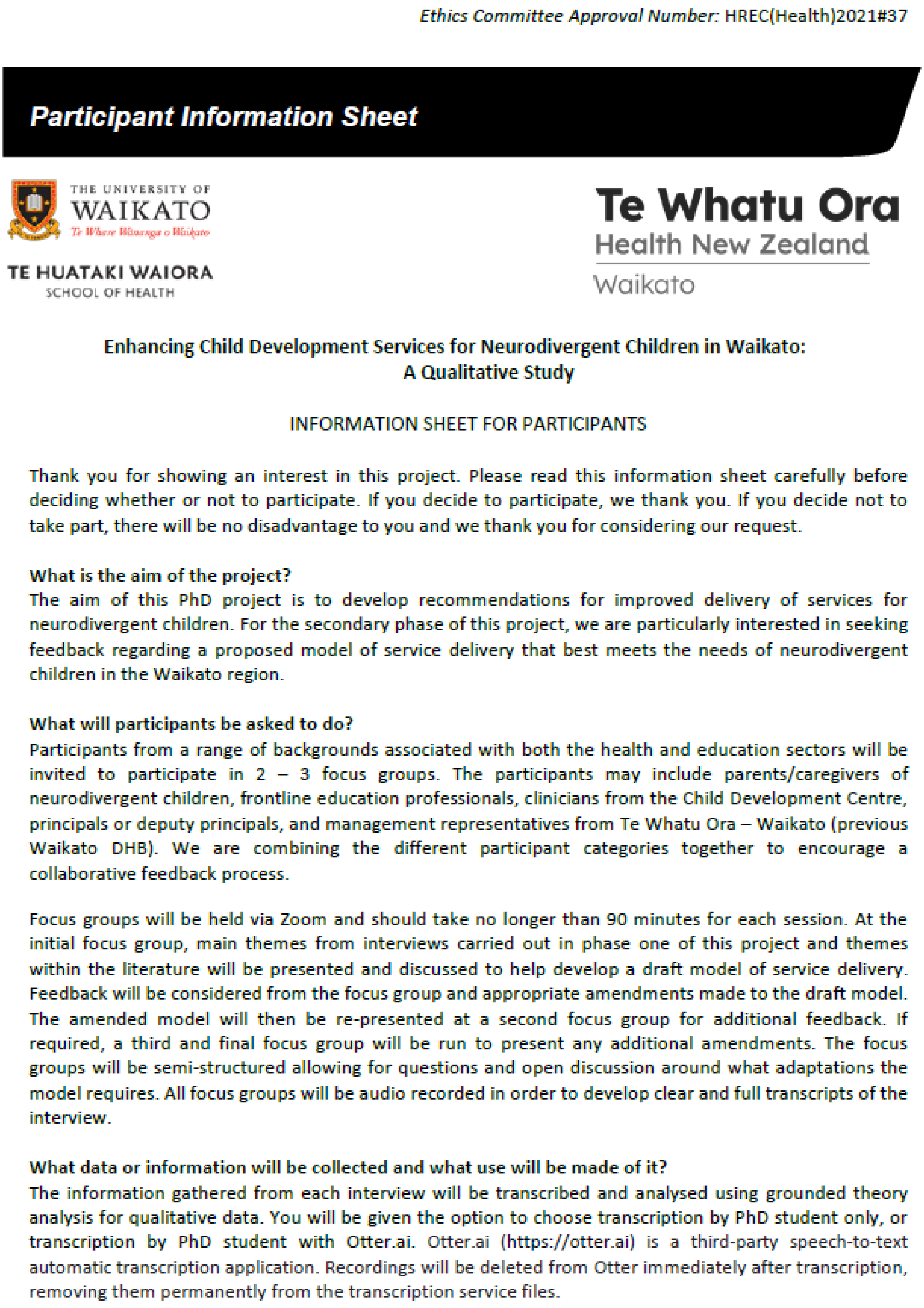
Please contact the committee by email (humanethics@waikato.ac.nz) if you wish to make changes to your project as it unfolds, quoting your application number with your future correspondence. Any minor changes or additions to the approved research activities can be handled outside the monthly application cycle.

We wish you all the best with your research.

Regards,

Emeritus Professor Roger Moltzen MNZM
Chairperson
University of Waikato Human Research Ethics Committee

Appendix J: Phase Two Participant Information Sheet



Ethics Committee Approval Number: HREC(Health)2021#37

Participant Information Sheet

THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

TE HUATAKI WAIORA
SCHOOL OF HEALTH

Te Whatu Ora
Health New Zealand
Waikato

Enhancing Child Development Services for Neurodivergent Children in Waikato: A Qualitative Study

INFORMATION SHEET FOR PARTICIPANTS

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate, we thank you. If you decide not to take part, there will be no disadvantage to you and we thank you for considering our request.

What is the aim of the project?

The aim of this PhD project is to develop recommendations for improved delivery of services for neurodivergent children. For the secondary phase of this project, we are particularly interested in seeking feedback regarding a proposed model of service delivery that best meets the needs of neurodivergent children in the Waikato region.

What will participants be asked to do?

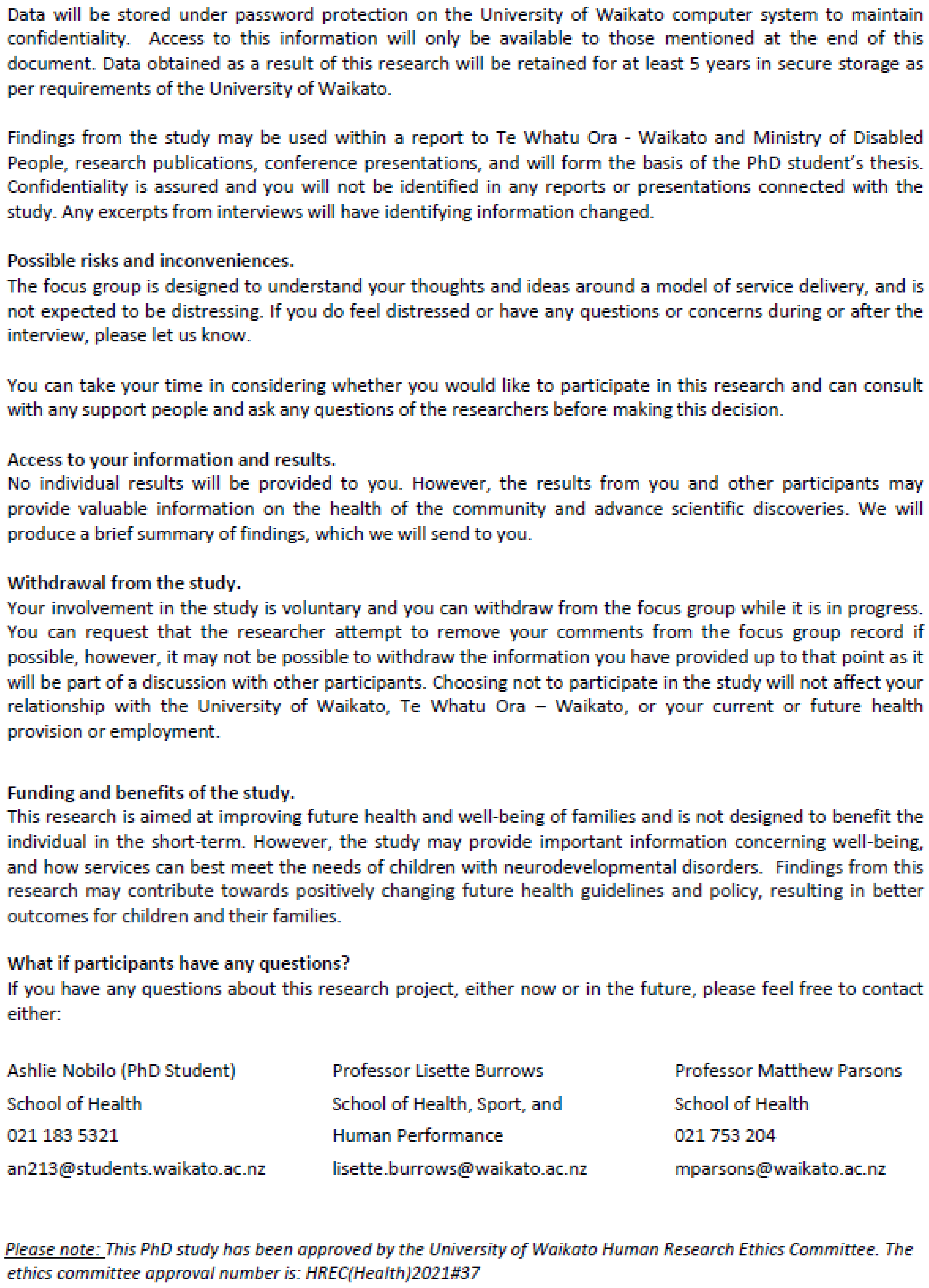
Participants from a range of backgrounds associated with both the health and education sectors will be invited to participate in 2 – 3 focus groups. The participants may include parents/caregivers of neurodivergent children, frontline education professionals, clinicians from the Child Development Centre, principals or deputy principals, and management representatives from Te Whatu Ora – Waikato (previous Waikato DHB). We are combining the different participant categories together to encourage a collaborative feedback process.

Focus groups will be held via Zoom and should take no longer than 90 minutes for each session. At the initial focus group, main themes from interviews carried out in phase one of this project and themes within the literature will be presented and discussed to help develop a draft model of service delivery. Feedback will be considered from the focus group and appropriate amendments made to the draft model. The amended model will then be re-presented at a second focus group for additional feedback. If required, a third and final focus group will be run to present any additional amendments. The focus groups will be semi-structured allowing for questions and open discussion around what adaptations the model requires. All focus groups will be audio recorded in order to develop clear and full transcripts of the interview.

What data or information will be collected and what use will be made of it?

The information gathered from each interview will be transcribed and analysed using grounded theory analysis for qualitative data. You will be given the option to choose transcription by PhD student only, or transcription by PhD student with Otter.ai. Otter.ai (https://otter.ai) is a third-party speech-to-text automatic transcription application. Recordings will be deleted from Otter immediately after transcription, removing them permanently from the transcription service files.

Appendix J: Phase Two Participant Information Sheet (continued).



Data will be stored under password protection on the University of Waikato computer system to maintain confidentiality. Access to this information will only be available to those mentioned at the end of this document. Data obtained as a result of this research will be retained for at least 5 years in secure storage as per requirements of the University of Waikato.

Findings from the study may be used within a report to Te Whatu Ora - Waikato and Ministry of Disabled People, research publications, conference presentations, and will form the basis of the PhD student's thesis. Confidentiality is assured and you will not be identified in any reports or presentations connected with the study. Any excerpts from interviews will have identifying information changed.

Possible risks and inconveniences.

The focus group is designed to understand your thoughts and ideas around a model of service delivery, and is not expected to be distressing. If you do feel distressed or have any questions or concerns during or after the interview, please let us know.

You can take your time in considering whether you would like to participate in this research and can consult with any support people and ask any questions of the researchers before making this decision.

Access to your information and results.

No individual results will be provided to you. However, the results from you and other participants may provide valuable information on the health of the community and advance scientific discoveries. We will produce a brief summary of findings, which we will send to you.

Withdrawal from the study.

Your involvement in the study is voluntary and you can withdraw from the focus group while it is in progress. You can request that the researcher attempt to remove your comments from the focus group record if possible, however, it may not be possible to withdraw the information you have provided up to that point as it will be part of a discussion with other participants. Choosing not to participate in the study will not affect your relationship with the University of Waikato, Te Whatu Ora – Waikato, or your current or future health provision or employment.

Funding and benefits of the study.

This research is aimed at improving future health and well-being of families and is not designed to benefit the individual in the short-term. However, the study may provide important information concerning well-being, and how services can best meet the needs of children with neurodevelopmental disorders. Findings from this research may contribute towards positively changing future health guidelines and policy, resulting in better outcomes for children and their families.

What if participants have any questions?

If you have any questions about this research project, either now or in the future, please feel free to contact either:

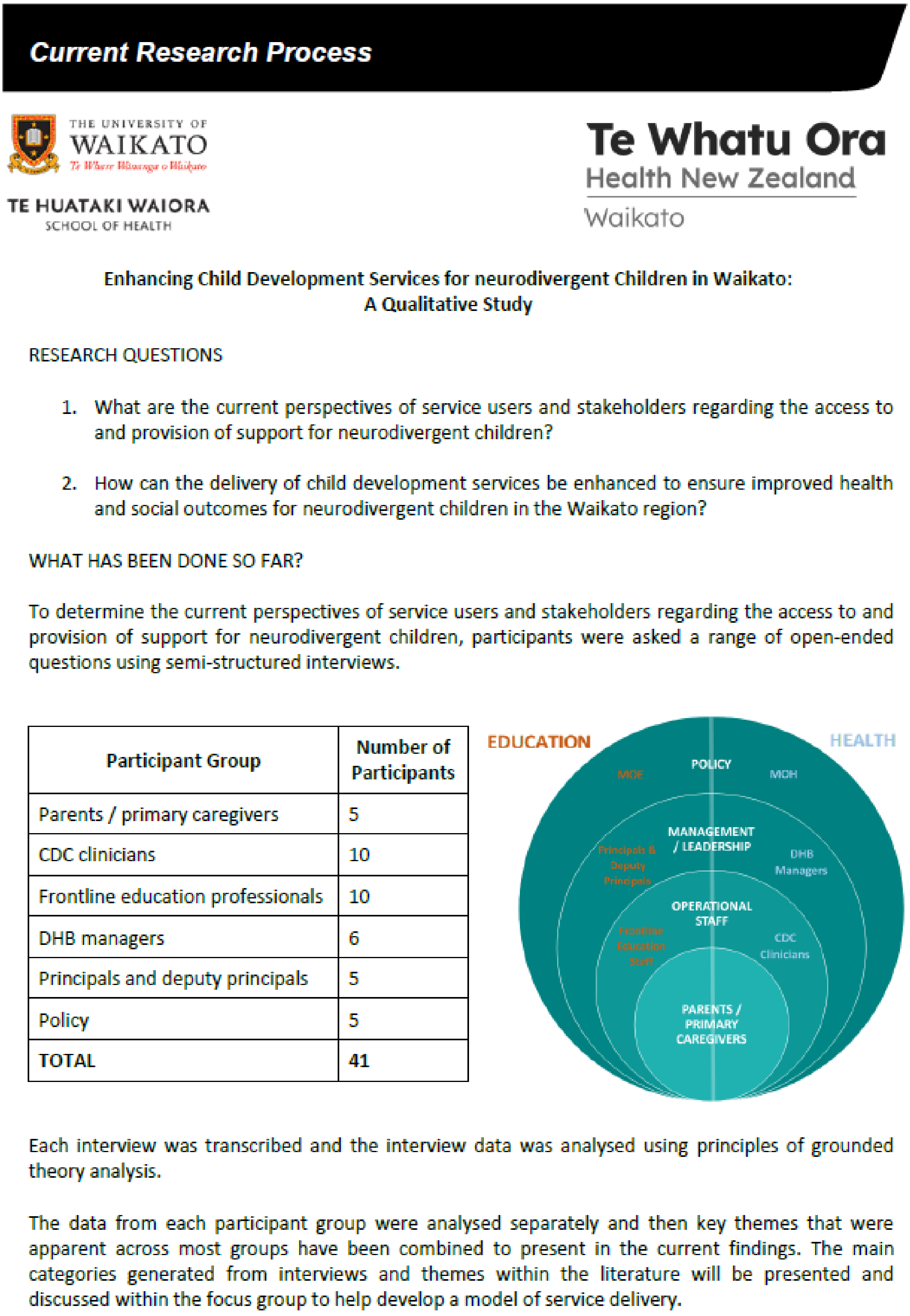
Ashlie Nobilo (PhD Student)
School of Health
021 183 5321
an213@students.waikato.ac.nz

Professor Lisette Burrows
School of Health, Sport, and
Human Performance
lisette.burrows@waikato.ac.nz

Professor Matthew Parsons
School of Health
021 753 204
mparsons@waikato.ac.nz

<u>Please note:</u> This PhD study has been approved by the University of Waikato Human Research Ethics Committee. The ethics committee approval number is: HREC(Health)2021#37

Appendix K: Summary of Phase One Research Process



Current Research Process

THE UNIVERSITY OF WAIKATO
Te Whare Wānanga o Waikato
TE HUATAKI WAIORA
SCHOOL OF HEALTH

Te Whatu Ora
Health New Zealand
Waikato

Enhancing Child Development Services for neurodivergent Children in Waikato:
A Qualitative Study

RESEARCH QUESTIONS

1. What are the current perspectives of service users and stakeholders regarding the access to and provision of support for neurodivergent children?
2. How can the delivery of child development services be enhanced to ensure improved health and social outcomes for neurodivergent children in the Waikato region?

WHAT HAS BEEN DONE SO FAR?

To determine the current perspectives of service users and stakeholders regarding the access to and provision of support for neurodivergent children, participants were asked a range of open-ended questions using semi-structured interviews.

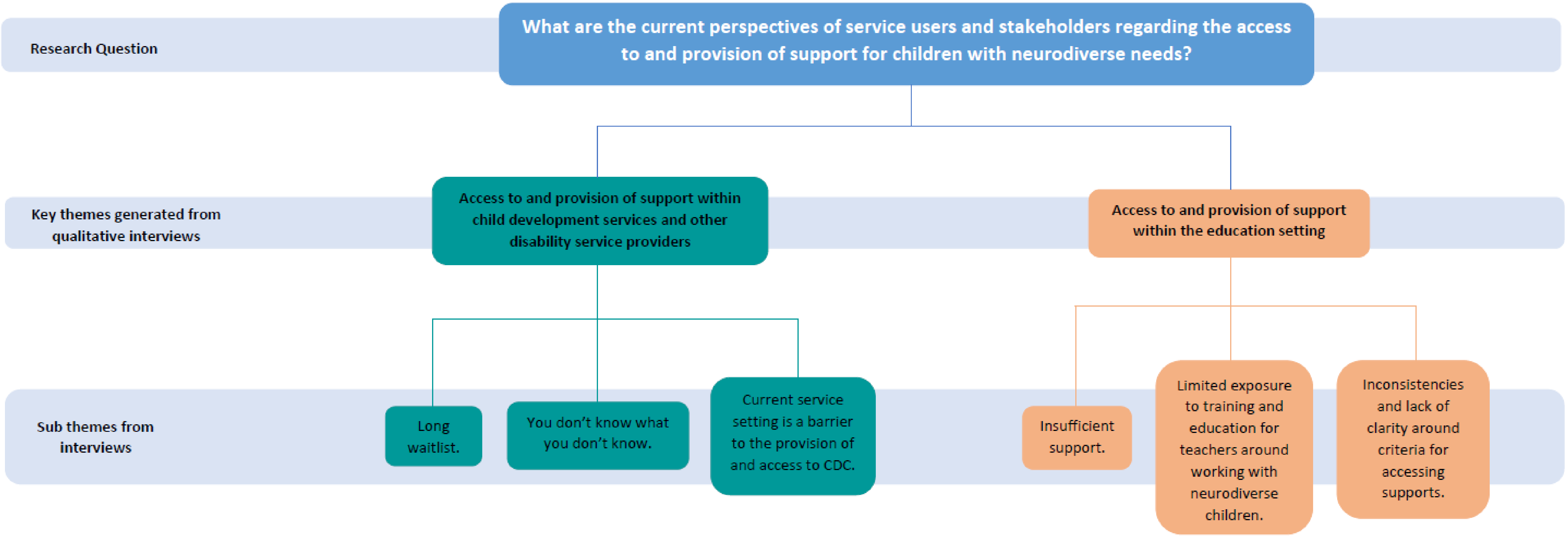
Participant Group	Number of Participants
Parents / primary caregivers	5
CDC clinicians	10
Frontline education professionals	10
DHB managers	6
Principals and deputy principals	5
Policy	5
TOTAL	**41**

Each interview was transcribed and the interview data was analysed using principles of grounded theory analysis.

The data from each participant group were analysed separately and then key themes that were apparent across most groups have been combined to present in the current findings. The main categories generated from interviews and themes within the literature will be presented and discussed within the focus group to help develop a model of service delivery.

Appendix L: Summary of Phase One Key Findings

Current Project Findings



Research Question

What are the current perspectives of service users and stakeholders regarding the access to and provision of support for children with neurodiverse needs?

Key themes generated from qualitative interviews

Access to and provision of support within child development services and other disability service providers

Access to and provision of support within the education setting

Sub themes from interviews

Long waitlist.

You don't know what you don't know.

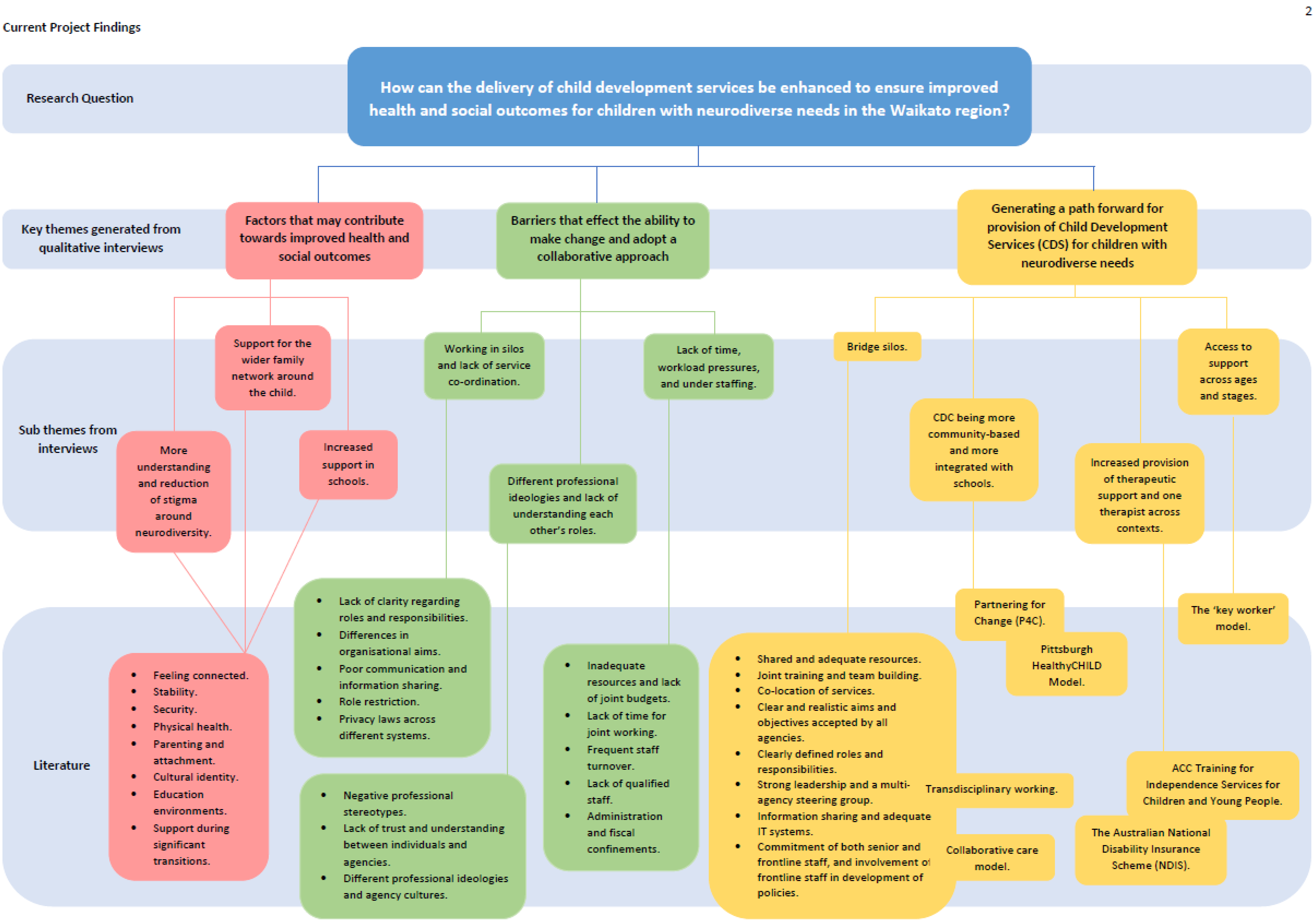
Current service setting is a barrier to the provision of and access to CDC.

Insufficient support.

Limited exposure to training and education for teachers around working with neurodiverse children.

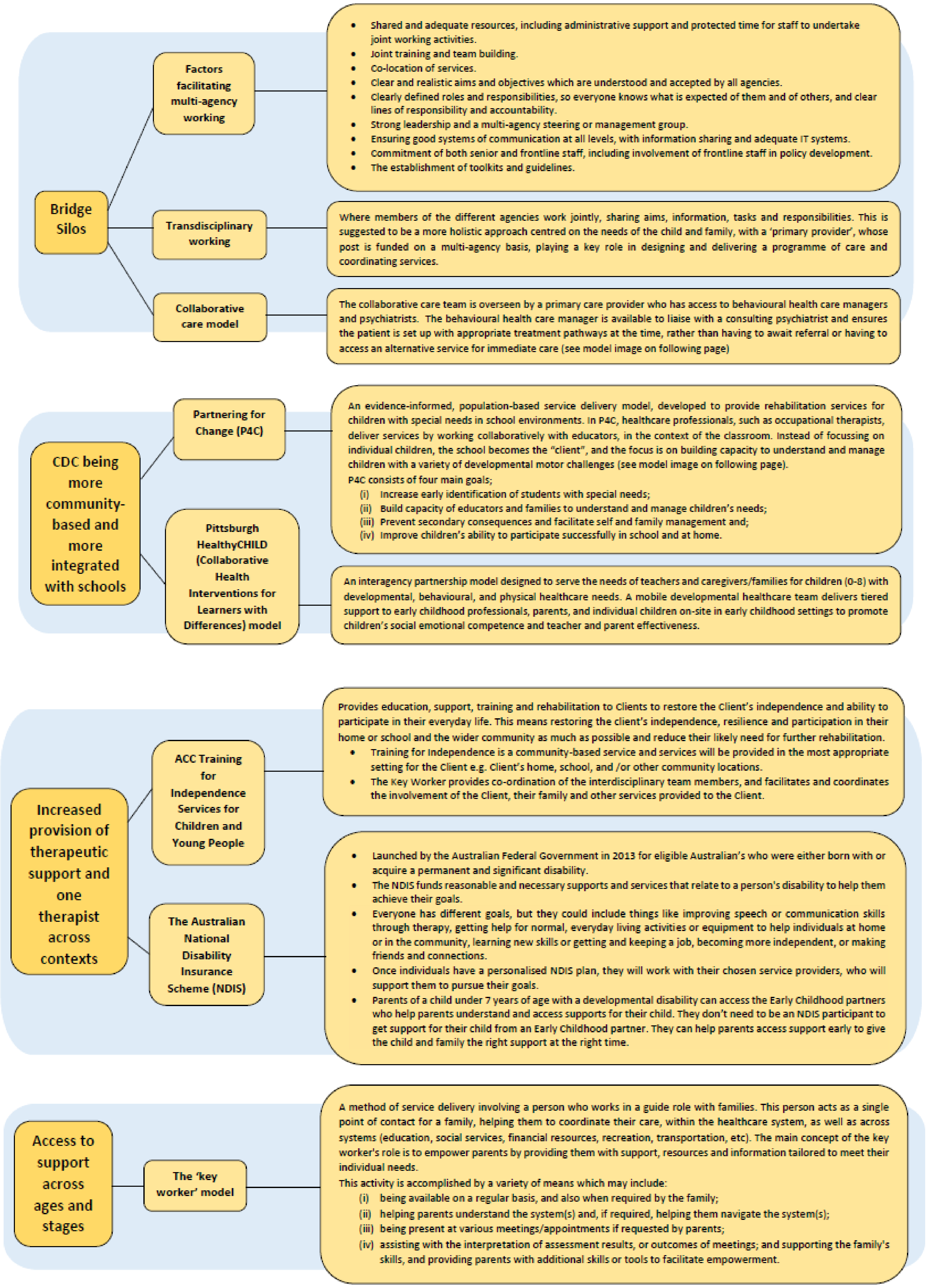
Inconsistencies and lack of clarity around criteria for accessing supports.

Appendix L: Summary of Phase One Key Findings (continued).



Appendix M: Summary of Relevant Evidence within the Literature

Generating a path forward for provision of Child Development Services for children with neurodiverse needs – The Literature



Bridge Silos

Factors facilitating multi-agency working

- Shared and adequate resources, including administrative support and protected time for staff to undertake joint working activities.
- Joint training and team building.
- Co-location of services.
- Clear and realistic aims and objectives which are understood and accepted by all agencies.
- Clearly defined roles and responsibilities, so everyone knows what is expected of them and of others, and clear lines of responsibility and accountability.
- Strong leadership and a multi-agency steering or management group.
- Ensuring good systems of communication at all levels, with information sharing and adequate IT systems.
- Commitment of both senior and frontline staff, including involvement of frontline staff in policy development.
- The establishment of toolkits and guidelines.

Transdisciplinary working

Where members of the different agencies work jointly, sharing aims, information, tasks and responsibilities. This is suggested to be a more holistic approach centred on the needs of the child and family, with a 'primary provider', whose post is funded on a multi-agency basis, playing a key role in designing and delivering a programme of care and coordinating services.

Collaborative care model

The collaborative care team is overseen by a primary care provider who has access to behavioural health care managers and psychiatrists. The behavioural health care manager is available to liaise with a consulting psychiatrist and ensures the patient is set up with appropriate treatment pathways at the time, rather than having to await referral or having to access an alternative service for immediate care (see model image on following page)

CDC being more community-based and more integrated with schools

Partnering for Change (P4C)

An evidence-informed, population-based service delivery model, developed to provide rehabilitation services for children with special needs in school environments. In P4C, healthcare professionals, such as occupational therapists, deliver services by working collaboratively with educators, in the context of the classroom. Instead of focussing on individual children, the school becomes the "client", and the focus is on building capacity to understand and manage children with a variety of developmental motor challenges (see model image on following page).

P4C consists of four main goals;

(i) Increase early identification of students with special needs;
(ii) Build capacity of educators and families to understand and manage children's needs;
(iii) Prevent secondary consequences and facilitate self and family management and;
(iv) Improve children's ability to participate successfully in school and at home.

Pittsburgh HealthyCHILD (Collaborative Health Interventions for Learners with Differences) model

An interagency partnership model designed to serve the needs of teachers and caregivers/families for children (0-8) with developmental, behavioural, and physical healthcare needs. A mobile developmental healthcare team delivers tiered support to early childhood professionals, parents, and individual children on-site in early childhood settings to promote children's social emotional competence and teacher and parent effectiveness.

Increased provision of therapeutic support and one therapist across contexts

ACC Training for Independence Services for Children and Young People

Provides education, support, training and rehabilitation to Clients to restore the Client's independence and ability to participate in their everyday life. This means restoring the client's independence, resilience and participation in their home or school and the wider community as much as possible and reduce their likely need for further rehabilitation.

- Training for Independence is a community-based service and services will be provided in the most appropriate setting for the Client e.g. Client's home, school, and /or other community locations.
- The Key Worker provides co-ordination of the interdisciplinary team members, and facilitates and coordinates the involvement of the Client, their family and other services provided to the Client.

The Australian National Disability Insurance Scheme (NDIS)

- Launched by the Australian Federal Government in 2013 for eligible Australian's who were either born with or acquire a permanent and significant disability.
- The NDIS funds reasonable and necessary supports and services that relate to a person's disability to help them achieve their goals.
- Everyone has different goals, but they could include things like improving speech or communication skills through therapy, getting help for normal, everyday living activities or equipment to help individuals at home or in the community, learning new skills or getting and keeping a job, becoming more independent, or making friends and connections.
- Once individuals have a personalised NDIS plan, they will work with their chosen service providers, who will support them to pursue their goals.
- Parents of a child under 7 years of age with a developmental disability can access the Early Childhood partners who help parents understand and access supports for their child. They don't need to be an NDIS participant to get support for their child from an Early Childhood partner. They can help parents access support early to give the child and family the right support at the right time.

Access to support across ages and stages

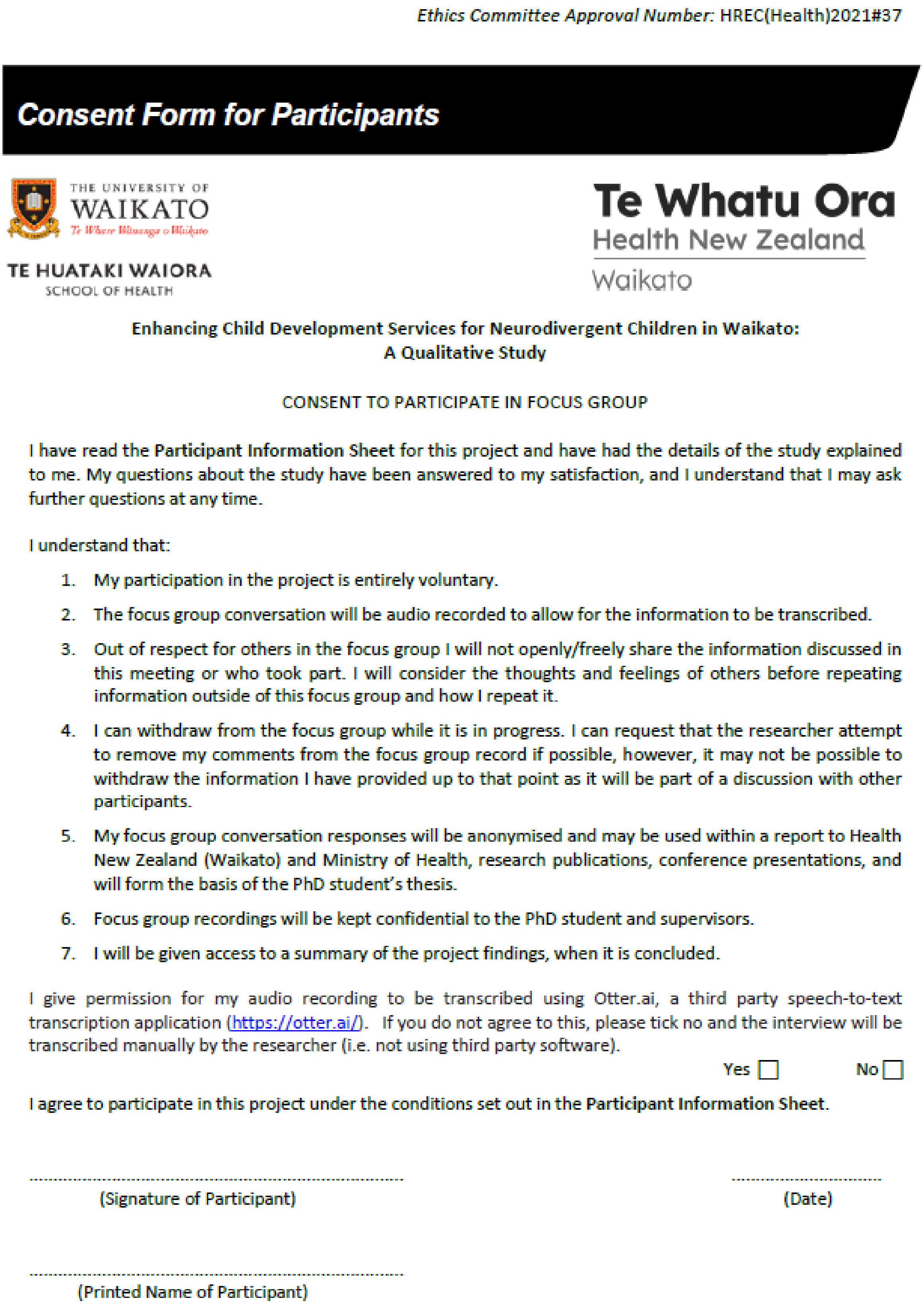
The 'key worker' model

A method of service delivery involving a person who works in a guide role with families. This person acts as a single point of contact for a family, helping them to coordinate their care, within the healthcare system, as well as across systems (education, social services, financial resources, recreation, transportation, etc). The main concept of the key worker's role is to empower parents by providing them with support, resources and information tailored to meet their individual needs.

This activity is accomplished by a variety of means which may include:

(i) being available on a regular basis, and also when required by the family;
(ii) helping parents understand the system(s) and, if required, helping them navigate the system(s);
(iii) being present at various meetings/appointments if requested by parents;
(iv) assisting with the interpretation of assessment results, or outcomes of meetings; and supporting the family's skills, and providing parents with additional skills or tools to facilitate empowerment.

Appendix N: Phase Two Consent Form



Ethics Committee Approval Number: HREC(Health)2021#37

Consent Form for Participants

THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

TE HUATAKI WAIORA
SCHOOL OF HEALTH

Te Whatu Ora
Health New Zealand
Waikato

Enhancing Child Development Services for Neurodivergent Children in Waikato:
A Qualitative Study

CONSENT TO PARTICIPATE IN FOCUS GROUP

I have read the **Participant Information Sheet** for this project and have had the details of the study explained to me. My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand that:

1. My participation in the project is entirely voluntary.
2. The focus group conversation will be audio recorded to allow for the information to be transcribed.
3. Out of respect for others in the focus group I will not openly/freely share the information discussed in this meeting or who took part. I will consider the thoughts and feelings of others before repeating information outside of this focus group and how I repeat it.
4. I can withdraw from the focus group while it is in progress. I can request that the researcher attempt to remove my comments from the focus group record if possible, however, it may not be possible to withdraw the information I have provided up to that point as it will be part of a discussion with other participants.
5. My focus group conversation responses will be anonymised and may be used within a report to Health New Zealand (Waikato) and Ministry of Health, research publications, conference presentations, and will form the basis of the PhD student's thesis.
6. Focus group recordings will be kept confidential to the PhD student and supervisors.
7. I will be given access to a summary of the project findings, when it is concluded.

I give permission for my audio recording to be transcribed using Otter.ai, a third party speech-to-text transcription application (https://otter.ai/). If you do not agree to this, please tick no and the interview will be transcribed manually by the researcher (i.e. not using third party software).

Yes ☐ No ☐

I agree to participate in this project under the conditions set out in the **Participant Information Sheet**.

……………………………………………………………………………… ………………………………
(Signature of Participant) (Date)

………………………………………………………………………………
(Printed Name of Participant)

Appendix O: Phase Two Focus Group Protocol

Opening

- Thank participants for joining.
- Run through the consent form and gain consent.
- Confirm the expected duration (maximum of 90 minutes) for the session.
- Brief introduction of participants.
- Advise participants that the facilitator is there to facilitate and will not be sharing their own personal perspectives.
- Run through the focus group guidelines
    - Out of respect for others in the focus group please do not openly/freely share the information discussed in this meeting or who took part. Take a minute to consider the thoughts and feelings of others before repeating information outside of this focus group and how you repeat it.
    - You do not need to agree with others, but you should listen respectfully as others share their views.
    - We would like to hear a wide range of opinions: please speak up on whether you agree or disagree
    - There are no right or wrong answers, every person's ideas and opinions are important.
    - The conversation should be interactive, however, because the meeting is audio recorded, please allow one person to speak at a time.
    - Please turn off your phones or put them on silent mode while the meeting is going on.
- Provide an opportunity for any questions before beginning.
- Begin audio recording and inform participants that recording is in progress.

<u>FOCUS GROUP ONE</u>

Briefly discuss the process so far – 'Current Research Process' Form

Enabling Good Lives Principles

- Since July, Child Development Services have transitioned from the Ministry of Health to Whaikaha - Ministry of Disabled People. A key programme of the Whaikaha system transformation is transforming the disability system in line with the EGL principles. They want to ensure all New Zealanders who are eligible to access disability support services through Whaikaha and their families have access to creating good lives for themselves.

Discuss current findings

- Highlight that these findings may not be things that focus group participants mentioned within their interview – but these were the main themes that were generated from the interviews across the different participant groups.
- Discuss current perspectives.
- Discuss Factors that may contribute towards improved health and social outcomes.
- Discuss the barriers that affect the ability to make change and adopt a collaborative approach
    - This is helpful to keep in mind as it helps us understand why we may not already be working more collaboratively and these barriers can be considered when contributing ideas about ways to work differently in the future.
- Generating a path forward for the provision of CDS for neurodivergent children.

Appendix O: Phase Two Focus Group Protocol (continued).

Focus Group One Question Guide

- What are your first impressions of the findings?
- Is there anything that surprised you? If so, what?
- Is there anything that you're relieved or reassured to see come through as a key theme?
- Is there anything that you strongly agree or disagree with?
- When considering the possibilities, is there anything that particularly excites or inspires you?
- Is there anything significant missing that should be considered or included?
- If we look at the current perspectives / main issues highlighted, as well as the ideas for how CDC could work differently, what do you think is most relevant from the findings (interviews and/or literature) for shaping what the future delivery of CDC could look like to address some of these key issues?
- Are there any particular elements that you think should or shouldn't sit within the role of CDC? If not CDC, where / who should it sit with?
- From the presented findings, what do you think is the priority for change / what should be the initial focus for improvement? (service user focus – what would make the most difference for you?)
- Is there anything else anyone would like to say or add?

FOCUS GROUP TWO

Facilitator to present proposed model of service delivery.

Focus Group Two Question Guide

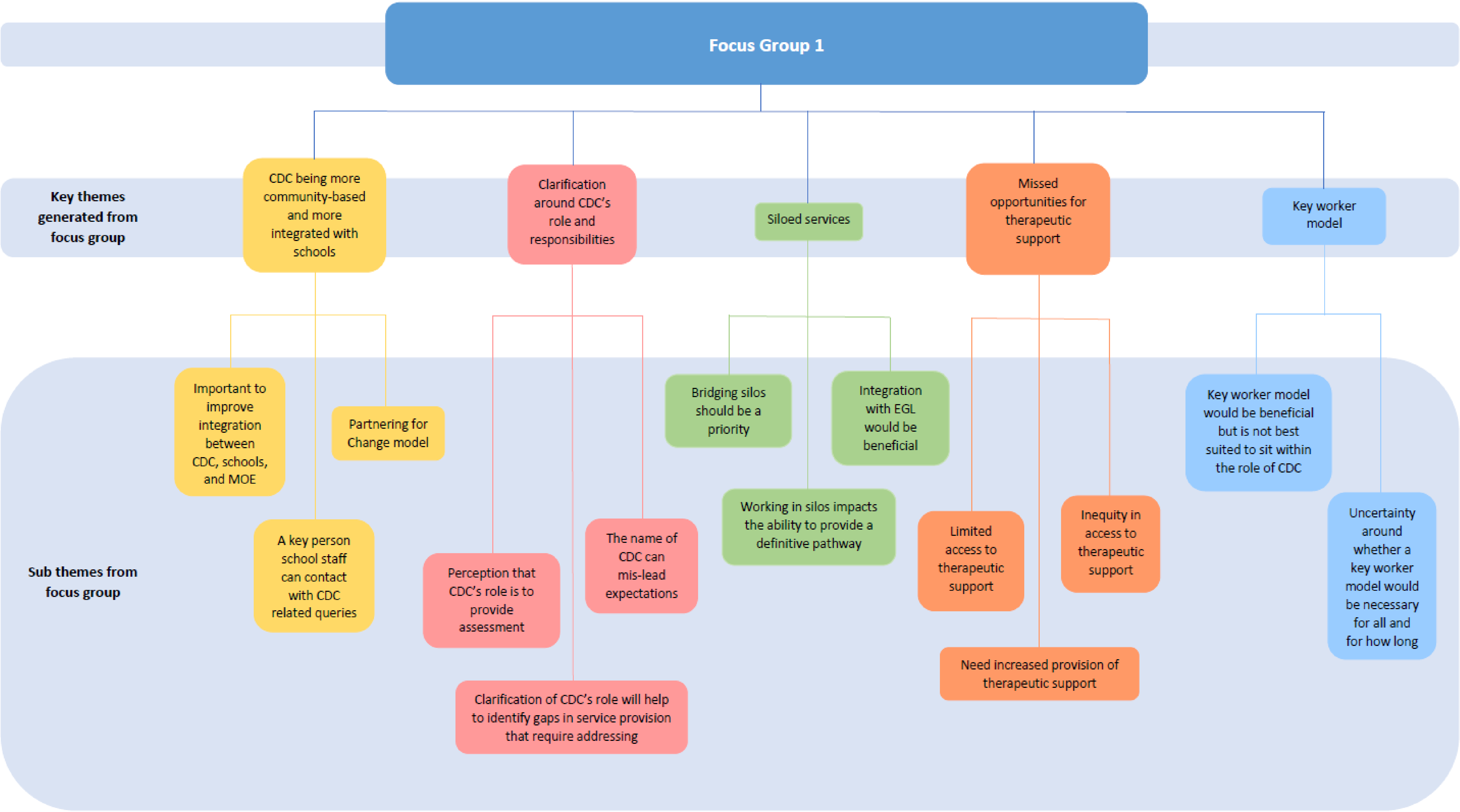
- What do you think are some of the strengths of this proposed model?
- What do you think are some of the weaknesses of this proposed model?
- What changes would you make to the proposed model?
- Is there anything else anyone would like to say or add?

Closing for Focus Groups

- Stop the audio recording.
- Thank participants for their time and participation and advise participants on the next steps in the research process from here.

Appendix P: Summary of Focus Group One Findings

Focus Group 1



Appendix Q: Storyline to Accompany Proposed Service Delivery Model for Improved Provision of CDC Services

Illustrative representation in the model	Storyline
1. Children and whānau on their journey.	The provision of CDC services begins with children and their whānau commencing their journey to access support for children who face additional challenges to achieving expected developmental milestones.
2. Gatekeepers are removed and children and whānau are welcomed to access CDC.	The open gate and the welcome sign represent the removal of gatekeepers to create open access to CDC services which is straightforward for families to navigate. Having clearer pathways will assist in making the system easier for families to navigate and reduce the chances of children getting passed back and forth between services, or missing out on services altogether. A strategy that may be beneficial for creating easier access to care and support is the implementation of a centralised triage/referral system such as CHIRP (Bay of Plenty District Health Board, 2021, October 29).
3. CDC service provision is rooted within EGL principles.	Just as tree roots are interconnected and firmly implanted, the provision of CDC services should be ingrained and connected to the principles of EGL. Policy representatives highlighted that the future direction of CDS includes being led by the EGL principles, therefore the principles must be incorporated within the enhanced delivery of CDC. Using the EGL principles as a foundation for improving service delivery will help maintain focus on achieving the goals and objectives of enhanced service delivery and assist in overcoming the main issues identified within the current project.
4. Bridging services working in silos.	The goal of the bridge is to symbolise the connecting of siloed services, such as child development and education, to enable increased collaboration and a multi-agency approach to supporting children with developmental differences to meet goals and live their best lives. This is supported by the findings of the current project, which suggest that bridging silos could be achieved through various means, including the implementation of a shared IT platform, increased opportunity to develop relationships and build connections between services, the establishment of a designated contact person at CDC for referrers to communicate with, and the creation of a centralised referral/triage system. An additional way of bridging silos included creating a system where a child has one therapist that supports their needs across all contexts, rather than different therapists that support them at home or at school. The benefits of adopting such strategies include the reduction of redundant information gathering, elimination of repetitive storytelling for families, minimisation of confusion for families, the ability to respond more effectively to the needs of families, and enhancement of service efficiency.
5. Community-based CDC providing outreach services to community settings.	The model proposes that CDC should be based within the community in a fit-for-purpose building that is child-friendly and accessible for disabled people. The model includes CDC providing outreach services to early education centres and schools. A range of benefits associated with the integration of CDC within education were highlighted. CDC could actively support the delivery of tiered support in schools which would contribute to increased provision of support, including therapy input, within the education setting. Integrating CDC clinicians within schools would allow for increased opportunities to develop relationships across services, and build the capacity of education staff and families. CDC clinicians would be available to provide prompt on-the-spot assistance and recommendations for teaching staff and would gain an increased understanding of what disability means for a child within the learning environment.

Appendix Q: Storyline to Accompany Proposed Service Delivery Model for Improved Provision of CDC Services (continued).

6.	Stronger collaborative partnership between CDC and EGL.	EGL has been identified as a key service to collaborate with and it has been proposed that establishing a key worker model within EGL could be a fitting approach to enhance the provision of support for neurodivergent children.
7.	Access to CDC service from birth up until school leaver age.	CDC will be accessible for children and youth from birth through until school leaving age; for some children, this will be around 18 years of age, however, those receiving ORS funding can attend school until 21 years. Equipment and Modification Services are provided within CDS for children under the age of 16 years.
8.	Two-way street to allow service users to access support as required.	To be flexible and responsive to children's changing needs across different ages and stages, the concept of a two-way street signifies that children can remain fluid within CDC services depending on their differing support needs throughout their development and transition circumstances.
9.	Services are positioned at the top of the cliff to ensure a proactive rather than reactive response.	Placing services at the top of a cliff, surrounded by a safety fence stems from the belief that relying on an 'ambulance at the bottom of the cliff' is ineffective. This analogy highlights the importance of addressing the root cause of issues rather than treating their consequences. Unlike a reactive approach, where an ambulance aids those who have already fallen, a proactive strategy involves installing a fence at the top for greater preventive benefits (Farlex, 2022). Therefore, the services are based at the top of the cliff to emphasise the delivery of CDC services that are proactive in response rather than reactive, and support is provided in a timely manner.
10.	Hei matau (fishhook) to represent needs-based funding.	In Māori culture, the hei matau (fishhook) represents prosperity and abundance. The hei matau finds its origin in Māori legend which holds that the North Island of New Zealand was once a large fish that was caught by Maui. It is considered that one who has the means to catch fish will prosper (Ministry of Business, n.d.). The hei matau is used to represent an abundance of needs-based funding regarding a whole-life approach rather than funding that is compartmentalised across services.
11.	The waka represents unity in a shared purpose.	The waka, a traditional Māori canoe, is often used as a metaphor for a journey. Building a waka and paddling a waka requires teamwork and collaboration. In relation to healthcare, the metaphor of a waka can represent a team of paddlers, such as whānau and health professionals, working side by side, bringing both worlds of knowledge together to work towards a goal (Elder, 2017). The Māori proverb "He waka eke noa" highlights the importance of unity and collective effort, with a reminder that we are all in this canoe together; we rise together, fall together, work together, and keep going together (McCaffery, 2018, August 13; Te kupu o te ra, n.d.). The waka is used to emphasise a client-centred approach to the delivery of CDC where service users are viewed as partners and their expertise are collaboratively incorporated alongside that of associated professionals, such as CDC clinicians and education professionals, to work towards a client-centred goal. This also aligns with 'ako', a traditional Māori value, which refers to both teaching and learning, encompassed by a reciprocal relationship of equal value (Ministry of Education, n.d.).