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Relational Practice in Context

Exploring parent and practitioner experiences of support services for children with disabilities

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Abstract

This research explores parent and professional experiences of support services for children with disabilities. Socioecological and critical disability theories are used to inform a qualitative examination of influences on disability support services' delivery, including parent and professional experiences, roles, and relationships. Vertical and horizontal analysis are used in constructing individual narrative case studies and performing thematic analysis of the findings. The study results are discussed using Relational Practices in Context, a new conceptual model to explain how relational practice influences, and is influenced by, the environment in which they operate. The thesis concludes with recommendations for policy and practice.

Dedication

This thesis is dedicated to my family, both biological and chosen.

To Peter and Parker, for your patience when my mind was elsewhere.

To Dylan, for not letting me quit despite my repeated attempts.

To Dawson, for demonstrating optimism in the face of adversity.

To Mary, for the gift of daily practice.

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I would like to thank my family and friends for their support, help with everything related to children and maintaining sanity. Their love, kindness, and generosity mean to the world to me.

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List of Abbreviations

MoE	Ministry of Education
MoH	Ministry of Health
MSD	Ministry of Social Development
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organisation

Glossary

Aotearoa New Zealand: Aotearoa is the Māori name for New Zealand

Māori: Indigenous people of Aotearoa New Zealand

Pākehā: European New Zealander

Tangata Whenua: Indigenous People, used in Aotearoa New Zealand to refer to indigenous Māori people

Tauiwi: Non-indigenous person living in Aotearoa New Zealand

Notes on Terminology

Disabled Children versus Children with Disabilities

The New Zealand Disability Strategy (2017) refers to persons with disabilities as *disabled persons*. This is the language agreed upon through the strategy consultation processes. However, the convention in academic literature is to use person-first language, as in children with disabilities. This is also the convention in the United States where person-first language is an important aspect of disability culture. As an immigrant to New Zealand from the United States, I am following the academic convention of using the person-first terminology throughout this thesis, except where quoting directly from other sources.

Special Education Practitioners

The New Zealand Ministry of Education (MoE) changed the way in which it refers to practitioners supporting children with disabilities. When this research began, the practitioners were referred to as Special Education practitioners. In 2017, the Ministry of Education changed the title of Special Education services to Learning Support services and, with the change in workstream title, also came a change in practitioners’ title for those working in that area. Learning Support practitioners are referred to here as Special Education practitioners to reflect the terminology in use when this research began.

Chapter one: Introduction

Introduction

In 2011, the first *New Zealand Report on Implementing the United Nations Convention on the Rights of Persons with Disabilities* (Ministry of Social Development, 2011, pp. 54-55) found that,

> …not all disabled children and their families have access to the supports that they need or knowledge about the full range of services available. With limited resources in the health and education systems and variable levels of co-ordinated services at local levels, both access to and the amount of resources provided can be less than optimal. Services for disabled children can be disjointed or fail to focus on their holistic needs because they are delivered or funded by different agencies in an unco-ordinated way. As in other areas, improved co-ordination of support is a current government focus.

Then, three years later, in 2014, the United Nations developed conclusions regarding New Zealand's implementation of United Nations Conventions on the Rights of Persons with Disabilities. The concluding observations (United Nations, 2015, p. 3) identified that, "it is still the case that some children with disabilities, especially Māori children with disabilities, have difficulty in accessing some government services, including health and education services." In the same report, the United Nations placed upon the government of New Zealand the responsibility for providing access for children with disabilities to get the services they need.

Currently, support services do not meet the needs of children with disabilities and their families. Parents and practitioners try to bridge the gaps between the support that children and families need and the services that are available. Sometimes the efforts to fill gaps in services are effective, sometimes the efforts mask underlying issues and, in other cases, efforts intensify already existing problems. For example, Macartney (2008, 2011) found that early childhood education centres were unprepared, and in some cases, unwilling, to meet the needs of children with disabilities. Parents were often left to fill gaps created by a lack of adequately trained early childhood education teachers and a dearth of early childhood education teacher aide hours by staying with the child at the centre to ensure they can participate in the same activities as the other children attending the centre.

In Aotearoa New Zealand, children with disabilities lack access to the same levels of education, health services and social activities as their non-disabled peers. For children with physical disabilities, this impacts on their full participation by restricting their ability to make friends, participate in school activities and attend school outings (Clark & Macarthur, 2008). Limits to full participation experienced by children with disabilities are problematic. New Zealand legislation (Education Act, 1989) states that children with special education needs "have the same rights to enrol and receive education at State schools as people who do not [have special education needs]" (p. 59).

Inadequate access to education and support services is a problem for children with disabilities, their families, practitioners providing care, communities, social services and government agencies. These problems for children and families in accessing services, and for practitioners in providing services, are not new. Brown (2014) and Stephenson (2014) describe the institutionalisation of people with disabilities under the Lunatics Ordinance 1864 as one of the earlies examples of state-sponsored exclusion. As rights-based perspectives gained traction in the 1970s there was a move away from institutionalised practices and toward community-based support services (Ministry of Social Development, 2016b). The need for increased support for those community-based services continues to this day.

Research has examined the problem of inadequate care and support services through examining discourses of disabilities (Macartney, 2008, 2011), cultural concepts of disability (Ballard, 1990), early intervention practices (Blackburn, 2016), special education policy (Wills, Morton, McLean, Stephenson, & Slee, 2014) and evaluation research (Widdowson, Dixon, & Kushner, 2015). I intend to contribute to the body of research by examining the ways in which practitioners and parents navigate the challenges of inadequate support in their everyday lives. This research focuses on early intervention services because they cross both health (allied health specifically, but co-located with health practitioners and funded through Ministry of Health) and education sectors.

This broader focus provides insight into sector differences and provides opportunities to look at early transitions between sectors. Parent participants are selected to provide the perspectives of service users. Although parents were not the focal point of the interventions provided by support services, they were involved in their children's services. My expectation is that we can learn from parents' and practitioners' experiences as to what is working, and what is not, and take these findings into account in making recommendations for changes at multiple levels of intervention.

Research Interest

This research is borne of issues arising from my professional practice supporting individuals with disabilities and their families. In my past work, I was fortunate to work alongside children, families and an array of practitioners in different disciplines in supporting people to actively participate in their communities. My work took me into people's homes, classrooms, doctors' offices, courtrooms, as well as to the beach, park and grocery store. And regardless of the setting, those I worked alongside wanted their voices to be heard and wanted to be shown the same respect as everyone else.

What I saw in practice was that, often the needs of the service recipients and their families were merely given "lip service". The actual interventions and services were delivered according to professional direction, organisation scope, availability of funding and resources, and skills of available practitioners. Often, these limitations resulted in a practice of asking for individual and family participation in decision making, while on the other hand, knowing that we as practitioners could not, or would not be able to, respect their input and decisions. Sometimes this mismatch was rationalised as "just the way it was" in a resource-scarce environment. Other times, individual practitioners and organisations would advocate for a family and find creative ways to subvert constraints and support the preferences expressed by individuals and their families. However, these opportunities for practitioner advocacy often came at a cost to the practitioner, who would usually be going above and beyond their scripted duties – contributing their own time and resources as well as placing themselves at professional risk by working outside the scope of their prescribed practice boundaries.

In my experience, the need for, and delivery of, truly family-centred support services was a site of contestation. Contestation arose, in part, from differences among professional disciplines and support organisations. Among professional disciplines, there were varied scopes of practice which established boundaries around what practitioners were meant to do as part of their role. Practice principles were unique to each discipline and set forth high-level standards by which to guide and measure practice. Among organisations, practice ethics were similar in their aim to involve service users in identifying and achieving goals. These aims were impacted by considerable variability among eligibility criteria for entry, maintenance, and exit, array of services offered, and service delivery methods. Sitting behind all of the issues were varied constructions of broader concepts of disability, practitioner role, and social participation. Further complicating matters was the likelihood that many of these practitioners needed to work alongside families, navigating the complexities of family relationships, as well as working together as part of multi-disciplinary teams and multi-agency planning processes in order to design and implement interventions considered necessary to promote individuals' full participation in society.

Work amongst varied professional disciplines and across agencies generated a need for collaborative work across disciplinary and organisational boundaries as part of delivering community-based support services to individuals with disabilities and their families. I found that the need for collaborative working practices was most apparent in community based services for children with disabilities and their families. Community based support for children with disabilities often involved services provided by multiple organisations across sectors. The age of the child, type of impairment and associated support needs, families' geographic location, cultural preferences and other factors influenced the level of participation from different organisations. Involved organisations often included those providing health, child development, early childhood, compulsory and special education, and community services.

My intentions with this research are to explore the complexities of professional practice in disability support services and their interactions across disciplinary and organisational boundaries in an unfamiliar practice environment. Are the issues I encountered seen elsewhere, and if so, how are they navigated? I adopt a critical constructivist (Kincheloe, 2005) approach (Schwandt, 2000) combining concepts from social theories of disability and socioecological systems theory to emphasise the role of social systems and institutions in maintaining and/or disrupting taken-for-granted assumptions of disability. And my hope is that this research can contribute to conversations around collaborative interprofessional practices, systems of influence, and resource allocation.

This study is also informed by an outsider perspective as I am not a member of the group I am researching. I am an immigrant to New Zealand, and I do not have professional practice experience in New Zealand based disability support services. As Dwyer and Buckle (2009) note, there are advantages and disadvantages for qualitative researchers relative to their status as insiders and outsiders. Insider status affords the researcher a level of trust and acceptance as “one of us” (p. 58) more readily than for that of an outsider researcher. There are also disadvantages to insider status such as personal bias and perspective to the topic. Conversely, outsider status brings with it questions as to the researcher’s ability to understand the experiences of the researched, even as the outsider provides an external perspective that might aid in disentangling complex issues. Appealing to a more nuanced positioning, Dwyer and Buckle (2009) make the case that insider–outsider is a false binary that obscures much of a qualitative researcher’s positioning in relation to that which they research. The process of identifying and refining my position to that of a connected outsider served to determine the research locations and settings of this study.

Research Questions

This research sets out to explore the complexities and challenges of providing support services to children with disabilities in New Zealand through the lens of parents, allied health, education and special education practitioners. Children’s perspectives were not included as part of this research. When deciding whether or not to include children’s perspectives, I determined the amount of benefit to the child participants did not outweigh the potential risk to child/family/professional relationships.

The following questions guided the research endeavour:

- What are parent and practitioner experiences of accessing and providing support services for children with disabilities?
- How do parents and practitioners interpret their roles?
- What influences professional practice and service delivery?

Summary of Chapters

Chapter 1: Introduction

This chapter introduces the reader to the background of the research problems and questions. It also includes explains my background as a practitioner working with children and families and how my practice experiences prompted interest in the research topic.

Chapter 2: Context of Disability

This chapter presents discussion of the multiple contexts of disability in Aotearoa New Zealand. The chapter opens with a general discussion of disability, and what disability looks like in an Aotearoa New Zealand context. Next, cultural, political and social contexts of disability are discussed in turn. The chapter concludes with description of support services for children with disabilities.

Chapter 3: Literature Review

This chapter reviews the research literature from multiple perspectives. The literature review begins with historical trends in understanding disability before discussing discourses and models of disability. The chapter then narrows focus to detail professional and parent interactions.

Chapter 4: Theoretical Framework

This chapter discusses the theoretical framework for the research. The chapter begins with discussion of the social socioecological systems theory before moving on to critical theory. The chapter concludes with a brief discussion of critical disability theory and a chapter summary.

Chapter 5: Methodology and Methods

The chapter details the qualitative methodology and naturalistic enquiry methods used in conducting the research project. Participant selection, data collection, and data analysis methods are discussed in detail. The chapter concludes with discussion of ethical considerations.

Chapter 6: Individual Case Study Findings

This chapter details findings from interviews with research participants in the shape of individual, vertical case studies. The chapter is divided into three sections. The first section contains vertical cases from parent interviews. The second details vertical cases from child development services practitioners. The third section contains cases developed from Ministry of Education Special Education Practitioners. The chapter concludes with a brief summary.

Chapter Seven: Horizontal (Thematic) Analysis

This chapter used horizontal analysis to identifies themes across the individual case studies. The chapter is organised into three main sections representing each of the primary themes: navigating barriers, building relationships, and interacting professionally.

Chapter 8: Discussion

This chapter brings into conversation data collected as part of the research endeavour, research literature and theory. A new conceptual model, *Relational Practice in Context*, is introduced and discussed in relation to the individual case study and thematic findings and literature.

Chapter 9: Conclusions and recommendations

This chapter begins by discussing summary conclusions and the significance of the research findings. The second section covers recommendations for policy and practice. The chapter ends with a review of the research's limitations and provides final conclusions.

Chapter two: Contexts of Disability

Introduction

In Aotearoa New Zealand, children with disabilities receive support from an array of agencies and organisations situated within education, health, allied health and social service systems. The systems of support are remarkably complex, fragmented, and are activated and restricted by a number of factors including the child's age; disability type; the onset and severity of disability; geographic location; availability of services; service personnel; and funding streams. In order to understand the systems of support, we need to investigate the social, political and cultural contexts of disability. The focus of this chapter is to provide background understanding for the reader by exploring the concept of disability through multiple lenses.

What is Disability?

The World Health Organisation (World Health Organisation, 2019) described disability as:

> An umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers. (p. 1)

According to the World Health Organisation's definition, disability is a fluid concept that might be defined and experienced differently by individuals and families and across various contexts. Worldwide, it has been estimated that over a billion people live with disability (World Health Organisation, 2011). The *Global Burden of Disease* (as cited in World Health Organisation, 2011) estimates that worldwide, 95 million children live with disability.

In 2013, Aotearoa New Zealand conducted the fourth disability survey. The 2013 New Zealand Disability Survey (Ministry of Social Development, 2013) found overall rates of disability increased from the previous survey conducted in 2001. They attributed the increase, in part, to the aging population. The Disability Survey (Ministry of Social Development, 2013) also found 11% of children aged 0-14 live with a disability. Learning difficulty was the most common, at 52% of children with disabilities or 6% of all children. In this survey, learning impairment was defined as: "a long-term condition or health problem that makes it hard in general for someone to learn" (p. 14). This question was asked in regard to children five years old and above. For children younger than five, a question was asked regarding developmental delay, defined as "a diagnosed disorder or impairment that significantly delays a child's development" (p. 13). A total of 49% percent of children were found to have a condition that was present at birth.

The same disability survey (Ministry of Social Development, 2013) found Māori children were affected by disability at higher rates than non-Māori children. Some 15% of Māori children and 9% of non-Māori children were living with disability. Disability categories included: psychiatric/psychological problems, difficulty speaking, difficulty learning and intellectual disability.

The disability survey (Ministry of Social Development, 2013) also found differences in disability rates by geographic region. Auckland, Aotearoa New Zealand's most populous city, had the lowest disability rate at 19% overall, lower than the national average of 24% of the population. The regions with the highest rates of disability were Taranaki (30%) and Northland (29%). Northland also had higher rates of learning (7%) and physical difficulties (19%) than the rest of the country. Rationale for variability in disability rates by region were not available at the time of writing.

Along with occurrence data, Statistics New Zealand surveyed and reported on outcomes for people with disabilities. In Aotearoa New Zealand, people with disabilities were more likely than their non-disabled counterparts to have lower income, rates of employment, participation in recreational activities and life satisfaction (Statistics New Zealand, 2013). They are also more likely to face discrimination, to feel lonely and to feel unsafe. Drawing on data from the 2001 Disability Survey in their research into the experiences of children with physical disabilities, Clark and Macarthur (2008) found that over two-thirds of children with physical disability "had a problem joining in and participating fully at school" (p. 457). If we consider the intertwined nature of disability as functional impairment limiting participation, and that these limits are outsized because of activities and environments designed for non-disabled people, we can see that, in increasing accessibility for people with disabilities, opportunities for full participation also increase.

National Context

Cultural context

There are multiple contexts of disability in Aotearoa New Zealand. Of particular interest to this research are the critical and cultural contexts of disability. Critical and cultural context of disability provide insight into how people came to be categorised, labelled and excluded (Meekosha, 2008, 2011). Speaking from the Global South perspective, Meekosha (2008, 2011) takes issue with the privileging of Northern (Europe, United Kingdom, and United States of America) perspectives and argues for more nuanced and contextually relevant conceptions of disability.

Aotearoa New Zealand has unique bi-cultural partnership obligations under the Treaty of Waitangi (Orange, 2015). There is overwhelming evidence of the inefficacy of the partnership between Māori and Pākehā, which has contributed to educational (Bishop, Berryman, Cavanagh, & Teddy, 2008), social, and economic, and health disparities between groups (Family Violence Death Review Committee, 2017; Reid, Taylor-Moore, & Varona, 2014). One area in particular is the over-representation of Māori in disability-related statistics as described earlier.

Māori have also been found to conceptualise disability more broadly than their European counterparts. In a 2000 report, a team of disability researchers from the Donald Beasley Institute (on intellectual disabilities), and health researchers from Ngai Tahu Māori Health Research Unit came together to explore Māori concepts of disability (Kingi & Bray, 2000). As part of this project, researchers interviewed participants about what disability means to them, their feelings around people with disabilities, differences in Māori and Pākehā conceptions of disability and how disability-related needs were addressed. Research participants in this study were initially found to vacillate between adoption of a medical model of disability and a broader view. However, the authors concluded that, upon further analysis, the primary view of disability from a Māori perspective was that disability was the result of colonisation – where disability included political, economic, social and cultural constraints enforced by western value systems through colonisation (Kingi & Bray, 2000). One participant described disability thus, "We are disabled in the Pakeha world – in our own world we're not" (Kingi & Bray, 2000, p. 21). Other researchers (Bevan-Brown, 2013) have found a Māori view of disability to include separation from Māori culture and language.

In their book, *Tales from School,* Wills and colleagues (2014) wrote and edited a collection of works from disability scholars, educators, family members and practitioners that detailed the development of special education and related practices in New Zealand. Brown (2014) and Stephenson (2014) describe the role of the state in defining disability starting with institutionalisation in the Lunatics Act of 1868 and the advent of compulsory schooling in 1877. With compulsory schooling came the advent of the "backward child" (p. 15) and notions of segregation for those deemed burdensome. The turn of the century then saw development of student classification and labelling practices which, in turn, elevated the status of medical and other professionals in areas of child development relative to the status of parents. In 1925, the Child Welfare Act created a special branch of the Department of Education to support "the maintenance, care and control of children under state guardianship. This included those in the schools for feeble-minded and in the industrial schools" (Stephenson & Thomson, 2014, p. 32). By the end of the 1940s, psychological services were established within the Department of Education and the link between education and allied health was institutionalised.

Political context

The political contestation discussed in this section is that described by the New Zealand Disability Strategy (Ministry of Social Development, 2001, 2016a). The New Zealand Disability Strategy is a framework for informing the work of government agencies and others working within the disability sector. It was developed by the Office for Disability Issues within the Ministry of Social Development and in consultation with people with disabilities and their families and whānau and others in the disability sector. The disability strategy documents described broad approaches to health and disability services, objectives and outcomes for people with disabilities. The current and previous national disability strategies (Ministry of Social Development, 2001, 2016a) provide context for the present-day entwining of cultural beliefs and practices across multiple sectors in support of developing a non-disabling society.

According to the Ministry of Social Development, “Disability is not something individuals have…Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have” (Ministry of Social Development, 2001, p. 1). The purpose, then, of this strategy, was to ameliorate barriers and exclusionary practices through integrating people with disabilities, “into community life on their own terms, their abilities will be valued, their diversity and interdependence will be recognized, and their human rights will be protected” (Ministry of Social Development, 2001, p. 1). Part of this effort to remove barriers included an emphasis on holistic and consistent services that fostered interagency collaboration.

In 2006, following media reports, an inquiry was made into services for people with disabilities (Fairbrother, 2008). A report was generated at the conclusion of the inquiry. The report detailed findings of inconsistencies in the level of support provided by government health and injury support agencies; inconsistencies with assessing disability-related needs and allocating supports to meet those needs; general inconsistency in services throughout the country; gaps in services; and service mismatch between local needs and services available. Overall the care and service for people with disabilities were said to “[lack] direction and leadership, services are variable throughout the country, and significant systemic problems have developed unchecked” (Fairbrother, 2008, p. 8). The findings documented as part of the inquiry in 2006, were similar to those findings detailed in the reports on Aotearoa New Zealand’s implementation of the United Nations Conventions on the Rights of Persons with Disabilities (United Nations, 2011, 2015) and the findings in the Child Development Services stocktake (Widdowson, Dixon, Kushner, 2015), indicating that issues identified in the inquiry continue to be insufficiently addressed.

During the time of this research, the New Zealand Disability Strategy has undergone review and revision. The latest Disability Strategy document (Ministry of Social Development, 2016a) has outlined the following eight priority outcome areas: education, employment and economic security, health and wellbeing, rights protection and justice, accessibility, attitudes, choice and control, and leadership. At the time of writing, actions for each of the eight priority outcome areas listed above have yet to be released. The review of outcomes and action areas makes this an especially relevant time to conduct research into the provision of support services for children with disabilities and their families.

In this section, the social context of disability refers to the disability support system and related services. Evidence suggests that people with disabilities face barriers in accessing the health and rehabilitation services they need in multiple settings (United Nations, 2011, 2015; World Health Organisation, 2019). In Aotearoa New Zealand, support services for children with disabilities are found in multiple sectors including: health, behavioural health, education, social development, housing, economic and other sectors. This research focuses on services provided in allied health child development services and special education services. Allied health child development services and special education services both provide an array of services within their respective teams with some overlap in the children and families they work with.

Early Intervention

In general, early intervention is an array of activities intended to enhance children's development (Ramey & Ramey, 1998). Services are generally those provided to children with, or at risk of, disability up until age five. The New Zealand Ministry of Health provides different types of disability support services. The different types of services include: autism support; behavioural support; community day and residential services; child development services; equipment; family care and individual funding; hearing and vision; home and community support, carer and respite support and assistance with supported living. However, data on specific service utilisation, barriers to specific services and outcomes specific to service use have been difficult to access due, in part, to small sample size and limited release (J. Tarr, personal communication, 2017).

Likewise, the New Zealand Ministry of Education provides a variety of support services for children identified as having special educational needs. Prior to school entry, and typically between ages 3-5 (though this can vary) children might be found eligible for Ministry of Education-funded early intervention services. Early intervention services under the Ministry of Education umbrella are those services that provide support for children where there are concerns related to their learning and development.

In Aotearoa New Zealand, early intervention services for children with, or at risk of, developmental delay and or disability are provided by a number of different government agencies, non-government organisations, and private service providers. Early intervention services are generally those concerned with developmental delay, disability, communication and/or behaviour difficulties (Ministry of Education, 2017a). Early intervention in Aotearoa New Zealand is a team-based support service provided by specialists who work with specialists in other fields like health and allied health.

Early intervention services for children with disabilities in Aotearoa New Zealand were modelled after early intervention efforts developed overseas. During the 1960s and 1970s in the United States, preschool and home-based early intervention programmes were developed with the intention of reducing the effects of poverty on learning. Discussing the efficacy of these early intervention programmes at the time, Bronfenbrenner (1974) identified as important principles related to intervention efficacy: that interventions delivered were family-centred and took into account socioecological systems in which children and families found themselves a part. In the United States, early intervention services for children with disabilities are regulated by Part C of the Individuals with Disabilities Education Act of 2004. Early intervention services for children with disabilities are those focused on supporting children's learning and development in instances of developmental delay and/or disability. In Aotearoa New Zealand, the Education Act 1989 sets out the right of children with additional education needs to have those needs met by their local school.

Special education—specialist services

The New Zealand Ministry of Education Special Education Services provide support for children identified as having special education needs. These needs are met though the provision of specialist services provided by cultural advisors; early intervention teachers; psychologists; speech language therapists; physiotherapists and occupational therapists; special education advisors and others. Specialist services are governed by a set of specialist service standards driven by practice values developed by specialists, parents and educators. The specialist service pathway, or poutama, is informed by value-based practice principles.

These principles include collaboration, children’s participation, inclusivity, family and whanau engagement, cultural affirmation and socioecological approaches (Ministry of Education, 2015). The principled practices are to support practitioners in working in a principle-based way to improve outcomes for children.

Figure 1.

Service Pathway and Practice Principles

Note. Reprinted from Aotearoa New Zealand Ministry of Education (2015, p.6) *Specialist Service Standards*

According to the *Specialist Service Standards* (Ministry of Education, 2015), the socioecological approach is used in assessment practices recognising the role of social situations, environment and context in impacting abilities and needs. The socioecological approach is also said to support the emphasis on relationships between family, specialist and educational settings.

Child development services

Children with disabilities from 0-5 may receive specialised support from Ministry of Education Special Education practitioners and/or Ministry of Health Child Development Services practitioners. Child Development Services are community-based, non-medical services delivered by a multidisciplinary allied health team (Ministry of Health, 2012). Child Development Services fall under disability support services as described by the Ministry of Social Development, Office for Disability Issues, and they are funded by the Ministry of Health. In the Child Development Services service specifications, which include descriptions of the services provided, there is explicit mention of the New Zealand Disability Strategy's (Ministry of Social Development, 2001) vision of a "fully inclusive society…that highly values our lives and continually enhances our full participation" (p. 1). The Child Development Services service specifications also specifically mention cultural practices for Māori and Pacifika. However, within the service specifications, there is no explicit mention of development theories or models used in assessing and providing services to those not receiving culturally informed services.

Eligibility for services

Eligibility criteria for Ministry of Health services include: having one or more physical, sensory or intellectual disabilities that are likely to last at least six months, impair independent functioning and require ongoing support (Ministry of Health, 2015a). Exclusions to eligibility include impairment caused by a serious injury, mental health, addiction, chronic health conditions (e.g. asthma), and age-related conditions (e.g., Alzheimer's). Also excluded were children with terminal illnesses, those receiving services funded elsewhere, those with acute post-operative needs and those needing only support for maintaining current levels of functioning (Ministry of Health, 2012). However, during the writing of this thesis, the Ministry of Health is undergoing a contract streamlining process and service specifications are under review. For ease of understating, let us assume that initial eligibility criteria have been met, the next step would be to inquire into Needs Assessment and Service Coordination services.

Needs Assessment and Service Coordination services are performed by organisations contracted to the Ministry of Health to work with families and individuals. Needs Assessment and Service Coordination services offer assistance identifying an individuals' needs and strengths, as well as the availability of, and eligibility for, support services (Ministry of Health, 2016). Needs Assessment Service Coordination services are anecdotally considered the gatekeepers of disability support services because of their role in identifying eligibility and availability of supports.

Eligibility for Ministry of Education Early Intervention services has been difficult to ascertain. Personal conversations (Ministry of Education Special Education, personal communications, 2017) have revealed eligibility and funding decision-making practices to be opaque and ad hoc. At the time of writing, details of eligibility processes and funding allocation remain veiled.

Summary

There are multiple contexts which shape understanding of, and support for, disability, including cultural, historical and political influences. Accessing support services for children with disabilities often requires obtaining services through multiple agencies in the health and education sectors. The process of access support is further complicated by differences in eligibility, service provision and funding criteria between sectors as well as changes in processes that occur within sectors over time.

Chapter Three: Literature Review

Introduction

The objective of the literature review is to provide a thorough background of the relevant issues related to the research topic as well as to identify the gap within the literature that the research study intends to fill. This chapter introduces literature pertaining to the changing concepts of disability and child development, professional practices in support of children with disabilities and relationships between parents and professionals providing those services. The chapter is divided into three sections with each of these presenting discussion on varying aspects of the literature. The first section discusses the conceptual and theoretical literature that informs how disability support services are understood. The second section presents discussion of critical disability, including discourse and models of disability. Finally, the third section discusses research literature involving disability support services, professional practices, and parent and practitioner relationships.

Historical Trends

International understanding of disability has changed significantly over the last five decades. Early ideas posited the impairment and the person impaired as the sole cause of disablement. The foci on treatments, interventions, and specialised education to remediate the disabled are considered characteristics of the medical model of disability (Brisenden, 1986; Goodley, 2011). Thomas (2007, citing Zola, 1972) argued, that within medical sociology, disability, like lifestyle behaviours and managing children, became medicalised. She described the medicalisation process “whereby medical control and jurisdiction has crept, overtly and covertly, into areas of life previously untouched” (Thomas, 2007, p. 31). The creep of medicalisation led some to criticise medicine as a social institution that compounds the effect of illness while purporting to be objective and value free (Brisenden, 1986; Thomas, 2007).

Inherent in the medical model are the ideas of individual pathology (biological or psychological) in need of repair by an expertly trained professional (Wills et al., 2014). Expertly trained professionals include physicians, allied health practitioners, social workers, psychologists and special education practitioners (Thomas, 2007). Citing Finkelstein (1980), Thomas (2007) discussed the growth in professional dominance in exerting control over individuals with disabilities needs, treatments and care decisions, which was seen as the result of impaired people's exclusion from the workforce. Oliver (1990) contends that this exclusion from the workforce, though unintentional, is systematic and symptomatic. He argues that systematic exclusion occurs in the type of job support programmes created. The type of job created reflects bias that people with disabilities are unable to perform in the workplace and must be made work-ready through increased dependency. For Oliver (1990) and Finkelstein (1980) the onus was on people with disabilities to interrupt the implicit acceptance of "the personal tragedy theory of disability…to provide both critiques of this implicit theory and to construct their own alternatives" (Finkelstein, 1980, p. 1). In his seminal work constructing a social theory of disability, Oliver (1990) discusses the positioning of disability frameworks within medical and psychological studies and discourses as a consequence of the marginalisation of disability.

As the medical model was contested, other theories and models were created offering alternative explanations of disability and disablement (Goodley, 2011). In the United States, parents and parent-involved advocacy groups were successful in advocating for legislation protecting the rights of people with disabilities. These efforts resulted in the assurance of federal protections for individuals with disabilities in education, initially through Public Law 94-142 (the precursor to what are now known as the Individuals with Disabilities Education Act and the more recent Individuals with Disabilities Education Improvement Act). The Americans with Disabilities Act provided similar protections to people with disabilities in workplaces and public life (Turnbull, 2013).

In the early 1970s, disability advocacy work and activism were featured prominently in both the United States and the United Kingdom. Oliver (1990) equated the marginalisation of disability to that of women and people of colour who have learned to document their own histories. Linking marginalisation of disabled people with that of other groups established commonalities in theoretical perspectives and established the placement of a social model of disability and what later became social theories of disability under critical theory paradigms (Hughes, Goodley, & Davis, 2012). The social theory of disability posits that impairment and disability are separate, and that disability is constructed from "disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities" (Union of the Physically Impaired Against Segregation, 1975, as cited in Shakespeare, 2013, p. 197).

Critiquing the social model of disability, Shakespeare (2013) discussed the distinction between impairment as *private and individual*, and disability as *public and structural*. Shakespeare (2013) went on to discuss what is missing when people's experiences of impairment is missing, as well as when those with non-physical disabilities are excluded from the theory as constructed by Oliver (1990), Finkelstein (1980) and others. Shakespeare (2013) derided the challenge of researching experiences of non-oppressed people with disabilities if the definition of disability necessitated oppression by way of associating disability with oppression. He also argued for accommodations and environmental adaptions over what he calls the concept of a utopian society without barriers, where all environments are accessible.

In the United Kingdom, the medical model of disability was challenged and, in response, a social model of disability was formed (Oliver, 1990). This model of disability has roots in materialism and has been expanded and revised over time to include post-structuralism and ideas such as bio-power (Thomas, 2007) as explanatory tools. More recent challenges to the strong social model like those presented by Shakespeare (2013) call for more "eclectic" approaches (Gabel & Peters, 2004). The resistance theories that Gabel and Peters (2004) put forth are those where elements of different models are used together to explain some universal characteristics of disablement while also allowing for individual agency and context-dependent specificity of experiences in the lives of disabled people in different parts of the world.

In *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology*, Carol Thomas (2007) presents the development of alterative accounts of disability as seen in medical sociology and disability studies. Alongside the shifts Thomas (2007) describes in medical sociology and disability studies were changes in psychology, which are evident in the work of Urie Bronfenbrenner (1974, 1979). The theories have in common an interest in the broader context of health and development.

Discourses of Disability

“Normal” child development discourse

Priestley (2003, pp. 64-65) taking aim at what he described as the “tyranny of ‘normal’ child development” identifies as a problem the role of biomedicine in developing, administering and fostering the use of technologies and tools to measure development of cognitive and physical norms. He argues that the standardisation of child development fosters the implementation of “standardized developmental sequences and timetables, against which children can be compared” (p. 65). Priestly argues that this standardisation of developmental milestones supports the development of an ever-expanding industry promoting the assessment and evaluation of children in health, education and social welfare. Priestly argues that these discourses, where children with disabilities do not measure up, fail to thrive, are globally delayed—mark them as inferior and subject them to “even more scrutiny, so children with impairments became disproportionally subject to new forms of surveillance, discipline and control” (Priestly, 1998, as cited in Priestly, 2003, p. 65). The normal childhood development discourse has implications for children with disabilities who become marked by differences in their developmental trajectory compared to that of their peers. Differences become magnified beginning when children are measured against growth and early developmental milestones through entrance assessment for school and standardised texting throughout their schooling years. As differences become more apparent, surveillance and control are increased as are the number of labels affixed to the differences and the children carrying those labels. “The effect of such labelling is to define those who develop differently as underdeveloped or incomplete people throughout their lives.” (Priestly, 2003, p. 66).

Professional Discourse

Thomas (2007) argues that, of all the professionals involved in the care and education of people with disabilities, physicians sit at the “apex of a professional hierarchy” (Thomas, 2007, p. 61). It is only when a “cure” for the disability or impairment fails that biomedicine invites participation from professionals in other disciplines. These other professionals are then invited in to support the rehabilitation and maximisation of functioning within given environments. Biomedical professionals are also seen to legitimise the assessment and evaluation practices used in identifying needs and directing care for individuals with disabilities.

The number of workers, professional and lay, in industrial societies who work in the field of disability has increased enormously. Almost every aspect of the life of a person who is disabled has its counterpart in a profession or voluntary organisation. Potential and real control over the life of individuals with disabilities is a modern fact. This has resulted in attitudes that individuals with disability are obviously, and particularly, dependent upon others for help. The growth of professional expertise in the field has also meant that these helpers have had an almost absolute monopoly in defining and articulating the problems of disability to the public (Finkelstein, 1980).

Assessment and evaluation practices are performed and controlled by professionals. Professionals are able to leverage their professional status to both legitimise assessment results and how they are interpreted. Weighting products of assessment and evaluation practices over the voices of those with lived experience of disability asserts an over-reach that Priestly (2003) and Finkelstein (1980) argue furthers the control of professionals over the bodies and lives of people with disabilities.

Ableist Discourse

Ableism includes the preference for abled bodies, the distinction of disabled bodies as other, and “at its core ableism characterises impairment or disability (irrespective of ‘type’) as *inherently* negative and should the opportunity present itself, to be ameliorated, cured or indeed eliminated” (Campbell, 2012, p. 213). Campbell (2012) discusses ableism as the suggestion of a universal definition of healthy mind, body and emotion and that deviation from these norms by way of disability cannot be tolerated. For Campbell (2012), ableism also suggests that those living with disability within a democracy are to be treated fairly, while disability should remain unacceptable and uncelebrated.

Models of Disability

Medical, professional and ableist discourses operate at various levels of influence. This influence can have an effect on issues, context and people affected by disability. In the following section, minority, cultural and social models of disability are discussed.

Minority

The minority model of disability, also referred to as social injustice, social oppression and social exclusion models, are popular and often in use within the United States. In this instance, social injustice and oppression can be summed up as:

> In [an] extended structural sense oppression refers to the vast and deep injustices some groups suffer as a consequence of often unconscious assumptions and reaction of well-meaning people in ordinary interactions, media and cultural stereotypes, and structural features of bureaucratic hierarchies and market mechanisms—in short, the normal processes of everyday life. We cannot eliminate this structural oppression by getting rid of the rules or making some new laws, because oppressions are systematically reproduced in major economic, political and cultural institutions. (Young, 1990, p. 41, as cited in Thomas, 2007, p. 10)

Oppression and exclusion resulted in a restricted access to resources and limitations on rights provided by the majority, thereby marginalising and disadvantaging those in the minor group—here, people with impairments and disabilities.

Within the fields of medical sociology, social deviance is a key concept for explaining illness as a form of deviant behaviour:

> The basis for describing illness as a form of deviant behaviour lies in the sociological definition of deviance as ay act or behaviour that violates the social norms within a given social system. Thus, deviant behaviour is not simply a variation from a statistical average. Instead, a pronouncement of deviant behaviour involves making a *social judgement* about what is right or proper behaviour according to a social norm. (Cockerham, 2004, pp.142-143 as cited in Thomas, 2007, pp. 11-12)

Under the minority model, disability status reduces opportunities and perception of potential positive contributions to individuals and society as well as establishes a basis for explaining disability as a form of deviance.

Cultural

Research evidence suggests that Māori define disability in wide-ranging ways. Kingi and Bray (2000) found that Māori defined and responded to disability differently than New Zealanders of European descent. The findings included notions of disability as it related to colonisation, loss of land and cultural knowledge, differing concepts of health and responses to health needs, as well as an emphasis that there is no one perspective of disability.

In *What's So Special About Special Education,* Wilkie (1999) engaged in research around perspectives of Special Education 2000, a policy that set out intentions for New Zealand's "world class education system". In the introduction, Wilkie (1999) suggested that:

> Many of the issues identified by both researchers and those developing the SE2000 policy are relevant to all New Zealanders: mobility of children who relocate before provision can be established; the effect of special needs children within mainstream settings on their fellow learners and their teachers; the challenges of provision and support within rural and isolated communities; the appropriate identification and response to behavioural and learning difficulties; the involvement of family/whanau in support of the child; the co-ordination of service provision for individual children involving a potentially wide range of professional "experts" and organizations, long with schools, or early childhood centres and families; the complexity of the SE2000 policy and stakeholders' access to information about the resourcing scheme; the needs of teachers for training and the development of skills to deal with learners with special needs in the "mainstream" settings. (Wilkie, 1999, p. 1)

There were also some issues identified specifically related to a Māori worldview. These issues included a lack of attention to spirituality, a misalignment of non-Māori and Māori approaches to support services and later finding that their needs as Māori continued to go unmet. Participants in Wilkie's (1999) research identified the process of labelling children to receive funding was contradictory to "kaupapa that considers the whole child on many levels and resists labelling" (p. 17). Wilkie's (1999) findings suggested that the basis of identifying children as being disabled was but one aspect of a system of supports and ways of working that directly contracted a Māori worldview.

Social

Oliver (1990), alongside Finkelstein (1980), developed the social theory of disability. Within the social theory, these authors described the creation of the construct of disability as a way of classifying people. Classifying people was a means to afford or deny social status on the basis of ability to work and on what was perceived as those who had ability to work but were not willing to do so, or perceived ability to work (Oliver, 1990)

In ‘Outside ‘Inside Out’ Finkelstein (1996) offered up a distinction between two expressions of the social model of disability. The first he called an “active social model of disability” which was used in the process of identifying and dismantling barriers created by an ableist society (Goodley, 2011; Goodley, Hughes & Davis, 2012). The second expression of the social model was a “passive social model of disability” where the emphasis was upon responding to, and reflecting upon, barriers erected by ableist society. Finkelstein (1996) deemed the latter as passive because it foregrounded the experience of discrimination and backgrounded actions that would disrupt that same discrimination. Ongoing debate continues within the disability studies community about which models of disability are most relevant and useful for progressing causes of importance to people with disabilities.

Disability Support Service Orientation and Provision

Stepping away from the more abstract theories that provide insight into frameworks and approaches for service delivery to children with disabilities, it is now helpful to look at the practical aspects of how these theories are operationalised in service provision. Early intervention services, in both the health and education sectors, are provided by teams of specialist practitioners who interact with one another to deliver services to children and families.

Professional interactions

Research literature on professional services for families of children with disabilities focuses on models of professional interaction. Models of professional interactions include multidisciplinary, interdisciplinary, and transdisciplinary working styles (Doyle, 1997; Sloper, 2004; Watson, Townsley, & Abbott, 2002). These models have been defined by the ways in which the professionals involved interact with one another, the client and the clients’ family. Multidisciplinary service is often comprised of professionals from different disciplines (e.g., physiotherapy, occupational therapy speech therapy, social work, etc.) working within a single agency (Watson et al., 2002). Interdisciplinary working is characterised by team composition where team members from different disciplines and agencies are working toward common goals but providing assessment and care separately. Transdisciplinary working is different again, in that the family or child is the focus of the service provision and practitioners meet together and plan for holistic goals (Watson et al., 2002).

Another way of exploring differences between the approaches is to look at the extent to which each of the three approaches makes permeable—or even dissolves—the disciplinary boundary around professional practice. Transdisciplinary working assumes, for example, that the practitioner can leave behind their restricted disciplinary identity and enter into another that is defined, less by their professional knowledge base, and more by the nature of the social problem being addressed together with other practitioners (moving from a medical/individual construction of the problem to a social/public multi-construction). Though the terms are commonly used interchangeably, in contrast to transdisciplinary working, multi-disciplinary working involves the collaboration of diverse practitioners who stay within the boundaries of their professional warrants (Choi & Pak, 2006).

Research literature favours models of interprofessional practice (Hillier, Civetta, & Pridham, 2010) to manage professional interactions and family-centred philosophy to drive service orientation (Dunst, 1997, 2002; Dunst & Dempsey, 2007; Dunst, Trivette, Boyd & Brookfield, 1994) —i.e., an “integrative” approach to disciplinary action. The philosophy behind family centred services seeks to remedy the issues that might arise from interactions with multiple practitioners acting from specific disciplinary perspectives by placing the family in the driver’s seat of service orientation.

Family-centred services can be identified by their reliance on four core beliefs: 1) the family is the constant in the child’s life; 2) the family is best suited to determine the challenges and well-being of the child; 3) helping the family helps the child; and 4) emphasis on family as the locus of control over care (Dempsey, Keen, Pennell, O’Reilly & Neilands, 2009; Dunst, 2002; Duwa, Wells, & Lalinde, 1993). Appeal to, and use of, family-centred practices have become common and are frequently mentioned in descriptions and specifications for early intervention practised for children with disabilities. The extent to which these practices maintain fidelity to their theoretical origins is difficult to assess and what might be seen on closer inspection is yet another generalised theory being implemented in diverse contexts.

Research literature describes the effects of family-centred care on parental empowerment (Dempsey & Dunst, 2004; Dunst, Trivette, Boyd, & Brookfield, 1994; Northouse, 1997) parental stress, competence and collaboration (Dempsey, Keen, Pennell, O'Reilly & Neilands, 2009). However, empirical research detailing outcomes of family-centred practice is scant (Dempsey & Keen, 2008). A series of studies conducted by Law and colleagues (1998) demonstrated some improvement in children's motor goals over a three-month time period. However, a control group was not used to rule out effects of maturation.

Dunst and colleagues (2007) conducted a meta-analysis of the impact of family-centred service orientation and children's developmental gains. The outcomes measured in the meta-analysis included: child behaviour and functioning; participant satisfaction; parenting behaviour; personal and family well-being; self-efficacy beliefs; and social support. The greatest effect was seen in levels of satisfaction, self-efficacy beliefs, and social support. Family-centred services were also found to have a positive effect on child behaviour, though the effect size was less than that of the indicators mentioned above. Dunst and colleagues (2007) address criticisms that family-centred services supplant the child's interest with those of the family by referring to FCS as a service delivery method, not an intervention. According to Dunst and colleagues:

> There is no reason to believe or expect that family-centred practices would be directly related to child development outcomes. Child focused, or parent/child focused interventions are what is done and family-centred practices are how the interventions are implemented. The latter is expected to influence the ways in which the former is carried out. (2007, p. 376)

Dunst and colleagues (2007) describe the contemporary shift away from models where individual pathology is the sole cause of disablement and focus attention on how practitioners, children, families and larger systems interact to construe and construct impairment and interaction within society.

Families and professionals

Children with disabilities and their families have been found to encounter difficulties when interacting with professionals in education, health and other support sectors (Ballard, 1994). Issues might arise from competing definitions and understandings of impairment and disability, ambiguous policies, tendencies to adhere to prescribed, needs-based frameworks shaped by the availability services while delegitimising preferences, deficit orientations and exclusionary practices (Ballard, 1994; Brown, 2014; Fairclough, 2013; Foster-Cohen & van Bysterveldt, 2016; Hornby, 2012; MacArthur & Dight, 2000; Macartney, 2011; McMenamin, 2014; Powell, 2012; Selvaraj, 2016; Wills et al., 2016; Wills et al., 2014).

Much of the research literature in New Zealand that addressed these topics is focused on interactions between families of children with disabilities and education professionals working in educational settings, with a few exceptions. Looking at relational practices in early intervention services, Blackburn (2016) argues for continued emphasis on building and maintaining relationships between practitioners and parents. There is then some caution when discussing this literature in relation to early intervention and related practices. Early intervention and related practices frequently include professionals outside of the educational sector, such as those in health and allied health, and professional/family/child interactions that took place in community and natural environments and beyond the school campus boundaries. This is not to say that the issues identified in the educational systems and practice for children with disabilities are irrelevant; instead, they are but one aspect of the complex practice environment in early intervention where professionals from various disciplines and sectors come together with parents in making decision on behalf of children.

Disability Support Services in New Zealand

A stocktake and needs analysis of child development services and conductive education services in Aotearoa New Zealand found that there were significant differences in the services offered throughout the country (Ministry of Health, 2014). The inconsistencies in team composition and resulting array of services on offer was partly the organic result of services responding to local needs. The stocktake also found that Child Development Services and Conductive Education teams were using various models of care, including family-centred care, and implementing practices at various levels of fidelity to evidence-based practice models. Also found were inconsistencies in referral practices, eligibility criteria (including age and impairment among others) and wait listing and prioritisation practices. Service gaps and needs identified were insufficient levels of staffing for specific disciplines or for a discipline as a whole as part of the larger team make-up. Cultural advisors, psychologists, and speech language therapist were particularly needed. In the case of speech language therapists, a lack of practitioners resulted in reduced availability of support for communication development as feeding and swallowing needs were prioritised as they were most likely to result in hospitalisations if needs went unmet.

The stocktake (Ministry of Health, 2014) also found services for children with mild to moderate needs were going unmet. Unmet requirements of children with mild/moderate needs were sometimes due to prioritisation of high and complex cases, criterial ineligibility for Child Development Services or Ministry of Education Special Education Services, and insufficient resources. Also noted in the stocktake were reports that early delivery of services to children with mild/moderate needs had the possibility to provide a significant positive impact on their development trajectory and future participation in society. Another gap identified was the resource limitation of Ministry of Education Special Education Services, differences in service criteria and disparate levels of services experienced by children and families when transitioning between services. The stocktake (Ministry of Health, 2014) also found Child Development Services teams in need of support for professional development opportunities.

Alongside a shift from institutional to community care, came the need for families to assume active roles in the care and education of their children (Mitchell, 1985; Wills et al., 2016). Mitchell (1985) clarified these roles in what he called developmental tasks of parents—what was required of parents in responding to the needs of their child with a disability. How a parent interacted with these tasks,

> …will depend on one's personal resources and on factors present in the family microsystem. Their resolution will depend, too, on the quality of reciprocal interactions between the family and the various mesosystem settings such as the hospital, the family doctor, the extended family, friends, neighbours and associates. (p. 142)

Mitchell (1985) described the principles that facilitated reciprocal interactions between parent and practitioners. Of particular importance was the sharing of correct information with parents in a transparent manner and in consideration of the family background and dynamics.

In 1988, the effort to increase parental access to information was furthered by creation of the *Parent Pack* (Baldock, 1998), for parents of children with special educational needs

(Stephenson & Thomson, 2015). The *Parent Pack* (Baldock, 1998) was created as an information toolkit assembled by parents and for parents and distributed to organisations without official backing (i.e., Ministry approval) (Stephenson & Thomson, 2015, p. 38). Also, in the *Parent Pack* were ideas around the role of professionals in supporting parents of children with disabilities. As stated in the *Parent Pack*,

> When families are well supported, when their needs are understood, and efforts made to meet them, when their voices are heard and when professionals realize their role is to facilitate decision-making more than it is to make decisions, then we have a climate that allows us to move toward the newer programme alternatives, which are available. We have looked closely at advocacy agencies in the United Kingdom, in the United States and in Australia. We are concerned that in some cases, particularly in the United States, the approach to advocacy taken by some of these agencies is confrontational in a fashion, which may well suit their needs but does not necessarily suit ours here in New Zealand. Here in New Zealand, we must ensure that our advocacy style suits our cultural environment and our legislative system. (Baldock, 1988, p.42)

Some 29 years later, early intervention practice research in the United States continues to find professional practices fraught with heavy reliance on legal compliance as the driver of professional–family collaboration (Lee, 2015; Skirtic, 1991). This finding is notable in documenting the challenges to strengthening opportunities for family and professional partnerships and makes a case that mandating partnering practices is not necessarily a route to ensuring collaborative working.

Relevance of international research

International social movements shape understandings and provision of services for children with disabilities in New Zealand (Stephenson & Thomson, 2015). The relevance of international research to the field of practice in New Zealand is difficult to ascertain. It is noteworthy that a majority of research on the topic of early intervention models is based on the models in use in the United States, United Kingdom, Canada and Australia. The research that came from the United States is based on models and practices that were aggressively controlled by federal legislation (Lee, 2015; Skirtic, 1991). The influence of legislation contributed to an atmosphere where practitioners subscribed to the letter and not the spirit of the law, which then saw parent participation that looked more like "compliance than communication" (Kalyanpur & Harry, 1999, p. 25 as cited in Lee, 2015). Compliance or non-compliance then mixed with the aggressive advocacy styles discussed by Baldock (1988) signal the importance of insuring a good fit between international research evidence and the local culture into which they are being imported.

Summary

This chapter reviewed the research literature related to supporting children with disabilities from different vantage points. The chapter began with an overview of historical trends and moved on to discuss prominent discourses and models of disability. The following section narrowed focus to show how those discourses and models were in operation through professional and parent and professional interactions. The next chapter builds on these ideas through more detailed discussion of the theoretical concepts.

Chapter Four: Theoretical Framework

Introduction

Several different pieces of research are particularly influential in informing the theoretical framework for this research. The first is Mitchell's (1985) use of Bronfenbrenner's (1979, 1996) socioecological theory in drawing on what he calls the developmental needs of parents. Mitchell's work explains the changing requirements occurring as the parents of children with disabilities follow a parallel development trajectory to their children. The second is McCartney's (2013) use of discourse analysis in exploring parental narrative journeys. McCartney's research (2013) opened up the possibilities of examining in depth the experiences of parents and their relationships with disability supports while refusing to accept traditional medical models of disability. The third primary influence is that of Ingolfsdottir, Traustadottir, Egilson, and Goodley (2012) in their paper examining the potential for research positing the usefulness of applying of cultural historical activity theory (CHAT) to inquiries into early intervention practices. Cultural historical activity theory is a third generation activity theory (Ingolfsdottir et al., 2012; Roth & Lee, 2007). It brings together the multiple layers of interactions found in Bronfenbrenner's (1979) socioecological theory with the influences of discourses and schematics found in critical disability theory. Ingolfsdottir and colleagues (2012) call attention to Bronfenbrenner's (1979) influence and its clear visibility in the construction of early-intervention team construction and intervention practices. Close examination of these three pieces of research, coupled with the purpose of the research to examine the experiences, influences, and interactions of those involved in the support of children with disabilities informed the conclusion that the way forward was to combine the aforementioned approaches. Thus, the three pieces influence my interpretation of socioecological and critical disabilities theory and influence development of the emerging integrated model.

Child Development in Context—Socioecological Systems Theory

Bronfenbrenner's socioecological systems theory (1979, 1996) is profoundly influential in how child development in context is understood. (Darling, 2007). Socioecological systems theory and the socioecological model are widely seen as informing and explanatory tools. Examples from Aotearoa New Zealand include socioecological systems theory in development of *Te Whaariki*, New Zealand's early childhood curriculum (Nuttall, 2013); early intervention services; and specialist support provided by child development services to understanding children's response to disasters such as that seen after the Canterbury earthquakes (Hu, 2015; Mutch, 2015).

In Bronfenbrenner's (1979) seminal work, *The Ecology of Human Development*, Bronfenbrenner theorises child development as changes over time resulting from complex interactions between the child and their environment. He argues:

> …that understanding of *human* development demands more than the direct observation of behaviour on the part of one or two persons in the same place; it requires examination of multi-person systems of interaction not limited to a single setting and must consider aspects of the environment beyond the immediate situation containing the subject. In the absence of such a broadened perspective, much of contemporary research can be characterized as the study of *development-out-of-context.* (Bronfenbrenner, 1979, p. 21, emphases in original)

Bronfenbrenner's work signalled a shift in psychology, concurrent with the work of disability studies scholars and political activists (Barnes, 1999). Disability studies scholars and activists were themselves looking beyond the traditional individual pathology paradigms and toward larger social and environmental influences that shaped the experience of impairment and disability, development, attitudes, and policy (Finkelstein, 1980; Goodley, 2011; Oliver, 1990; Thomas, 2007).

Accounting for the myriad of contexts in which human development occurs, Bronfenbrenner (1979) developed the socioecological systems model of development. The socioecological systems model is an analytic tool that can be used to view and explore different systems of which humans are a part. Often referred to as a "Russian nesting doll" (See Figure 2) for the way it is visually depicted as a model made up of concentric shapes nested within one another. The socioecological systems model sets forth expanding spheres of influence in which a person may be directly or indirectly involved. At the centre is the individual. Beyond the individual are hierarchical systems of influence that include the microsystem, mesosystem, exosystem and macro system.

Figure 2.

Socioecological Systems Model

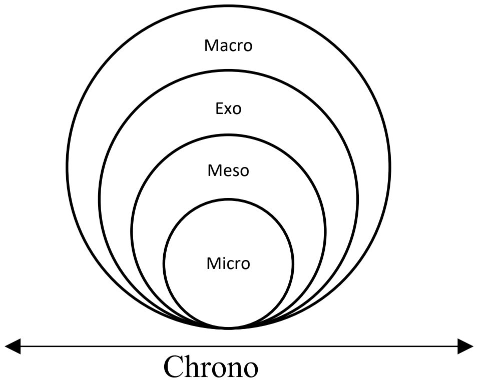


Image Adapted from (Bronfenbrenner, 1979)

The microsystem is “a pattern of activities, roles, and interpersonal relations experienced by the developing person in a given setting with particular physical and material characteristics” (Bronfenbrenner, 1979, p. 22). In disability research involving infants and toddlers, the microsystems studied often include the home, immediate family, and caregivers. For older children, between three and five years of age, the microsystems studied are likely to include early learning and caregiving settings and teachers/carers (Sontag, 1996). Of particular importance is individual perception of the experiences occurring within this system (Bronfenbrenner, 1979).

The mesosystem is the next system up in the socioecological systems model. The mesosystem “comprises the interrelations among two or more settings in which the developing person actively participates (such as, for a child, the relations among home, school, and neighbourhood peer group...)” (Bronfenbrenner, 1979, p. 25). The mesosystem is considered “a system of microsystems” (p. 25). Sontag (1996), in describing Bronfenbrenner (1979), discussed the four primary types of interconnections: *multi-setting participation* (activity in more than one setting), *indirect linkage* (a parent or other who acts as a connection between settings), *inter-setting communications* (messages between settings) and *inter-setting knowledge* (experiences and information that participants in different settings have about each other) (Sontag, 1996, p. 329).

The third stage in the socioecological systems hierarchy is the exosystem. The exosystem "refers to one or more settings that do not involve the developing person as an active participant, but in which events occur that affect or are affected by, what happens in the setting containing the developing person" (Bronfenbrenner, 1979, p. 25). The exosystem might contain local politics, industry, social services, or neighbours. Sontag (1996) identified elements, emphasised by Bronfenbrenner, of both the meso and exosystems that were especially salient in disability research: positive orientation, goal consensus, and mutual trust.

The fourth level up in socioecological systems theory is the macro system. The macro system is made up of "consistencies, in the form and content of lower-order systems (micro, meso, and exo) that exist, or could exist, at the level of the subculture or the culture as a whole, along with any belief systems or ideology underlying such consistencies" (Bronfenbrenner, 1979, p. 26). Macrosystems are likely to contain ideas and influences of culture, religion, politics, and economics. Drawing on Bronfenbrenner (1979), Sontag (1996) explains how cultures hold a repertoire of belief systems and these belief systems inform the context in which children develop. These contexts assert influence on how risks, goals and practices in child development are defined, and therefore have potential top moderate or create causal effects on behaviour.

Chronosystem (Bronfenbrenner, 1994) is the part of the model proposed by Bronfenbrenner that allows of examination of changes in behaviour over time, and across the changing environments of which they are a part. Simple chronosystems look at single transitions such as how a child transitions into school or, is affected by the death of a parent (Bronfenbrenner, 1994). More complex chronosystems examine the "cumulative effects of an entire sequence of developmental transition over period of the person's life" (p. 724). This conception of the chronosystem is similar to life course theory (Elder, 1974, 1985, as cited in Bronfenbrenner, 1994). In this research context, the chronosystem model would apply to investigations that explore a person's response to transition beginning at early childhood care and education, school entry, school leaving, and transition to adult services and beyond. In disability research, the chronosystems model has been used in a wide array of investigations from school to home communication (Lemmer, 2012) to investigations of resilience in disaster responses (Boon, Cottrell, King, Stevenson, & Millar, 2012),

While Bronfenbrenner's (1979, 1992) work has become widely used as a basis for the inclusion of parents, family, professionals and others into the education, care and planning for children with disabilities, less emphasis has been placed on the influence of the macro systems on interpersonal interactions in setting, directing care, and planning. This is especially interesting because part of this over-emphasis on the individual is what led to Bronfenbrenner's development of the socioecological model. Describing the classic equation of behaviour as the function of a person the environment, B=f(PE), (Lewin, 1935, p.73, as cited in Bronfenbrenner, 1979), Bronfenbrenner stated,

> One would therefore expect psychology, defined as the science of behaviour, to give substantial, if not equal emphasis to both elements on the independent side of the equation, to investigate the person *and* the environment, with special attention to the interaction between the two. What we find in practice, however, is a marked asymmetry, a hypertrophy of theory and research focusing on the properties of the person and only the most rudimentary conception and characterization of the environment in which the person is found. (Bronfenbrenner, 1979, p. 16)

It can be argued that this over-emphasis on the person (P) and not the environment (E) continues to this day, and has been the impetus for the development of social theories of disability (Corker & Shakespeare, 2002; Finkelstein, 1980; Gabel & Peters, 2004; Goodley, 2011, 2014; Goodley, Hughes, & Davis, 2012; Grue, 2015; Hughes, Goodley, & Davis, 2012; Oliver, 1990; Shakespeare, 2013; Thomas, 2007; Tremain, 2005) and a main focus of disability studies (discussed in detail further along in this chapter).

Bronfenbrenner's (1979) original socioecological systems theory has undergone some revision, critique (Belsky, 1980) and modification since its publication in 1979. Arguing for the applicability of Bronfenbrenner's revised socioecological systems theory (1992) in disability research, Sontag (1996) stated that the expanded socioecological systems theory supports "[r]esearch efforts related to family and community influences that refocus on the child's *development-in-context,* at the same time providing a viable framework to better understand the multiple systems of interaction influencing children's educational outcomes." (p. 321, emphasis in original).

Sontag (1996) is especially focused on the use of what Bronfenbrenner (1992) calls socioecological niches. Socioecological niches “are particular regions in the environment that are especially favourable or unfavourable to the development of individuals with particular personal characteristics.” (Bronfenbrenner, 1992, p. 323, as cited in Sontag, 1996, p. 323). These socioecological niches are then used to explain person/environment interactions in a particular context.

Socioecological model in the Aotearoa New Zealand context

Te Whariki (Ministry of Education, 1996) uses Bronfenbrenner’s socioecological systems model, along with sociocultural theory, and bi-cultural influences unique to Aotearoa New Zealand, to establish the developmental context for children from birth to school entry. *Te Whaariki* describes multi-systemic influences on how children perceive and navigate their environment.

It is based on a sociocultural constructivist model where knowledge development is an interactive process (Golding, 2011; Hedges & Cullen, 2005; Nuttall, 2013). Implicit then, under the *Te Whariki* curriculum, is the expectation that children are to actively participate in knowledge creation drawing from their cultural and social experiences (Hedges & Cullen, 2012). For children with disabilities, cultural and social experiences include experiences of their impairment and navigating spaces designed for the un-impaired. These spaces include the physical environments of early childhood centres, curricular spaces which shape expectations for what a child with impairments might be expected to learn, and relationship spaces that shape how some children with disabilities and their families are included within the larger milieu of the early childhood learning communities.

Critical Theory

Critical theory is not a single theory, but a label applied to theories that reject a positivist approach to social inquiry, and which argues that human activities are socially constructed and interpreted, and that social inquiry is value laden (Gibson, 1986). Kincheloe and McLaren (2000) argue that critical theories are not about constructing a world view but, instead, are used for developing questions to explore the world. They (Kincheloe & McLaren, 2000, p. 281) consider critical theories to be those concerned with "issues of power and justice, and the ways that the economy, matters of race, class and gender, ideologies, discourses, education, religion and other social institutions, and cultural dynamics interact to construct a social system."

Arguments exist as to the extent to which critical theories should be identified as emancipatory or not. Kinchole and McLaren (2011) argue there are power dynamics inherent in the ideas of emancipation of others, as well as a socio-political context that one cannot completely remove oneself from. Gibson (1986) argues that critical theories have emancipatory potential in their ability to reveal interests of various social actors and provide multiple valid representations of realities, which can then be acted upon in change. The question, "Whose interests are being served?" (Gibson, 1986, p. 5) is used to critically question the reasoning behind social action. Of particular interest to this study is the emphasis in critical theory on critiquing instrumental rationality. Gibson (1986) describes this as exploring the "Why do it?" question, to get beyond the "How to do it?" to get at the values imbibed in the social activities or facts (p. 7). Critical theories also argue that social events can be explained on three levels: (1) personal and interpersonal; (2) institutional; and (3) structural (p. 14).

In this study, critical theories are applied at the levels described above by applying critical disability theories in reviewing literature, identifying methodological preferences, collecting and analysing data, and discussing findings. Critical disability theories are used in analysing empirical data in unveiling values behind the social actions and institutional and environmental contexts described by participants. Finally, critical theory is also used to explain structural discourses that enable and enforce professional practice and service delivery.

Critical Disability Theory

In this research, critical disability theory relates to those theories that problematise traditional western conceptions of disability as an individual issue requiring mediation and warranting sympathy. In *Theorizing Disability*, Grue (2015) discusses disability as an "always-already theoretically informed concept" the meaning of which varies across and among those using the term. Grue (2015) goes on to state there are three prominent areas of disability studies scholarship, each with their own conception of critical disability theory underpinning their work. In the United States, people with disabilities are considered a minority group. In the United Kingdom, they are considered an "oppressed class" and in Scandinavian countries, people with disabilities are considered "beneficiaries of welfare state programmes and interventions." (Grue, 2015, p. 30). Conceptions of disability are related to the prominent discourses in use. Discourses are the wider schematics, influences of history and culture that shape what is known and how concepts come to be known and understood. Discourses differ from models and theories in that models and theories sit within discourses (Grue, 2015).

> This is one of the reasons why models, and theories, should be distinguished from discourse. Models of disability, taken as schematic, explanatory tools, are parts of discourse, are elaborated in discourse, and are usually embedded in discourse. Theories, too, draw on discourse in order to produce meaning, while discourse is usually too complex and too variable to be reducible to either theories or models. (Grue, 2015, p. 33)

In the research, I handle discussion of discourse, models and theories by including discourses of disabilities in the literature review chapter and using a model of social disability theories to show their relationship to one another.

One way of explaining the differences between social theories of disability is to use a continuum to juxtapose the medical, universal and social theories of disability. In the diagram below, theories of disability are placed along a horizontal continuum, with a strong medical model (Brisenden, 1986, Goodley, 2011) at one end and a strong social model (Finkelstein, 1980; Oliver, 1990) at the other end. The universal model (Shakespeare, 2013; Zola, 2005) of disability is in the middle as it is comprised of elements of medical and social constructions of disability.

Figure 3:
Social Construction of Disability Continuum

Medical	Universal	Social
Understanding disability as an individual or personal problem	Understanding disability as a complex phenomenon with individual and social aspects	Understanding disability as a social and environmental problem

The notion of universality is problematised by critical disability studies scholars in the Global South. Speaking from an Australian context, Meekosha (2008, 2011) cites evidence of the exclusion, erasure, colonialism and power and control dynamics dominating the US and UK disability studies literature. Meekosha (2008, 2011) issues a challenge to recognise privileged discourses of disability, like those in the US and UK, where certain levels of access to basic services, healthcare, food and sanitation are assumed and their impact on the theorising of disability. An example from the current context is the assumption that universal services are sufficient to meet the needs of children and families across Aotearoa New Zealand, even when the evidence (United Nations, 2011, 2015) is suggesting otherwise.

Summary

This study endeavours to incorporate multiple perspectives at each stage of the research process. This chapter rationalises bringing together two different theoretical constructs into an emerging framework to support choosing a critical constructivism methodology, use of naturalistic methods and a multi-tiered approach to data analysis. Bringing together various concepts can complicate and muddy the metaphorical waters of research, such are the realities of practice, and especially so for the participants of this research study. The developing theoretical framework provides an imperfect, but useful, tool for explaining how differing conceptions of disability, roles, relationships and practices influence disability support provision.

Chapter Five: Methodology and Methods

Introduction

This chapter describes the methodology used in designing the research study, the methods used in location of, and participant selection, data collection, data analysis, and the rationale for using a qualitative critical constructivist approach. The chapter provides a detailed description of the research methods including participant recruitment, ethical considerations, data collection and analysis, and the establishment of trustworthiness.

Methodology

A paradigm can be described as a set of beliefs and corresponding methods (Lincoln & Guba, 1985) that guide action (Lincoln, Lynham, & Guba, 2000). A paradigm is also a “world view, a general perspective, a way of breaking down the complexity of the real world” additionally, “paradigms are also normative, telling the practitioner what to do without the necessity of long existential or epistemological consideration” (Patton, 1980, as cited in Lincoln & Guba, 1985, p. 201). Research paradigms are then the researchers’ beliefs that shape how they see the world, the ways in which they explore the world, and how they ascribe meaning to what is learned through exploration.

Identifying the research paradigm requires uncovering beliefs of what research is and what it should be. This tension is described in the literature as the result of differences in ontological (nature of existence), epistemological (knowing what exists), axiological (process of discovering value), and methodological (process of inquiry) perspectives attributed to different research paradigms (Lincoln et al., 2000). This study takes an interpretive approach to defining the research paradigm by applying elements of critical and constructivist theories in developing the research methodology.

Guba (1990) described the constructivist methodology as one whose “aim to identify the variety of constructions that exist and bring them into as much consensus as possible” (p. 26). The reasons he (Guba, 1990) gave for doing so are twofold: to portray individual constructions “as accurately as possible” (p. 26) and to bring those constructs into dialogue with others’ constructions through comparisons and contrasts. Constructivism is underpinned by a set of basic beliefs of knowledge construction. First, that knowledge is transactional and co-constructed through lived experience (Lincoln et al., 2000). Second, knowledge is local and context-dependent, which leads to the interpretations of findings as the consequence of the interactions between researcher and participant in their environment (Lincoln et al., 2000). Lincoln et al. (2000) identify qualitative methods as better suited to offering support for an emergent research design and facilitating dialogue between researcher and researched, the result of which aids in the interpretation of research findings. Third, the aim of constructivism is to build understanding and weigh the quality of findings according to trustworthiness and authenticity (Lincoln et al., 2000).

This study deals with these tensions by employing a moderate social constructivist epistemology (Schwandt, 2000). The moderate social constructivist epistemology, or what Longino terms “contextual empiricism” (Longino, 1993a, p. 263, as cited in Schwandt, 2000) is the basis for “a theory of inquiry that reveals the ideological dimension of knowledge construction while at the same time offering criteria for the comparative evaluation of scientific theories and research programs” (Longino, 1994a, p. 257, as cited in Schwant, 2000). Contextual empiricism (Schwandt, 2000) provides an epistemological position that supports the exploration of ideological values alongside empirical data. Using a similar approach, Kincheloe (2005) applies what he calls critical constructivism to his work in the educational field. He (Kincheloe, 2005) applies critical constructivist concepts in explaining the bidirectional influence of teaching and learning on knowledge and development in the classroom. A moderate social constructivist epistemology (Shwandt, 2000) provides the framework for incorporating critical and constructivist lenses in a process of critical constructivism (Kincheloe, 2005). In this study, critical constructivism is used to explore the experiences of participants through multiple forms of analysis to reveal multidirectional influences of interactions of participants, between parents of children with disabilities and practitioners providing care and education.

Qualitative research

Qualitative research is an activity that locates the observer in the world (Denzin & Lincoln, 2000). It allows for the exploration of research endeavours through multiple perspectives providing a complex and holistic view of the topic under scrutiny. Qualitative research also provides a pathway to exploring situatedness of knowledge where explanations and interpretations can be reconciled (Gergen & Gergen, 2000).

Qualitative research consists of a set of interpretive material practices that "make the world visible" (Denzin & Lincoln, 2000, p. 3). In this study, the world made visible is that which is made up of the experiences, interactions, and expectations of parents and professionals involved in the lives of children with disabilities. Practice experience and evidence from the research literature signal potential for the research to surface tension between participants' roles and boundaries. In the interest of providing a wide representation of views from different professional disciplines and parental roles, a methodological approach that supports the exploration of meaning in diverse contexts is needed. Qualitative methodology affords opportunity to "embrace tensions and contradictions" (Denzin & Lincoln, 2011, p. 6) and bring to light the construction and meaning of social interactions and, "by focusing on participants' personal meanings, qualitative research, 'gives voice' to people who have been historically silenced or marginalised" (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005, p. 199). The use of multiple methods is a characteristic of qualitative research (Flick, 2014), and well suited to interdisciplinary research where professional roles and perspectives differ.

Naturalistic inquiry is an expression of the constructivist paradigm. Lincoln and Guba (1985) ascribe to the naturalistic paradigm five axioms relating to multiple realities constructed through an interaction between the knower and what is known which is context bound. In naturalistic inquiry, the act of inquiring is a value expression and because of the constant interaction between knower and known, cause and effect are indistinguishable from one another. In addition to the five axioms, Lincoln and Guba (1985) also ascribe to naturalistic inquiry 14 primary characteristics. Seven of the primary characteristics are related to data collection. The data collection characteristics suggest research be conducted in the setting in which the activities typically take place and using the researcher as the instrument, who can then contribute tacit knowledge. The researcher employs methods sensitive to the ideas and values emerging from the research, chooses samples that are context-dependent, and enables the research design to unfold in response to interactions between researchers, participants, and research context. The research boundaries are determined in vivo and in response to emerging focus and demands.

Purposive sampling is described as having four main features: 1) *emergent sampling design* that is not prescribed prior to starting the research; 2) *serial selection of sampling units* such that each unit is chosen after analysing the one before so that information can be built upon and information gaps filled; 3) continuous adjustment or *focusing the sample* to ensure participant relevance to the research project and working hypothesis; and 4) *selection to the point of redundancy* when it can be determined that no new information is being generated (Lincoln & Guba, 1985).

Four of the primary characteristics of naturalistic inquiry (Lincoln & Guba, 1985) describe analytic methods. Inductive data analysis is used to uncover multiple realities and make researcher–researched interactions and values explicit. Using grounded theory, the researcher finds theory emerging from data, rather than using a priori theory to explain what is seen (Charmaz, 1996). In this process, the researcher is involved in an iterative process of interacting with data, theory and empirical literature and particulars of local context. Idiographic interpretation signals data that are interpreted according to the particulars of the case and the researcher negotiates the meaning of data with those who provided the data.

The remaining three primary characteristics deal with the application of findings—*case study reporting*, *tentative application* and *trustworthiness*. Case study reporting provides opportunity to describe researcher–researched interactions as well as support "naturalist generalizations" (Stake, 1980, as cited in Lincoln and Guba, 1985, p. 42). Case study is defined in numerous ways (Creswell, 2013; Lincoln & Guba, 1985; Macdonald & Walker, 1975; Stake, 1995; Yin, 2014). Lincoln and Guba (1985) describe variations in the content (from individuals to cultures, incidents and programmes) and purpose of case study reports. Discussing the different purposes of case study reports, Lincoln and Guba (1985) posit there is no simple structure for organising the variation in case study reporting and purpose. Case studies can be used to "chronicle, render, teach or test"; they can be "written at different analytic levels, demand different actions from inquirer, and yield different *"*products*"* (p. 361). Case study is also described as a method for understanding how people, events and organisations interact in dynamic ways (Macdonald & Walker, 1975) within a localised set of circumstances (Stake, 2006).

Here, case study is used to define case boundaries (Stake, 1995) as they emerge through researcher interaction with the data. Case study is also used as a reporting method (Lincoln &

Guba, 1985), a way in which to process and record the data gathered in interviews, observations and researcher/participant interactions. Individual case studies are composed from transcribed interview text as well as observations and research memos. After completing individual case studies, horizontal case studies are created from themes identified within the individual case studies. Case development process is described in further detail later, in the Methods section.

Using variations of naturalistic practices across different participant groups offers opportunities to remain responsive to local contexts as well as opportunities for exploring different perspectives of complex interactions (Flick, 2014). Following the example provided by McInnes and colleagues (2017) as adapted from Lincoln and Guba (1985), the table below details how the characteristics of naturalistic inquiry are used in this research endeavour.

Table 1.

Characteristics of Naturalistic Inquiry

	Characteristic	Research Example
1	Natural setting	Interviews are conducted in home and workplace settings
2	Human instrument	Researcher conducts the interviews and analyses the data
3	Use of tacit knowledge	Researcher is an experienced practitioner
4	Qualitative methods	Multidisciplinarity of practitioners and inclusion of lay people and professionals support the use of qualitative methods for understanding multiple realities of participants
5	Purposive sampling	Purposive sampling increases the likelihood that that participants have a range of experiences of interest to the research
6	Inductive data analysis	Data are analysed in multiple ways including the use of an inductive process of thematic analysis (Braun & Clarke, 2006)
7	Grounded theory	A priori theories are not generated prior to data collection and analysis
8	Emergent design	Research design is developed in response to emerging data

9	Negotiated outcomes	Member checking is not negotiated as part of the research process
10	Case study reporting	Individual and horizontal case studies are constructed from individual interviews and cross case analysis (Yin, 2009, as cited in Creswell, 2013)
11	Idiographic interpretation	Findings are particular to research contexts
12	Tentative application	Findings are discussed in non-definitive terms
13	Focus determined boundaries	Research focus is determined by emerging data rather than by researcher's predetermined ideas of where boundaries lay
14	Special criteria for trustworthiness	Following naturalistic inquiry, procedures for ensuring trustworthiness are imbedded in the methods selection and implementation process and are described in the following section.

(adapted for this research from McInnes et al., 2017)

Qualitative inquiry, especially naturalistic case study, aims to illuminate the lived experience of those engaged in, and affected by, the phenomenon studied (Lincoln & Guba, 1985; Stake, 1995). The nature of interactions within a naturalistic inquiry (Lincoln & Guba, 1985) paradigm takes into consideration the particulars of the research environment, interactions between researcher and researched, the time frame within which the research is conducted, and the use of researcher as research instrument. The particularity of these interactions and the contexts in which they occur make it difficult, if not impossible, to reproduce these research findings in other contexts. That said, the criteria upon which naturalist inquiry are to be assessed is not by the limits of replication, validity or reliability as used in positivist approaches (Lincoln & Guba, 1985). The criteria for assessing the value of naturalist inquiry lies within its trustworthiness—in the quality of the data, thick description of context, and depth of understanding demonstrated as a result of the research (Lincoln & Guba, 1985; Lincoln et al., 2000).

Methods

Data for this study were collected following a critical constructivist paradigm and using naturalistic inquiry methods (Guba, 1990; Lincoln & Guba, 1985; Lincoln et al., 2000). Participant selection evolved through progressive focusing (Parlett & Hamilton, 1972) to capture a selection of perspectives from differing professional and lay participants as well as rural and urban contexts. A broad conceptual understanding was applied as a way of quilting together a research methodology and developing research agenda allowing for "tinkering" (Denzin & Lincoln, 2011, p. 168) with research methods, taking into account the research context, field-based experiences, and the researcher's previous experiences (Kincheloe, McLaren, & Steinberg, 2011). The research agenda was subject to local processes and networks, both formal and informal, and was guided by an interest in the experiences and stories of the research participants.

Research location

This research was set across a large geographic region on the North Island of Aotearoa New Zealand. The area was made up of rural and urban localities and is serviced by one local district health board. The research area had high rates of material deprivation, an ageing population and a high percentage of Māori (tangata whenua or indigenous people) compared to other areas of Aotearoa New Zealand (Ministry of Health, 2016b). The research area also had high rates of disability prevalence (Statistics New Zealand, 2013). The area's high rates of disability, wide geographic area, urban and rural localities, and relatively limited access to private disability support providers offered an opportunity to explore government-provided disability support practice in a reasonably contained environment.

Choosing the fieldwork location was also a practical decision based on access. Tapping into known networks was a process that facilitated access to practitioners who were likely to be interested in participating in the research through telling stories of their experiences (Chase, 2011). It was important to develop rapport with research participants so that they were willing to examine, in depth, their experiences, the complexities of their practice, and their practice environments.

Participant selection

Research participants were located using purposive sampling and progressive focusing (Parlett & Hamilton, 1972). Lincoln and Guba (1985) describe all sampling as purposeful—including a random sample that has the goals of identifying a representative sample. In this research, the aim was to identify practitioners and parents that were open to engaging in a process of critical reflection. Interview participants were identified using snowball (Lincoln & Guba, 1985), network, and chain-referral (Biernacki & Waldorf, 1981) sampling techniques, where participants are identified though collegial networks of practitioners and parents.

Study participants were located through an "each one reach one" approach (Lincoln & Guba, 1985) as the focus of the study narrowed. Disability support services colleagues were contacted and asked to facilitate access to other practitioners within a Child Development Service. Child Development Services practitioners then facilitated access to colleagues in the Ministry of Education Special Education Services. Both Child Development Services and Special Education practitioners worked in multiple sites across the region. However, some Special Education practitioners were restricted to working in some particular areas of the region, while others covered the entire region. Parent participants were located through the local district health board's community council. The selection process for each participant group is described in the following sections.

Participant Selection Stages

Stage one: child development services allied health team

Access to child development services was negotiated through the district health board's ethics application process. An application for approval to conduct research was submitted and I participated in a telephone interview with the medical director and cultural advisor. Recommendations were made for the researcher to consult with the District Health Board's consumer council to review participant information sheets and consent forms (Appendix 1). The District Health Board consumer council was contacted and a member of the council volunteered to work with me to review and make recommendations on the participant information sheet and consent forms. The community council member and I met and discussed the language used on the forms. The council member suggested changes. I amended the forms and resubmitted them to the council for review and then resubmitted to the University of Auckland Human Participants Ethics Committee (UAHPEC) for re-approval.

Once the ethics committee re-approval was granted, I participated in a pre-research discussion was with Child Development Services team members during one of their team meetings. The pre-research meeting provided an opportunity for me to introduce myself as the researcher, discuss the research project and participation, and respond to any questions. Participant information sheets and consent forms with my contact information were distributed. Those who were interested in participating in the research were asked to contact me directly.

Contact with District Health Board consumer council members facilitated links to parent participants. A council member forwarded participant information sheets and consent forms to parents and discussed the research project with them. Interested parents were asked to contact me directly to express interest in participation. A detailed account of parent recruitment follows in the next section.

Stage two: parents

Parents were sought as research participants in an effort to broaden the variation in perspectives gathered. Potential risks to practitioner–parent relationships were considered (J. Tarr, personal communication, 2015). Potential risks included possible harm to practitioner/family rapport and engagement when inviting participation from parents whose children were currently participating in child development and early intervention services. To avoid the possibility of jeopardising delicate relationships, research participation was limited to parents with past experience with child development and Special Education services. However, restricting participants to those with historical involvement posed limitations. Here historical involvement referred to parents who had interacted with Child Development Services and Ministry of Education Special Education Services over the past 23 years. Limitations included the freshness of events recalled and the possibility that parents would have, over time, reconstructed previous interactions in a more positive or negative light because of experiences since the time of service involvement. However, historical interactions were able to shield current practitioner/family relationships, as well as juxtapose historical and current practices and perceptions. Historical perspectives also offered opportunities to view changes to service policy and provision through the accounts of those involved across time and place.

Introduction to parents was initiated through the process of applying for approval to conduct research with the local district health board. The District Health Board chief medical officer directed review of participant information and consent documents through the consumer council. The Consumer Council was asked to review research consent and information documents to ensure they were readable and understandable for the intended local audience. Readability was an important consideration as the area was one of several with lower levels of educational participation and attainment as well as low levels of employment and job growth (Johnson, 2015).

Potential parent participants and parent recruitment were also discussed at document review and revision meetings. The Consumer Council member was involved with parent support and advocacy groups, both local and national, and offered to assist with brokering access to parent networks. Access to these networks revealed two additional parents of children with disabilities who were interested in participating in the study. The three parent participants were known to each other and expressed interest in talking together as a group. The dynamics of a group discussion have the potential to influence the information shared, either by helping or hindering, participant disclosure. Here, the participants were well known to each other and requested to meet as a group suggesting an increased comfort in participating when doing so within this particular peer group.

Parent case studies were developed from findings generated during the focus group. The focus group was held, by request, at the home of one of the participants. As mentioned earlier, participants knew one another from other settings, and two of their children participated in the same child development services. All three participants' children had transitioned into adult services in the same community prior to the focus group.

Stage three: Ministry of Education Special Education Services.

The information gathered in interviews with child development services practitioners and parents signalled the need to include practitioners' voices from the Ministry of Education Special Education Services. A Child Development Services practitioner informed colleagues from the Ministry of Education of the study and invited their participation. I sought approval to conduct research within the Ministry of Education. The application and approval process entailed review of the research consent and participant information documents and face-to-face meetings with local area management. Approval was granted and participant information sheets and consent forms were shared among practitioner colleagues. Practitioners contacted me directly to express interest in participating and to schedule interviews.

Participant summary

There was a total of 11 participants from four sites—parents' home, child development services centre, semi-urban and rural special education offices. A detailed description is provided below (see Table 2).

Table 2

Summary of Participants and Research Sites.

Research participants *n* = 11		
Age: Mixed adult **Gender: Male and female**		
Site	Type	Location
Child Development Services	(2) Visiting Neurodevelopmental Therapist / Physical Therapist (1) Occupational therapist (1) Team Leader	North Island – urban
Special Education	(1) Early Intervention Teacher (1) Occupational Therapist	North Island – urban
Special Education	(1) Early Intervention Teacher (1) Speech Language Therapist	North Island – rural
Parents	(3) Mothers of adult children with developmental/intellectual disabilities	North Island – urban

Data Collection

Data collection took place in three stages over an 11-month time period from May 2015 to April 2016. Each stage was marked by the completion of an approval process granting access to the research site. A summary of the access and entry process is described in the earlier section on participant selection. Data collection methods were the same across stages and research sites and are described in the following section.

Narrative interviews

Narrative face-to-face interviews were selected as the primary data collection method because they allowed me to actively explore the participants' stories of their experiences. In narrative interviewing, the researcher treats the participants' stories as expressions of their constructed identities and realities (Chase, 2011) and active interviewing (Holstein & Gubriem, 1995) techniques support the researcher's ability to respond within the interview by asking questions or for further clarification. The aim was to develop sufficient rapport between researcher and participant so that the participant would feel comfortable to discuss the stories that demonstrate the complexities of their experiences, practices and of the practice environment. Individual and small group interviews were chosen because larger groups might have dissuaded parents and practitioners from discussing some of the more challenging aspects of their experiences. Individual and small group interviews also provided opportunity for more flexibility in responding to what came up in conversation and more in line with an emerging research agenda.

Narrative interviews incorporated a reflection-on-action (Schön, 1987) framework where participants were asked questions about their thinking and responses in the moment as well as their current reflections on past experiences. As areas of interest emerged within the interview and eventually across interviews, the interviews followed a progressive focusing (Parlett & Hamilton, 1972) process to prompt more nuanced discussion with research participants about emerging areas of interest. I prepared general interview topics in advance to provide some common foundation from which to initiate the conversations between myself and the practitioner. Initial interview prompts included the following topics:

- Relationships, experiences, and interactions with children with disabilities, families and practitioners
- Experiences with allied health and education systems

- Facilitators and barriers to services
- Opportunities for improvement

Child Development Services practitioners were asked to explain their role in working with children, families and in working as a team. They were asked to describe the settings in which they worked and discuss the interactions between themselves and the people with whom they worked—as service providers, colleagues, educators, collaborators and members of the community. Child Development Services practitioners were asked to reflect on all aspects of their practice including: what was going well, opportunities for improvement in individual and team practices and within systems of care. Parent participants were asked to tell stories related to their families' involvement with child development and/or education services. Similar to what was asked of Child Development Services practitioners, parents were asked to describe what worked well for their family and where they encountered challenges. Parents were asked to discuss the nature and function of their relationships with Child Development Services and Ministry of Education Special Education practitioners as well as with the larger care and education systems. Ministry of Education Special Education practitioners were asked questions similar to those asked of the other practitioners. They were asked to describe their roles, their relationships with children, families and colleagues, and their interactions with the education and care systems.

Narrative memos and research journal

The interviews varied in length and lasted between 45 minutes to two-and-a-half hours. Following each interview, I recorded my own narrative accounts of the research experience. The narratives included descriptions of the location, setting, rapport between researcher and participant, as well as researcher reflections on the experience. These narratives were used as memos, or little reminders, of the fieldwork experience on any given day. I kept a research journal throughout the research process. Journal entries included notes on research activities, emerging links between the participants' reports, and between observations, interviews and the research literature. The research journaling exercise was part of the ongoing effort to develop meaning emerging from data (Charmaz, 1996).

Transcripts

All interviews were audio recorded with the participants’ permission. Interview recordings were transcribed verbatim to ensure closeness between the researcher and the interview text (Halcomb & Davidson, 2006). Transcription was completed by myself and a professional transcriptionist. The interview texts, along with text from narrative memos, were used in developing the individual case studies. Where the transcriptionist transcribed the interview, I reviewed each section of text used in the individual and thematic analysis for accuracy.

Data Analysis

In order to preserve the authenticity of participant voices and experiences, a three-step analytic process was used. First, and in line with the naturalistic paradigm, data were processed tacitly at each stage of data collection (Lincoln & Guba, 1985) and this initial process of analysis was used to guide the research agenda. In the tacit process, data were analysed in situ through process checks with participants and the use of a reflexive journal (Lincoln & Guba, 1985). This layer of analysis was also an inductive process, similar to the constant comparison aspects of grounded theory (Charmaz, 1996; Charmaz & Belgrave, 2007) where concepts and patterns emerging from the data were noted and used to compare and contrast data from other cases.

Second, an iterative and detailed narrative analysis of each interview was conducted. As the experiences described by participants clustered around the roles they held, I decided to illustrate the lived reality of the different types of experiences through what Mutch (2017, personal communication) calls vertical analysis. Vertical analysis is when each individual interview is examined closely to reveal the narrative (Smith, 2000) inherent in the participants’ experience. This requires the researcher to shape the narrative in a way that remains true to the perspective and voice of the participant. Once this analysis was performed with each interview, the narratives were shaped into individual cases. They appear in the next chapter as individual case studies (Stake, 1995).

Once the lived experiences of the participants were established, the third tier of analysis was conducted. This appears in chapter 6. Mutch (2017, personal communication) explains this as horizontal analysis. Stake (2013) describes this type of analysis as *cross-case* analysis. This approach requires the researcher to examine all cases, and in this research study, all transcripts and vertical case narratives in a horizontal manner. Researchers (Baxter & Jack, 2008; Stake, 2006, 2013) suggest this analysis might be performed around issues. In this research study, I organised the horizontal analysis around issues that occurred as dominant themes in the interview text. I sorted related issues identified in the text into groups with similar information and then assigned labels to each of the groups. Each issue grouping was then further developed into a broader theme.

The vertical analysis introduced the experiences of participants; the horizontal analysis drew themes from across the cases; and the final analysis reintroduced the literature and theoretical framework to propose an explanation for why the participants experienced their roles and relationships the way they did. This is elaborated in the discussion in chapter 8.

Reliability and Trustworthiness

Lincoln and Guba (1985) responded to critics who describe naturalistic inquiry as "undisciplined", "sloppy" and lacking rigor by demonstrating why the four criteria that establish trustworthiness in positivist research (truth-value, applicability, consistency, and neutrality) are inapplicable to naturalistic inquiry (p. 289). Critiquing both truth-value and applicability in terms of naïve realism, they (Lincoln & Guba, 1985) claim that once the assumption of realism is rejected, so too is truth-value as there is then no single reference point with which to provide comparison. Lincoln and Guba (1985) also critique applicability, problematising conceptions of population and representativeness as being independent of time and context. Finally, Lincoln and Guba respond to the call for neutrality by using Scriven's (1971, as cited in Lincoln & Guba, 1985) description of subjective or qualitative objectivity—that which described the "*quality* of the… evidence" (p. 300), the quality being the characteristic of data for which qualitative researchers are searching.

Lincoln and Guba (1985) make the case for moving away from reliability and validity and towards authenticity and trustworthiness. Richardson (2003), well known for her work in asserting that writing itself is a method of analysis, proposes moving beyond validation and triangulation to a process of crystallisation that she says, "provides us with a deepened, complex, thoroughly partial, understanding of the topic" (p. 934). Complexity and partiality are expected within post-modern paradigms of knowledge, which reject grand narratives and emphasise local practice and knowledge (Flick, 2014).

In this research, the quality and trustworthiness criteria were met by using multiple interviews with lay and professional participants and document review as multiple data sources and protracted engagement in the field through collecting data over a one-year period. I established transferability through the use of in process member checks by asking for clarification and testing emerging theories during interviews. Dependability was demonstrated by way of thick description (Geertz, 1973) of the research context, setting, participants, and methods. Confirmability was established through the research journal and memos kept throughout the data collection and research process.

Ethical Considerations

Ethical considerations were negotiated at each stage of data collection. Prior to the start of each interview, participant information sheets and consent forms were reviewed. Interviewees were invited to ask questions regarding any part of the research process and I informed participants of the aspects of voluntary participation, including their ability to refuse to answer any question and withdraw data. All interview, transcript and narrative data were stored in a secured electronic format and are able to be retrieved for future review as needed.

Confidentiality was maintained through the use of pseudonyms in writing up the research and obscuring of details that would make any of the sites, organisations, communities and/or individuals identifiable. Process consent was practised and provided participants opportunity to withdraw consent at any time (Silverman, 2010, 2013). Process consent allowed participants the freedom to speak candidly with the knowledge that the information they provided could be retracted at will. Informed consent was ensured through the draft, review and revision of consent forms and participant information sheets that provided succinct information that was relevant, timely and meaningful for participants (Gray, 2014). Interest in the interactions of power divergent dyads prompted this research endeavour. Perceived imbalances of power, especially those between researcher and participant, were a foremost consideration. A means of managing this was making explicit the research process and researcher’s position, using a practice of process consent, and engaging in critical reflection at each stage of the research process.

Negotiating Māori relationships was supported through formal and informal advisors. Identification of a cultural advisor was required as part of the ethics process for access to

DHB service personnel. A lecturer at the University of Auckland agreed to formally act as a cultural advisor. However, informal advice was also found to be helpful. Through the research process, relationships were developed with local Māori colleagues. With time and attention came opportunities to ask questions, invite feedback, and explore issues related to navigating Māori–Tauiwi relationships.

Summary

This chapter detailed the qualitative methodology and naturalistic enquiry methods used in the research. Rationale was provided for the participant sampling, data collection and data analysis approaches. The next chapter discusses findings from the participant interviews.

Chapter Six: Individual Case Study Findings

Introduction

This chapter details findings from participant interviews in the form of individual or vertical (Mutch, 2018) case studies. The chapter is divided into three main sections. The first section is comprised of three vertical cases, one for each of the parent participants. The second section is made up of four vertical cases, each developed from interviews with child development services practitioners. The final section contains four vertical cases, one for each of the Ministry of Education Special Education practitioners. In contrast to the previous chapter, this chapter is written in the present tense in order to provide the reader greater access to the lived experience of research participants as well as to convey a sense of urgency around their voiced concerns. The chapter concludes with a brief summary and introduces the next stage of analysis.

Rationale for the Presentation of Findings

Individual case studies are constructed following a lattice-work pproach where vertical analysis is used to uncover the narrative inherent in the participant's experience before moving on to examine broader horizontal themes (Mutch, 2017, personal communication; Mutch, 2018). Here, narrative analysis (Holstein & Gubrium, 1995; Silverman, 2000), is used in uncovering the stories, or narratives, participants are telling about their experiences (Holstein & Gubrium, 1995). Revealing the stories parents and practitioners are telling about their experiences provides an opportunity to explore how parent and professional relationships are understood by individuals as well as how their experiences might reinforce alternative accounts while resisting dominant narratives" (Richardson, 1990, as cited in Silverman, 2000).

Naturalistic inquiry (Lincoln & Guba, 1985) methods, discussed in detail in the previous chapter are used in developing individual case studies. Naturalistic inquiry (Lincoln & Guba, 1985) includes the researcher's use of themselves as a research instrument (Janesick, 2000). In this research, active interviewing (Holstein & Gubrium, 1995, 1997) is used to support participants in telling the stories of their experiences. Participant stories are then retold through narrative case study reporting in order to engage the reader by provoking what Stake and Trumbull (1982) refer to as “vicarious experiences.” Cases that inspire vicarious experience then serve as prompts for expanding perspectives and informing professional practice (Lincoln & Guba, 1985; Stake & Trumbull, 1982).

Parent Case Studies

Parent participants are all mothers of children with a similar developmental impairment. The mothers know each other through their shared involvement in a local developmental disability support and advocacy group. The case studies that follow are developed from the individual narratives shared during a focus group held at a participant’s house.

Jolene

Jolene is a mother of three adult children, the youngest of whom lives at home. Hayden, her youngest, was diagnosed with Down Syndrome at birth. They live in the same area where Hayden was born and utilise the full range of support services available in the area, transitioning between one service and another as Hayden has grown.

Jolene describes parenting as a pragmatic activity. “Parents often find practical solutions. And I think when you’re told, with your kids, that they can’t do something, you are determined then that they will.” Her reflections appear to have the benefit of hindsight as she describes the process of developing confidence to disregard professional advice. She says, “early on you probably think, I better follow that, they’re the experts. Oh gosh, I better do this.” Jolene goes on to describe that, through a process of trial and error, of discovering that professionals’ recommendations while often well intended, are not feasible for the realities of raising a child—let alone three children. She goes on to say, “You start to think that might work in my family, that might be useful…and you tend to share that with younger and new parents. It’s what works for you, your family.”

For Jolene there was a big emphasis on relationships, both with other parents in similar situations and with practitioners involved in the care and support of their children. She recalls their experiences with child development services, “Coming from such a small place…the child health therapists—they became like they were part of our family…and there’s quite an attachment there, a reliance, and a lifeline sometimes, when your child is that ill.” Jolene says that their frequent trips to the hospital were made less frightening because of the relationships they had with practitioners, saying, “You felt comfortable going in there because you know somebody there. You got that relationship.”

Jolene recalls a specific conversation with Hayden’s paediatrician discussing the timelines for an upcoming operation. When she enquires about the date for the surgery, the paediatrician responds by asking, “How long is a piece of string?” Jolene interprets the paediatrician’s statement to mean that he did not know when the surgery would be scheduled either. She goes on to say, “It’s important to have that support around you, and caring people.” Jolene’s response to what might be considered a glib, offhand comment as an honest and informal appraisal of the situation suggests that her management of uncertainty appears to be mitigated by her trusting relationships with practitioners.

Jolene says her family did hit barriers on occasion. Describing one interaction she says,

> We did get blocked once, but that’s because they changed the set up and he [paediatrician] apologized. We threatened to leave [Hayden] there with them and walk away. He [paediatrician] apologized and says this child has really bad pneumonia and needs to be admitted. I think there was that little bit of gate keeping happening, because they changed their system and maybe we didn’t know. Or you don’t think when you’re stressed. Maybe we should have taken him up [to the hospital].

Jolene talks about the need for parents to be informed and be prepared to fight for your child to be admitted to the hospital or to receive other services they need. She says, “You have to know what answers to give sometimes and stand your ground.”

She recalls advocacy skills being especially valuable once Hayden entered the education system. “[People within the education sector says] we don’t have any more money. Go find it.” And so, she did, saying “I came in with specialized resources that they’ve never seen.” Jolene explains that the differences she sees between health and education result from differences in therapeutic service delivery. “When we were in child health, [we had] one on one therapy, and then you flip over into a different system and it was hands on in the beginning and then it changed over into this consultancy. That’s your difference.” She feels that the consultancy model doesn’t provide adequate levels of support for children or their teachers.

Jolene views the change from hands on therapeutic services to consultancy-based services as perpetuating gaps in service continuity and coordination. “We never saw them again after the initial [visit]. The paediatrician isn’t there coordinating [so], we’ve got nothing. Getting back into those systems should be easy, but it’s not.” She says this was most apparent in the transition from child to adult services. Speaking of a recent experience she says,

> You have to think of everything [before] you go in. [Having some] coordination would be so much better. Just because they turned 18, they're [considered] an adult—in the adult world. Well they’re not…He’s considered to be an adult and not dependent on us. But how can you say that? We still have to run around after them.

And Jolene reports there is not much out there for Hayden to do now that he’s left school. The supports that are available, she says, are fortified by barriers—things like geographic eligibility criteria and transportation. “There’s [supported employment] for him to go to, but not funding for transport to get there.”

Beth

Beth is also a mother to three children, all of whom are grown. Her youngest, Josh, has a terminal heart condition as well as Down Syndrome. Her children were born in the same area as Jolene’s and Beth and Josh came through the same health and education services as Jolene and Hayden.

Beth speaks highly of her relationships with practitioners at the child development services where Josh's paediatrician and allied health practitioners are based. She says, “You do rely on them [practitioners] so much, because we don’t know. We are just mum at the end of the day and we really don’t know. So, to have that support was brilliant.” Beth feels that relationships with practitioners are facilitated by home visits. “Right from the word go, they would come and work with you.” For Beth, home visits are important because they provide opportunities for developing trusting relationships, so that practitioners know the history of what the child and their family have experienced in the past and that when a crisis inevitably occurs, parents’ perceptions of what is going on and their reporting of events and symptoms are taken seriously. “I think that is why it is so important that when you’ve got these kids sick, that you’ve got access and access to people that know you, that know [what] you’re saying, what's going on, that they actually believe you.”

Beth’s thinks that her relationships with practitioners grants access to professional information and services that might not be available without those connections. Beth recalls, “There was also one of the staff [member] there, the receptionist/nurse, and she was a mine of information. And she was absolutely wonderful you could ring her, and she would make sure you got in to see whoever you needed.” Beth says that when Josh was younger, her relationships with practitioners provided reassurance. She felt that even when she did not know what to do for Josh, she had immediate access to the children’s ward at the hospital, bypassing the lengthy delays associated with first going through the emergency department.

Relationships with other parents are also a source of support for Beth and her family. Recalling their experiences in a playgroup that was sponsored by the child development service, Beth speaks of the opportunity to meet other parents in similar situations—with sick kids and dealing with multiple systems of care. She says,

> I think that disability community—even though sometimes you don't really want anything to do with it, but it’s really quite supportive. I think [it’s] something that is important to all parents, because sometimes you just need to vent. You could yell and shout and tell exactly how you feel with another parent.

Beth says that other parents of children with disabilities understand each other’s often dark sense of humour and that understanding helps them get through the rough patches. She explains that parents of kids with disabilities have thicker skin, or they learn to develop thicker skin, and parents of typically developing kids just cannot relate in the same way.

From Beth’s perspective, the opportunity to develop relationships with practitioners and other parents did not continue when Josh transitioned into special education services. Speaking of the transition between services, Beth says,

> I think the difference between the health and the school is the school is focused on the funding and the lack of funding. Whereas, the early childhood therapists are very hands on. Very much encouraging and yes, they need this extra [support or piece of equipment]. And the schools inclined to be more focused on that funding, and [they have the attitude] that “she’ll be right.”

Beth took the schools' "she'll be right" attitude to mean that they accept the barriers Josh faced in learning in environments designed for typically developing kids. And when Josh could not join in because of the barriers present, it was due to Josh's "deficits," not the education system's deficits in their inability to create an inclusive learning environment. Beth goes on to say, "Education is very much what they can't do, and the health was very much what they could do."

Beth understood the focus on Josh's perceived deficits to be a follow-on effect from a lack of adequate funding for supporting children with additional needs within the education system. She recalls an experience of applying for ongoing resource scheme (ORS) funding, saying, "We were one of the first [to apply for] ORS funding and [fill in] that horrible, horrible report. You had to write what they can't do [and] have it verified for the funding." Making matters worse, Beth recalls that parents were also made to feel that accessing more support for their own child decreased the amount of support available for other children. She says, "All parents, I assure, have been told that [increasing their child's hourly amount of support would decrease that of another child]."

Beth feels the lack of adequate special education support is exacerbated by teachers' limited skills for working with children who have additional needs. She says that, "When teachers go through training they have no special needs; they've got a very small box of it. It's really irrelevant. [Teachers who] went through it and says it was a joke." Beth says she is aware of instances where children get good support from their school and special education services. However, she says, "There's no consistency. There's no consistent service."

Beth attributes a part of the problem to service fragmentation and a reduction in practitioners engaged in hands-on therapy. She says,

> There seems to be an awful lot of chiefs but no Indians actually working with our kids, especially because of Special Ed, because so many littlies have to rely on that system. Everyone writes reports about things, or is doing a report or a review, but nothing actually happens. Nothing actually ever changes.

Beth says she and others have no choice but to deal with what the education systems offers: "And we all leave our kids there [at school] until 21 because there is nothing else." She says that once children are 21, they must leave school and transition into what are referred to as "adult services." Beth explains that this means the family GP becomes the care coordinator. She finds this arrangement unsuitable, citing that GPs are too busy to do this work, and the result she says, is that kids "drop off into the abyss of nothing."

Beth sums up Josh's transition into adult services saying his needs are no different than before he turned 18, or 21, "There's no difference, except they've turned older. They still depend on us."

Jacqui

Jacqui is a mother of three adult children, two of whom have disabilities. Together with her family, she has lived in different areas of New Zealand and her children have participated in health and educational services in multiple locations. Jacqui's children, now adults, continue to live in their family home on a quiet, tree-lined street where the group interview takes place.

Jacqui is both an adoptive and biological mother. She learned of her daughter, Ari's, impairment prior to adoption, though she had little information at the time. Jacqui describes initial appointments with paediatricians saying, "Our first experience was taking this child along, who they thought has cerebral palsy, and…rocking up at the paediatrician and going, 'What do we do with her?'"

Jacqui says that Ari's condition was unfamiliar to the paediatrician and he appeared to have little more information than she did. Jacqui recalls the paediatrician being emotionally supportive, yet he was not able to provide much information aside from that taken directly from a textbook, which she says, he photocopied for her. Jacqui assumes that was, "probably all the literature he could find at the given time." Despite the apparent lack of information specific to Ari's diagnosis, the paediatrician and other medical experts nonetheless shared what they thought to be developmental expectations for Ari. Jacqui recalls the paediatrician stating that her daughter would never feed herself. She reports responding with defiance:

> I went home, and I was like, "she will feed herself" and I could tell she wanted to but couldn't hold a spoon…So, I got a bandage and I bandaged the spoon to her hand and she could do that. I went back and told him, and he says, "I only told you that because I knew you'd go home and do it."

Jacqui says this type of response from practitioners was not uncommon. When met with conflicting evidence, practitioners would revise their original statement or intent rather than acknowledge professional error or parental expertise.

Jacqui recalls developing competence and confidence as a care-giver through long-term relationships with practitioners where she learned to assess Ari's needs and become confident in confronting professional opinions. She says,

> As the years went on, I'd ring him [the paediatrician] up out of courtesy and say, you know what, I'm actually going to drop that by 50 milligrams because her personality has changed…Or I'd ring him up and say, "what do you think about this?" And he'd say, "you're with her all the time—what's your judgment call?" He really treated us like we knew what we were talking about. And our experience with her was way beyond anything he could imagine.

Jacqui recalls how having a mutually trusting relationship with the paediatrician and his trust in her judgment bolstered her confidence. She speaks of being able to disagree with his assessment and other professional recommendations. This confidence also informs negotiations for trialling recommendations rather than opting for an outright acceptance or rejection of the proposed solutions.

Jacqui says, "I've disagreed with the paediatrician. And said, 'I don't agree with you, but I'll try it.' Actually, I disagreed with the school and [the paediatrician] said 'let's humour them and do it.' And he said, 'let's do it for x amount of time' and we agreed."

Jacqui, along with the others in the focus group, describes facing challenging situations in health and education systems. One issue in particular stood out: resource allocation. Jacqui says that she had been told on more than one occasion that the amount of support her child received would negatively impact the amount of support available to other children. She recalls,

> I did have one person [in special education] tell me…if we give [support services hours] to her, we have to take them off someone else. And because I have heard that before, I was prepared. And I said, actually, that's not my concern. Ari's safety is paramount to me. I walked away and inside my stomach I felt sick, really felt bad, but I put on the hardest exterior I could.

Resource scarcity proved pivotal in the conversation as it shifted the discussion toward the role of supportive people, with whom they shared experiences. Specifically, Jacqui mentions the value of developing relationships with other parents of children with disabilities.

> I think the humour thing is really important because we will say things in our family that we probably wouldn't say in front of other people. We said to [Ari] the other night, "if you don't sleep tonight, we'll have to hit you over the head with a sledgehammer"—it's a joke and we all crack up laughing. But [parents of children without disabilities] wouldn't understand that she takes all this melatonin to make her sleep and it may not work tonight. Or there may be 50 seizures in the night. But they don't know that; don't get that. But if you're in a group with other people [with similar experiences], they know you're not about to hit someone over the head with a sledgehammer.

Jacqui says there is also a flip-side to frequent interaction with parents in similar situations. While Jacqui may have learned to not compare her children's' development with that of their non-disabled peers, in-group comparisons can still pose problems. She speaks of seeing children with similar impairments who were three or four years older than Ari, and their developmental achievements were lower than she had projected for her own daughter. Jacqui describes finding it challenging to be confronted with the realities of the developmental trajectories of Ari's peers.

Jacqui also speaks of some of the challenges she faces in caring for Ari. Coordinating specialist and support services is one major issue, as is dealing with transitions between support services and systems. Differences in language and terminology across health and education sectors, as well as differences in service allocation and configuration, causes headaches for parents trying to figure out how to get what their children need in the various settings. Jacqui says that, as Ari has aged out of children's services, there is less practitioner attention for coordinating care and managing follow-up visits. Jacqui also laments the lack of post-compulsory schooling options available for people with disabilities. Ari is now considered an adult, but she still requires family and non-familial support and her needs have not significantly decreased in correlation with her advancing age.

Child Development Services Practitioners Case Studies

Child development services participants are all members of a multidisciplinary team of allied health practitioners. The practitioners have been working together on the same team for many years, with the exception of Pam, who has worked with the team in the past and has recently returned to working with them in a permanent capacity. The team work together in the same urban centre and share responsibility for visiting children and families in the more remote rural parts of their service catchment area.

Lynn

Lynn is a physiotherapist and visiting neurodevelopmental therapist (VNT). She is a member of the child development services' allied health team and has been so for over ten years. Her affinity for working with children is obvious, it's one of the first things she mentions in the interview, saying, "They're a lot easier than grown-ups and way more fun, both in terms of treatment and in terms of getting progress." She speaks pointedly about how disability can create impairments beyond the immediate effects of the impairment itself. She says,

> Opportunities are restricted for kids when they don't get to move as much early on… So, when you're not moving, you don't get to choose to go and get the ball or the cup of coffee when mum says no. You just don't do it. So, you don't get to have all those kinds of "oops—that was a bad idea" kind of experiences that little fellas have, hundreds of times in a day…

In the example Lynne provides where a child's movement is restricted by a physical impairment, so too are their opportunities to explore their environment, to make and learn from mistakes, as well as their practice in making decisions.

She talks about her attempts to limit the restrictions imposed by impairments by involving children in making decisions about their therapy.

> I think the kids should be involved in leading stuff—from the get go…lots of kids, given the opportunity to develop decision-making skills [will make their own decisions]. I think a lot of the reason kids aren't like that is because we haven't given [them the] opportunity—not because the potential [isn't] there. I think children, regardless of communication, are often making choices and we just miss cues.

To catch the cues, she speaks of paying attention to how families and children interact with one another. She describes that families have their own unique culture, “Where kids are allowed to make choices within certain defined kinds of things. Children always find ways to make those choices, we just need to find ways to build skills.” For Lynne, this skill building happens through a process of working alongside of families, being respectful of the skills they already possess and of the choices they are making. She says, “When we come into a situation, we come in a way that allows families to accept things—going in gently, having respect for the skills that are already there, the strategies that are used are being used for really good reasons.” For Lynne, working with families in this way in a product of ensuring a good fit between family and practitioner, and above all showing that her work is beneficial for the child and family. She says, “It’s not my job to tell people what to think about their child or my role, I just have to show that I’m useful.”

Being useful gets complicated when there are multiple practitioners involved in a child’s life. She says it can be confusing for parents when they have many people involved, multiple appointments, and different practitioners “saying very similar things from slightly different perspectives.” Her team tries to mitigate the impact of involvement with multiple practitioners through the use of a key worker role. The key worker is often the VNT, provided they are a good match for the family. The VNT can then be the family’s primary contact person, and they are often able to provide some intervention that in other instances would be considered out of scope.

Lynn speaks of the importance of good collaborative relationships with peers both on her team and with other agencies because there are often grey areas between which service does what. Children’s eligibility for services is determined by age, geographical location, impairment type and severity, recent hospitalizations, early childhood and school attendance, etc. Lynne says,

> It’s a system set up for the way people are funding things, it’s not set up around the needs of a child. In terms of families or teachers or anybody actually in the system I think that’s a real challenge for anyone working on it.

Services used to be allocated via contracts to provide services for children who meet eligibility criteria. Now, Lynne says, they are asked to conceptualise their activities in terms of “pieces of work.”’ These pieces of work are funded around a child’s needs; however, she sees the definition of need to be rather narrow in scope. Lynne says, “it’s a piece of work…It’s a particular need as opposed to ‘let’s use this as an opportunity to have a refresh around. Is everything in this environment working for this child?’”

Lynne explains that, in education the focus is on promoting access to the curriculum, whereas, in health they are, “trying to remove the disability that our society creates around that child’s impairments.” Her solution to the problem is creating a service built around the needs of children and families. Lynne says, “I think it would make a lot more sense to have a therapy service for children with additional needs and I don’t care where the money comes from, it is one service.” Within her ideal service, Lynne says she would include practitioners with specialty areas in health and education, but they would work together, in the same place and be able to support children and families in a more connected and comprehensive way.

In addition to what appear to be challenges in collaborating with others while navigating service criteria and differing practices’ paradigms, Lynne says her team used to do more hands-on work than they do now. She recalls,

> When I first came, we used to do a lot more therapy and we were able to be a bit more flexible, like seeing kids that we thought were not too bad, you know. Because you get this skewed scale of normal.

Now, with an increase in demand for her teams’ services, and limited resources she feels she is pulled in different directions saying,

> I’m trying to be a therapist, to ration—save money, save money. [But also] the child’s right to access curriculum, access food, communication, UNCROC bill of rights. The collision of all the factors. Our duty as a community and a society to support that setup to be as stable and sustainable as possible or just meet an essential need.

And she says, “The bit that nobody likes is the system constraints, but, that’s all good.”

Bronwyn

Bronwyn is a paediatric physiotherapist and VNT on the same allied health team as Lynne. She has two decades of experience working with children, and many of those years were spent as part of child development services. Bronwyn says she has seen significant changes in how services are provided, and she describes the challenges for practitioners and families alike in responding to those changes.

Sitting in a large therapy room and surrounded by equipment, the conversation opens with a discussion of recent changes to the equipment request application process. In describing the changes, she mentions a new process that physiotherapists now go through to apply for equipment. According to Bronwyn, it is essentially the same as before with additional steps tacked to the beginning and end of the previous multistep process. This task, like some of the other administrative work she describes, takes time away from hands-on therapy. Bronwyn says that, “In the last couple of years we’ve had some changes with equipment, what’s funded and what’s not funded. And you finally get your head around it and it goes and changes—then we’ve got to explain the change.”

Bronwyn recognises the paradox of her role’s responsibilities and expresses her frustration. Explaining changes, completing applications, and engaging in other administrative work takes time away from what she’s trained to do—provide therapy.

> When I go see a child, I always have the intention to engage and do some play, because that’s the fun part. Filling out forms and having tough discussions… it can make or break your day. And if you don’t get the funding—you have to go back to the family and have another discussion about where we're going to go now to look for some funding.

The issue of funding comes up several times in the interview. Bronwyn describes funding issues regarding requests for equipment, and applications for expensive items such as specialised high chairs and standing frames. She also speaks of the impact of changes in staffing patterns in the more rural parts of the organisation’s catchment area, areas which, historically, have struggled with retaining practitioners. The lack of practitioners increases the length of waitlists for services, which often stretches the maximum allotted waiting time allowed by Ministry of Health contracts, and limits the range of services available. Bronwyn’s examples all signal the impacts of resource scarcity on service provision, saying, “If it’s this hard for us, imagine what it’s like for parents.”

Bronwyn imagines what life was like for parents, some of whom were learning to parent for the first time along with learning to respond to changes in expectations. She describes her VNT role as work with families where,

> You’re really working through that stage of, your child is looking a bit different from other children, they do have some needs that are a bit different. It’s that whole grieving thing of my child is a bit different; my child has a disability—what does that mean? What might my future look like? What might their future look like? Often, you’re supporting families through that, to deal with all of that stuff, which is not small.

Bronwyn speaks of how the team, as whole, takes on broader issues. She speaks of the team working together to arrange joint visits to minimise the number of individual appointments a family has. She says the team arranges home visits to minimise the costs caregivers would otherwise grapple with for clinical appointments, including taking time from work, finding care for siblings, and travel. However, she mentions that joint visits are not always possible, and for some services like speech therapy, wait times are excessive.

> I think most parents would want more [speech language therapy]. I guess with the feeding issues—it’s got the most potential to wind up in the hospital. And that’s never a win. So, I think it’s understood that—that's the priority. It’s not that they [speech language therapists, hereafter, SLTs] don’t give them any direction around language and stuff and communication, but [feeding] definitely is the priority. For those families who don’t have feeding issues, but do have communication issues, all that they would know is that perhaps they’re not getting seen as much as they would like.

Bronwyn says that the team manages the lack of speech and communication related services through what is referred to as “role release.” She describes practitioners’ supporting children’s communication goals by sharing knowledge and interventions amongst themselves and discussing how they might be adapted by practitioners in their particular roles. Bronwyn says,

> We talk about the impact of what we [the other therapists] can do [to improve] their ability to communicate. We’re not silent. We talk and engage with them. We are also giving families recommendations and basic stuff around language and communication.

However, Bronwyn also notes that, sometimes, the services provided are not an ideal match for what the children and their families perceive as their needs. This, she says, is sometimes the case for parents who are still in the initial stages of processing their child’s diagnosis. Bronwyn says, “I often talk about selling parents on [therapy], because you’ve got to make it sound good. You’ve got to demonstrate that [therapy] will do what we say it will do. Otherwise they’ll have no reason to use it.”

She says that part of this work, of demonstrating the usefulness of therapy, is supporting parents to accept that their child is different from other children and maybe different from what they expected. Bronwyn says that these discussions lay the groundwork for enabling children to fully participate in their communities and for developing advocacy skills in parents.

Bronwyn feels that advocacy skills are necessary for parents to participate in decision-making processes that direct the services supporting their children. She speaks of the way her team approaches planning meetings, saying, “Here we’ve got family centred planning meetings…We sit down with the family on a once a year basis to say, ‘how are things at the moment?’, ‘what are your concerns?’ Sometimes those meetings go really well.” And sometimes the meetings do not go well. Bronwyn mentions an over-reliance on questions and responses related to practitioners’ discipline specific topics. One example she provides is, “When we’re talking about a child [and someone says]: ‘tell me about physiotherapy.’ Well, a child isn’t about physiotherapy…this child is about how they play, how [they are] socializing with their friends.”

Bronwyn expresses frustration at wanting to see planning processes and family-centred planning meetings address the children and families’ needs in a more holistic manner. She believes this entails a more relaxed, informal context that takes into consideration the activities that children and families engage in as well as the language they used to talk about those activities. Her team addressed this need by drafting a new document to guide family-centred planning meetings. However, she also notes the challenges of providing services in some geographic areas could overwhelm even a robust planning process.

Bronwyn speaks of the importance of joint visits, where multiple practitioners can see a family together. Joint visits are more difficult in rural areas, where it is not feasible for two team members to see the child and family together. She says physical isolation also creates practice isolation for practitioners where they are unable to “have a sounding board” of other practitioners with whom to discuss the case. Bronwyn says, “We keep talking about wanting to stop working in silos. When things get busy, confrontational, then you come back to that and it becomes harder to work with families in a collaborative way.”

Pam

Pam is an occupational therapist on the allied health team. She is new in her current role, though she has worked with the team intermittently over the years as a temporary team member. Pam has an extensive background working with both children and adults in community settings.

Conversation opens with discussion of reflective practice. One of the first things Pam mentions is using her daily commute to and from work to plan for and then evaluate the day's activities. She speaks of approaching her role with a spirit of generosity—by trying to make visits with families as painless as possible for them. Pam says,

> When I start meeting with families, I always offer them a home visit first. I want them to be comfortable, and it's a big thing coming up here. Getting all your kids in the car and getting a car park…I always offer a home visit first.

For Pam, making families feel welcome includes anticipating potential barriers. Potential barriers to appointments include arranging and paying for childcare for other children, travel and parking expenses, as well as mitigating feelings of unease around health providers. Addressing barriers to care is a topic that arose repeatedly during the discussion.

Pam identifies a narrow definition of functionality as a barrier to service provision. Pam notes that sometimes she is challenged to relate her approach to working with children and families to a stricter definition of improving functionality. She says,

> Sometimes I think that supporting the family, networking and providing them with a sounding board and some strategies, to me, is a valid use of my role here. And maybe what I need to get better at is articulating how it links to the functional—that might be the missing link.

Pam feels that the providing of support to families is one of (if not *the most*) the important factors in working with children, as supporting families enables families to provide better care to their children. Pam provides an example of a family who has recently completed a lengthy assessment and planning process through another agency. One of Pam's responsibilities now is to assist the family in implementing the recommendations provided to them. However, when Pam arrives at the home for scheduled visits, she finds the family unable to engage in therapeutic activities with their daughter. She says,

> Sitting down with the young [family], and my thought was we will just run through a couple of these recommendations and see what we can start implementing. But when I got there, the parents were still asleep. And so, I thought, back to the beginning. So that expert report was there [from another agency] and I could be focusing my work on these recommendations…but it wasn't going to go anywhere if mum and dad were still too tired to get up in the morning. So, the next time I visited, it was a discussion around sleep and routines…and then we could start looking at what the recommendations are.

Pam says that one of her goals is getting to know families as well as she can. Knowing families well, she feels she can then make recommendations that fit with who they are and are tailored to a working pace with which they were comfortable. One of the ways she does this is through arranging joint visits with other therapists, especially if the family was already involved with another therapist on the team. She says, "I think for the families, if they are already comfortable with one staff member it can be less threatening."

Another strategy Pam uses to connect with families is using phone calls and text messages to schedule appointments. Although this might seem obvious, traditionally, initial appointments with Child Development Services' therapists are scheduled without family input. Families are then notified of the appointment by mail. By the time the notice for the appointment is mailed, the family might not be living at that address. Pam notes that, even if the letter does reach the family, sometimes the family does not recognise the name of the practitioner. In other instances, referrals may have been made several months ago by a paediatrician and the family no longer recalls the purpose of the referral. Pam's strategy of ensuring families are involved in booking appointments helps her to identify early on any issues the family might be working through. She says,

> If the appointment was arranged by text and confirmed, and the family can't organize themselves to be ready, and this is family centred therapy—then I need to discuss with them what would help. And how can I support you to get organized? Do you really want this therapy to keep going?

For Pam, shaping the environment so that parents are in a space to be able to support their child is an essential element of supporting a child's therapeutic goals. She cites rehabilitation principles around developing rapport with families, starting where the family is at, moving at the family's pace, and focusing on goals relevant to the family as the foundation to her practice. However, she notes that other team members did not necessarily share her approach.

She says it could be hard to parse the approach of her team members because of a lack of process for formal case review and limited opportunities for team reflection. She identifies these as challenges to her practice saying,

> As a wider team, I don't think [reflection is] highly valued—it's not discussed at our team meetings. And also, that, what I've become aware of is that we don't have any specific clinical meetings [where] we review our clinical caseload. There is a team meeting for a team meeting and there is no actual multidisciplinary review.

Pam says that case review happens informally in conversations with colleagues in what are called "corridor" conversations. But she also mentions these conversations are easy to avoid, if someone was so inclined. Pam reports,

To be honest, I think it's a gap—if you talk about clinical oversight, what does that mean? Checking with other clinicians, getting some supervision, is there someone they can talk to when they need to? I could go to my other colleagues who have been here longer, and our team leader, but still, it's an issue. I don't think it's a very formalized process.

For Pam, supporting children is about also supporting families and to do so, she feels there is a need for more formalised processes to ensure adequate opportunity for case review and discussion.

Lucy

Lucy is one of the team leaders at child development services. She joined Child Development Services over ten years ago, beginning her work there as a registered therapist. Lucy reports enjoying the various aspects of her role and having clinical discussions with other clinicians on the team.

As a line manager, Lucy's role is different to that of her colleagues. Lucy says that she spends a lot of time with new staff, teaching them the culture and practices of the team. She reports doing this by creating an open-door culture, where new and seasoned team members know she is available for questions and consultation. Her availability appears to be important at least in part, because the dynamics of service delivery are changing. Lucy notes:

> We have more kids, and more complex children…but also [the] social circumstance of families [are] getting more complex, so then that takes up more time, puts more pressure on the team. Trying to get more FTE's is extremely

> challenging, so we have to just keep being [creative] in how we provide services.

Lucy goes on to explain that the criteria a child must meet to be eligible for child development services is vague. She says that, to qualify for their services, “for a child, at the moment it’s kind of loose. For a child that has a disability or developmental delay that lasts longer than six months.” For Lucy’s team, broad criteria for eligibility mean that the team is then tasked with prioritising which children will receive services first and having to manage completing priorities, including growing waitlists and the wellbeing of children who are not receiving services.

> What’s our responsibility for families we don’t get funding for? When we’ve got really complex children, we just don’t have the time to see that [unfunded] child. There is still a need there, so if we’re not providing it, then who’s going to? You know, like in the scheme of things, I think it would be great if our taxes paid for every child…but we’ve got to look at where we can focus our funding.

Lucy says her team do their best to navigate conflicting government, community, and professional expectations.

One way her team manages their challenges is by building relationships and working collaboratively with families and other organisations.

> In general, we’re able to build really good rapport and long-term relationships with families. Some families might be known to our service from birth to 16. We’re good at setting goals with families and hopefully putting their concerns and needs at the forefront of our interventions. We have good relationships with other agencies.

Providing information and supporting families to make an informed decision seems to be a cornerstone of the team’s practice approach. Lucy shares another anecdote of coaching a new staff member to use child- and family-friendly language on toileting recommendations she is providing to a family. Lucy recalls the team member’s discomfort in using informal words, for example, “wees” instead of “urination,” but, Lucy says, “in everyday language you don’t talk to your children in that way.” She says the team works with families by, “thinking from the parents’ perspective.” She provides an example of someone who is clinically able to return to school. Lucy reports,

> Although we can look from the [outside] in and say, “Oh, at the moment he’s well and there’s no reason he can’t go to school”—we don’t have all that background. We don’t have that emotional response, I think parents are quite scared about his tubes getting knocked by other children, and children being unwell at school and giving him bugs. They need to work through the process and it’s our role to support them and give them that information.

Lucy describes her team as

> …a multidisciplinary team and we have a family centred approach and child centred, but probably more family centred because we are looking at where the child fits into the whole family. The age of the child very much directs where we’re negotiating goals and planning.

In addition to where the child fits in the family, Lucy says her team also considers the circumstances of the family, and how those circumstances impact on the family’s ability to support their child participating in therapeutic activities. She says:

> It’s getting more and more difficult for families to get to appointments or get time off from work to come to appointments. We have more flexibility when we go out to homes and we try to book appointments around what suits the family. But, it still can be challenge especially as our service runs from 8 until 4:30 Monday until Friday.

Lucy says they do what they can to accommodate parents’ schedules by offering home visits (and doing so even when families are geographically isolated), joint visits, and collaborating as a team around the child to minimise the impact of multiple appointments and practitioners. And, she notes, that their collaboration, travel and efforts accommodating family’s needs takes time. She feels that:

> Waiting times, well, just keep going and saying this is a problem. We know we’re not going to get more staff. We can’t just keep doing this—something’s got to give, and I don’t want it to be the staff’s wellbeing or children not being seen. We have to be inventive and think outside the square, and to do that you’ve got to set aside that time and that space to think about it.

Unfortunately, from Lucy’s point of view, the time they need is in short supply.

Ministry of Education Special Education Practitioners Case Studies

The individual case studies in this section are collated from interviews conducted with practitioners at two different Ministry of Education sites. Although they are in different locations, both sites fall within the same regional office of Ministry of Education Special Education services. However, practitioners working in the more isolated area have fewer colleagues both within their office and in the general community. The two sites are separated by roughly two-and-a-half hours of travel time each way. Practitioners at both sites work in concert with their colleagues in child development services on cases that might be shared for a variety of reasons, including geographic location, complexity of need, transition between services or into school, follow-on care from acute medical issues, etc. There are local-level agreements between the Ministry of Health and the Ministry of Education that delineate who does what and when, and the boundaries of these criteria flex in response to individual situations.

Debra

Debra is an early intervention teacher in a small town within a large rural area. The town is known for having high rates of poverty as well as pervasive negative social and health outcomes. She works closely with her department colleagues co-located in her home office and with other practitioners in the immediate and surrounding community. Debra has extensive experience as both a practitioner and manager in her discipline. She openly expresses her preference for working directly with children and families over work that is more managerial in nature. Debra indicates that the relationships she develops with children and families is what provides her with job satisfaction.

Debra speaks of her role as varied. Her role includes overseeing a caseload of 30 children, supporting those children’s transition into school, writing Ongoing Resourcing Scheme (funding for additional learning supports) applications, overseeing Education Support Workers (ESWs) and running courses for the community. She says they have an advantage, working in a small community, in that they could “build up the people we work with [and] support each other”.

Debra says that it is different there, compared to other parts of the country, because over here, "You become sort of early childhood educator, early intervention teacher and social worker and speech language therapist and, and, and... You're sort of everything up here." She feels that working out of role is due in part to a mismatch between community needs and the amount of services allocated for the region, and to the lack of professional development opportunities for those working in education and community services.

The lack of professional development opportunities for staff and the challenges that come with coordinating care between services could often pose difficulties for children and families during transitions. One major transition for children and families is the transition into school. Debra says, "It's quite harsh for the parents as well, because they go from having quite consistent support to very limited support. And a lot of it is left up to the schools—so that transition is really important."

Before entering school, a child is likely to receive services from the same practitioners year after year. When a child transitions into school they often go from having the support of familiar practitioners to seeing new faces and needing to regularly re-apply for services. The new services, if approved, are likely to be provided by a new group of people or by familiar people in a different manner. From ages 0-5, a child might see an early intervention teacher and possibly education support workers as well as Child Development Services and Ministry of Education therapists. When in school they receive instruction from a new classroom teacher each year and are likely to have different teacher aides. In all likelihood, Debra says, the classroom teacher may lack the specific training needed to deliver tailored lessons, provide materials and a classroom environment that is conducive to individual children's learning needs.

Debra reports of attempts to bridge these gaps by getting the early childhood and primary school teachers to meet together to build their relationships. Debra describes this process as one that could facilitate information exchange between the two groups to help strengthen the child's transition into primary school. However, transitions are more difficult in situations where children are involved with multiple agencies. Different agencies, such as Oranga Tamariki (Ministry for Children, formerly Child, Youth, and Family) can, in the interests of protecting privacy, hinder information sharing among organisations.

Debra says that families often meet barriers early on and encounter difficulties with the referral process. Referrals (to early intervention services) are rejected because the information provided in them is ill-matched to what the reviewers need to see. According to Debra, "Referrals are being turned down because people don't know how to write them…they weren't putting in enough information."

This issue is not exclusive to written referrals. Debra notes that, "Quite often a phone call can be a barrier too. Because you don't see that child and it depends on the person on the other end of the line and what they see as normal and not normal." The problems created by refused referrals go beyond those of children being denied services. Debra speaks of eroding trust in early intervention and educational systems when families and the larger community fail to access the support they need. Debra says, "[When referrals are rejected] they are going to lose faith in our service—why bother[?]. We try to take them really seriously, because we want them to be able to come to us, no matter what it is."

Debra and her colleagues attempt to remove barriers to referral by enacting an open-door policy. Debra indicates that anyone could walk into their office to ask questions, talk about what they see happening with their child, and learn of existing support options. She notes that their open-door policy is in direct opposition to some of the Ministry's policies, which stipulate that open-door arrangements should only occur when a suitable number of staff members are present. Debra acknowledges this policy exists for safety reasons, stemming from a violent incident at another agency office several years ago. However, the crux of her issue is that ministry policy does not reflect local conditions, is not responsive to local needs, and is an outside intrusion into local knowledge and practice. As such, Debra and her colleagues feel validated to supersede official policy.

Sylvie

Sylvie is a speech and language therapist working in the same office as Debra. Sylvie comes to her role with extensive experience in working with children and families and in practice management. Similar to Debra, Sylvie expresses her preference for working directly with children, families, and community members over the more administrative aspects of the role.

Sylvie sees her role quite broadly. She speaks of language in terms of how it supports relationship development and facilitates access to the broader world. She says,

> We think in language, we reason, all our emotions, translate in language, and if we have difficulties it impacts us on every level. In our relationships because we say the wrong word, in our thinking because we feel an emotion, but we can't express it and, in our work, because we can't understand properly what our boss is saying.

Sylvie considers the scope of her practice to include the larger community. She appears to see her role as located within the community she serves, which sometimes compels her to navigate through a range of boundaries and competing demands. Some of these demands include the need to balance privacy and service coordination even as requests for information are pressing. Sylvie says this is made more prominent by the small population size of the community where she works.

She speaks of negotiating boundaries when it was prudent to do so. Sylvie echoes the sentiments of her colleague in that keeping office doors—and therefore communication—open facilitates information exchange. An example she provides is that of a family interested in requesting a referral for services. Sylvie asks the family to come in to discuss their concerns rather than send them through the formal channels. This type of contact, she says, enables expedited access for those in most need of services from the Ministry of Education, and also assists those whose needs are better served elsewhere. Sylvie says that this process actually saves time and resources since it routes people to the appropriate providers rather than having them languish on waiting lists for unneeded services. Additionally, she notes that promoting a more flexible access path to exploring services can prevent the later reappearance of students for referral who were previously denied services. When asked how her office managed this process, Sylvie replies that they do this by, "[Up-skilling] people in your community so they get stronger and they can do it. And a phone call can quickly fix what normally would have been a referral."

Sylvie views the process of up-skilling community members as more than just supporting access to services—it was part of how she participates in community life. She says, "I really enjoy working with other people because I can learn from them and hopefully I can give something back—that is what I see as the purpose in life—that you exchange knowledge and you never withhold." Sylvie describes developing relationships as the process through which knowledge is exchanged. She says that as community members become increasingly familiar with each other, develop trust, and know that communication lines are open, they feel more comfortable talking with practitioners about their questions and seeking advice.

Sylvie states that relationship development between specialist practitioners and educators is especially important for supporting individual children, the community, and establishing inclusive practices. She notes the difficulties that teachers face when teaching a class of over 20 students, any number of whom might have specific learning needs. Sylvie says that teacher-training programmes do not sufficiently prepare teachers to meet the needs of all students. As a result, teachers frequently feel that someone else is needed to come and address the issues they see in the classroom but for which they themselves are ill-equipped to manage.

Sylvie sees a link between some of the challenges that educators are reporting and the differences in approach used in medical and education sectors. She says,

> There is still a discrepancy between medical approaches and educational approaches…in the medical field, you get the people to the appointment and you tell them what they need to do. Whereas in education you try to have discussion and ask, "What would you like to do? What's your focus? How can we support your focus? What would you need to make that happen?"

Yet, Sylvie notices that educators are not adequately trained or experienced in identifying and providing the support needed to deliver an approach that meets the needs of children and families.

Sylvie notes that lack of training and experience accounted for some of the difficulties she sees community members encountering. The geographic location of her community compounds these challenges. She speaks of the difficulties involved in accompanying families to specialist appointments (located hours away) and participating in joint visits because of the travel time involved—tasks other practitioners might take for granted. Sylvie says travelling times have a large impact on her role and restrict her ability to support children and families because five hours of travel for an hour-long appointment essentially consumes an entire workday. Sylvie feels that there are not enough practitioners in her community to step in and provide cover for her and her colleagues if they are to attend these appointments located a great distance away. If Sylvie goes along to offer her support to a child during an appointment, others in the community go without services. Sylvie says,

> Our request is always to have more staffing, anything else [will not make a] difference, because the difference is [made] when you've enough staff to support the community, and I think, that is where a lot of the struggle falls. We feel it because there is one early intervention teacher and one SLT, and one contractor.

Sylvie feels that staffing levels are insufficient to meet her community's needs and that her requests for more assistance are ignored.

> My voice wasn't heard when I say caseload is increasing, increasing. Only when Wellington saw that our waiting list…for children to be seen had increased to 90 days. And then we were working against the law…that's it—that's when an action has to happen—not from below when somebody says, "this is what would help me."

Sylvie sees that the lack of responsiveness extends to broader policy issues involving the allocation of funds for services. She says it is well known that her region is host to a variety of negative statistics around poverty, social and health outcomes. She says those factors are not considered because the amount of money allocated to regions was done so according to population counts. Sylvie reports, "If we have [dis]proportionally, which we know, higher rates of children with special needs…it's not [taken into consideration]."

Despite the unique challenges she faces in providing services in her town, there is much Sylvie finds positive about her community and region. One benefit she notes is the ability to be more flexible in negotiating criteria for service provision:

> In cities it's the rule that up to three it's the hospital, and then its education after 3. But in rural there was always a verbal agreement that because we are local, they can come early…it really depends a lot on the individual people… [relationships are] established so well, that we just email or ring each other… if we need any information.

According to Sylvie, the relationships she and her colleagues develop are well-placed to support a more informal network of team members who are able to work closely together. She says,

> We're trying to bring people from all sectors together, parent support groups, early childhood, health, social workers… and say, we're doing this to support

> oral language. There's not just one pathway of helping people to talk. We're gathering lots of ideas and then everyone can go away and try it. Bringing the ideas, sharing it, trying it and then bringing it back and trying to widen it for more people to have access.

The network Sylvie and her colleagues create supports the team of people working together for children and families and ultimately, she feels the network supports children, families and their whole community.

Paul

Paul is an occupational therapist at the Ministry of Education Special Education services. He has over two decades of experience working within his discipline as a practitioner and educator. Paul keeps with him a large bag that contains toys, supportive equipment and a binder filled with informational sheets on different modifications and intervention techniques.

Paul describes his role as unique among his colleagues within the discipline. He says it is,

> A bit different, it's more consolatory—as opposed to hands on therapy. I don't do blocks of therapy. I do observations, assessments, [and] review that allow me to give ideas…pass on information, strategies, demonstrate as much as I [can] to show them how to do it with the child.

Paul works primarily with teachers and teacher aides providing training and strategy implementation. He says that, when used correctly, the techniques and activities he offers should be straightforward and easy to use. Paul notes the strategies he promotes are designed to minimise class interruption and to be implemented alongside what was already happening in the classroom. Paul provides the example of how a teacher could support one child with developing her handwriting skills while the other children in the classroom engage in a different activity.

Paul sees his role as that of a "professional problem solver." He says he approaches his role through experimentation—trialling different strategies until finding one that works. Sometimes, he says, it is the environment that needed modification, so he arranges objects in the environment. If that fails, he might try introducing a piece of equipment. Paul says that, over time, the strategies are layered in such a way that eventually the issue is solved.

Paul considers risk management to be a primary concern for those he works with. He says he tries to minimise risk by demonstrating activities to those who would regularly perform them saying,

> I usually do it myself first, to show them and then I'll take photos, so we've got a record of the correct way of doing it. Then we will look at the child- in the sense of if the child's safe, comfortable, not in pain. I always get them involved as much as possible in the way that we work. It takes the pressure off doing as much of the physical lifting.

Paul feels that his way of working fosters knowledge development within the school community. He says, "What I do is empower the school to have the knowledge-based awareness and confidence to be able to adapt the curriculum to allow the child to participate." He notes that those involved in implementing the interventions need support to ensure the modifications are successful. He states that,

> Whether the child picks up any of them or not is down to the teacher aids being persistent—doing it daily—graduating the amount of effort to put in with the activity. I always give them a lot of ideas because if that way something doesn't work, or the child refuses, there might be one or two other ones they will tolerate.

Paul acknowledges that the consultant model had its challenges, not the least of which is reliance on others to implement strategies appropriately and repeatedly over time.

Paul notes that attitudes toward children receiving support services varies greatly. Different attitudes and perceptions of both the child and their supports influence someone's ability to implement the strategy at hand. "Sometimes the problem is how they're relating to [a child's] needs and how other people perceive [a child]. So, you have to make sure that you get an understanding for the person working with the child." Nonetheless, he states that research evidence demonstrates that the consultant model was "proven to be a better model than actual therapy."

Describing his role, Paul says his work is about a child's participation, functioning, safety, and the safety of those caring for them. He emphasises that his work is focused around supporting a child to remain in their current environment saying,

> So, what you have to do is adapt the activity, adapt the environment, to make sure that they can still try and do as much as they can in that environment, but it's in a way that is safe. If the environment is safe, and the activity is safe then it's more likely to develop and improve.

Paul gives an example of a boy who uses a wheelchair for mobility. One of the strategies Paul is working on is training the other children and adults within the school to manoeuvre the wheelchair around campus. Paul describes how this strategy fosters relationships between the boy receiving support and his peers, develops opportunities for increased peer interactions, and releases adults to attend to other duties. He sees this example as one of the ways that his consultant approach has a positive effect on the wider school community.

Nikki

Nikki is an early intervention teacher with the Ministry of Education Special Education services. She works out of the same office as Paul, although the area she is responsible for supporting is smaller and localised around the city centre. Like the others, Nikki works in concert with a larger team of special education colleagues as well as practitioners from other agencies, schools, early childhood centres and families.

Nikki speaks about the importance of providing support early on in a child's life because, "huge development happens in the early years—so it's getting on board with families and supporting them with developmental strategies and encouraging play—that sort of thing in the home." She finds families especially need support when their child exhibits challenging behaviours. Nikki says early development can be challenging for any family and a large part of her role is providing parents with support through the parenting process.

She says that she receives referrals from early childhood centres and, once received, Nikki makes contact with parents to begin developing a relationship with the family. She says relationships with families are especially important for getting to know what matters to them and where they might need some support. Nikki notes that, with a change to a more routine-based assessment there are increased opportunities for families to feel confronted by practitioners because of the depth and detail of the assessment process. She says,

> There's a bit of resistance to it [a new assessment framework], because of the time factor, like having a family sit down for 3 hours and tell a stranger pretty

> intense things. To me, it's a process of building a relationship with the family… and I feel it's quite a confrontational way to work with a family, especially if you don't know them. And they don't know you. To me, the important thing is building a relationship. Through building a relationship you get a sense of where families are at, what part of their day is difficult.

Finding out what is happening for families matters because there are often competing demands for their attention. Nikki reports:

> And sometimes having food on the table, paying bills are what's on top for these families. That's the realities too—it's really taking on board where families are at. Putting their son in a standing frame for a few hours a day is just too big an ask for some families. And for some families that might seem like something that's very achievable. For other families, where they've got so many other stresses going on in their lives, it's just not the priority.

Here is where family-driven goals come in. Nikki notes that the theory behind developing family-driven goals is that the family is more likely to follow through because the goals are based on what is important to them. Nikki says that developing family-driven goals is about putting the family in control. She notes,

> Sometimes it's about putting my own agenda, my own thoughts and wishes for this child aside, and just being there for the family. Discussing with them, okay, how can I support you? What other supports in the community may be of use? Sometimes a child is not even discussed—it's about supporting the family, because in order to support their child, they need to be supported.

One of the ways that Nikki supports families is by helping them to understand their child's behaviour in terms of communicating needs. She says understanding children's behaviour is about realising children are not "naughty," they are behaving in a way that expresses needs they are not able to communicate in another way.

Nikki also offers to help families by completing the ORS application and supporting children through their transition into school. She reiterates how important it is to offer support and strategies for children when they are in preschool, so that they are better prepared for going to school. Nikki says that collaborative teaming with parents, early childhood practitioners and school teachers helps children and teachers to be aware of where the child is developmentally and how they can be supported meet the expectations of the school environment.

Nikki notices changes in early intervention service provision. She says,

> We're now probably seeing the higher needs children, whereas before we would see them all. But, because of caseloads and having to prioritize, some of the referrals are questioned. And even though there is a need, it's not deemed to be high enough need.

Nikki gives an example of one boy with autism who has only three hours a week of teacher aide support. She says, "That, to me is a constraint, because I feel if he had more support, his development would be progressing more." But, she also reports that teachers need more exposure to special education strategies so they are able to recognise the diversity of children's needs. Nikki notes that, "teachers are coming out, new grads, have done absolutely no special education study in their 3 or 4 years of completing their diploma or degree." For Nikki, offering support early and adequately preparing teachers would do more make sure "we're not the ambulance at the foot of the cliff."

Summary

The individual case studies in this chapter provide representations of parent, child development services and special education practitioners' experiences. Parent participants find their relationships with practitioners to be essential for developing their confidence and skills as well as for accessing needed services. Their relationships with other parents give them the support they need to deal with the day-to-day challenges of parenting as well as necessary advice for dealing with difficult system constraints. Child Development Services practitioners also highlight the need for relationships with parents and colleagues for supporting children. These practitioners are struggling with competing demands on their time, changes in service provision, and a growing number of children and families needing their support. Similar to parents and Child Development Services practitioners, Special Education practitioners also claim the importance of relationships in supporting children and families. Special Education practitioners' roles vary from that of their Child Development Services colleagues and their narratives offer some insight into the issues parents note on the difficulties of transition between Child Development Services and Special Education Services. The next chapter uses horizontal analysis (Mutch, 2017, 2018) to explore in depth the themes that arise across individual and group narratives.

Chapter Seven: Horizontal (Thematic) Analysis

Introduction

This chapter moves on from individual case studies to identifying themes across participants' narratives. Horizontal analysis (Mutch, 2017, 2018) is undertaken to uncover themes across participants' narratives, as well as those that do not align with common features of the other narratives. Bringing themes to light provides a platform to then discuss research findings in conversation with the larger bodies of research literature. The following chapter is divided into four main sections, each corresponding to one of the three prominent themes. Major and sub-themes are listed in the table below.

Table 3.

Cross-case Themes

Cross Case Themes		
Major themes		
Navigating Barriers	Building Relationships	Interacting Professionally
Sub-themes		
- Geographic location - Sector differences - Case complexity - Education sector capability development	- Parent–practitioner relationships - Parental role development	- Collegial practitioner relationships - Coaching - Advocacy - Collaborative practices

Navigating Barriers

All participants tell of the barriers they face in their efforts to provide and access care for children with disabilities. Parents and practitioners alike share frustrations of having to work around geographical constraints, differences between allied health and education sectors services delivery, and the increasingly complex issues facing children and families. Parents, Child Development Services and Special Education practitioners also identify that teachers and teacher aides need increased professional development and tailored tertiary training.

Geographic location

Geographic location proses unique challenges for providing and accessing support services. Parents speak of living just outside the boundaries of where particular services are provided, and of being eligible for a service, but living too far away to utilise the transportation to that service, which left them with no access it. One parent says, *"*We don't qualify for that because we live slightly out of town. There are boundaries around it. And [for another service] we live out of the bus route." In the instances above, access is restricted both by service delivery boundaries and by the lack of local public transportation infrastructure.

Practitioners note issues posed by geographic location. Practitioners from Child Development Services share their perspective of trying to provide services to a vast region. "We'd like to be able to provide an equitable service to children no matter where they live, and that can be a challenge." Another notes that, while they make efforts to provide the same services across the region, there are logistical issues to be navigated. Another practitioner reports,

> It's fair to say that if we need to see a child down the road, we can give them a text and we can pop in and see them. Whereas if I go to [farther aspect of the region], that requires a bit of organizing, I do a lot more clinic-based stuff there.

Noted in the previous chapter, home-based visits are not just about convenience and reducing travel costs to families. When practitioners visit families in their own homes they have opportunities to observe children and families in their own surroundings where they can pick up vital information about what families prioritise, their needs and how families function in their environments.

In addition to providing more clinic-based services in more rural areas, practitioners note there are fewer opportunities to match skills with needs. One Child Development Services practitioner describes having more flexibility to match families and practitioners when the family was closer to the main clinic. She said:

> We look at our workloads and geographical areas, and who's traveling [to the more isolated regions] and we try and work it out like that. The local ones we can be a bit more about who has got skills in that area and might match that sort of need.

Rural practitioners also identified the skill/need mismatch. Practitioner participants working in rural environments describe managing challenges posed by their isolated location by working outside of their traditionally defined professional roles. They said:

> Here we haven't got many other services. We haven't got anything for autism, we haven't got anything for down syndrome…we are so far away that sometimes we are the jack of all trades. You do a little bit of physio, you do a little bit of OT, and you do a little bit of social work—because you don't have those other colleagues. You try the best you can. It may be, sometimes, superficial, but you do it with good intention. And as long as it works for the families, they don't mind. They're very appreciative of everything you can offer.

Rural practitioners also mentioned flexibility in applying service entry criteria owing to their local status. Meaning it makes more sense in their area that the local practitioners, regardless of their home agency affiliation, would make themselves available to families as soon as practicable, rather than waiting until the formal service entry criteria are met. One rural practitioner says, "In cities it's the rule that up to 3 it's the hospital, and then its education after 3. But in rural there was always a verbal agreement that because we are local, they can come early."

Sector differences–service delivery

Parents speak pointedly about the changes they see between support services provided in allied health and education sectors. One parent recalls noticing what she saw as a reduction in support services upon her daughter's transition from Child Development Services into Special Education services. She says:

> They said she had 12 hours of teacher aide time. And I said "No, what I want you to do is to start really high and then decrease it. I want this to be a success, not an ambulance at the bottom of the hill." And they [said] "No we can't do that." And they did in the end. And they did, but it was such a fight and it was about the funding. Wasn't about the education point of view of how to make this work really well.

For parents, what they perceive as a reduction in support hours is one aspect of the problem. The other aspect is the shift in how special education support is provided. Parent participants do not speak favourably of the shift in practitioner roles from those of more hands-on therapy in their children's early years to therapists performing more training and administrative duties when their children enter school. One parent reports,

> Education has turned into more of consultants now than hands on. We had very hands on, when we were in [Child Development Services]—one-on-one therapy—and then you flip over into a different system and it was hands-on in the beginning and then it changed over into this consultancy. That's your difference.

Another parent participant says,

> I think an awful lot of those services have become so fragmented and very little of the input; one-on-one with the kids is happening. There seems to be an awful lot of chiefs but no Indians actually working with our kids… Everyone writes reports about things, or is doing a report or a review, but nothing actually happens.

Consistent across parent participants is the feeling of adversarial relationships between themselves and those arranging special education services. One mother recalls being told by a ministry staff member, "We don't have any more money. Go find it." Also common for parents are memories of being told by ministry practitioners that the services dedicated to their child reduce the services available to another child.

Ministry practitioners are aware that restricted recourses impact service delivery and access for children and families. One practitioner identifies national-level policy that impacts resource allocation. She says, *"*Ministry looks at the population, where they're based, whether or not they have one SLT [speech language therapist] and one EIT [early intervention teacher]. It's based on population, not based on need*."* Ministry colleagues agree and posit a lack of understanding about practitioner roles and region-specific needs. Speaking to this, another practitioner says,

> The government doesn't see special education staff as frontline workers—that's why they've put the cap on. Each region is allocated a certain number of fixed employees, and we are not allowed to go above that, even if we have more needs. I think if they put in—especially in early intervention in those first 5, 6 years—more money we could prevent so much at the end of the day. Because children even with hard difficulties, if their family gets well supported in those early years [that sets] the foundation. They develop resilience.

For special education practitioners, a training and consultation practice approach is necessary given the current staffing number and policy climate.

Case complexity and competing demands

Practitioners report increasing complexity in the lives of the children and families they work with. Meeting the demands of increasing case complexity is challenging for practitioners. One special education practitioner describes the issue saying,

> There's another change that's happened with early intervention, we're now probably seeing the higher needs children, whereas before we would see them all (moderate needs). Because of the fact [in] early intervention, we get in early; you can make a big difference. But, because of caseloads and having to prioritize, some of the referrals are questioned. And even though there is a need, it's not deemed to be high enough need.

Child Development Services practitioners also describe concerns about meeting the children and families' needs. Child Development Services practitioners report feeling pressure to manage competing interests of providing adequate treatment to the children on their caseload while meeting community demand for services with the current staffing levels. One practitioner says,

> We have more kids and more complex children, we're definitely noticing the complexity of children, their presentations…but also social circumstance of families is getting more complex, so then that takes up more time, puts more pressure on the team. Trying to get more FTE's [full time equivalent staff members] is extremely challenging, so we have to just keep being [flexible] in how we provide services.

Child Development Services practitioners speak of prioritizing cases based on risk management. Children whose impairments might result in a hospitalisation are seen first. One Child Development Services practitioner notes how prioritisation impacts waitlists and affects families with children on the waitlists. She reports,

> Everyone has waiting lists. We try and get our kids seen for an initial assessment within 4 months. And if your child's 4 months [old] and they're sitting on the waiting list for 4 months, that's 100 percent of their lives.

Several Child Development Services practitioners discuss uncertainty around changes to the funding of services and the impact this has on their practice and the families and children they provide services to. One practitioner emphasises the impact of competing demands stating that they need to be,

> clear what the Ministry of Health are purchasing for their dollar from us. What's our responsibility for families we don't get funding for? There is still a need there. So, if we're not providing it, then who is going to?

Parent participants see case complexity differently to practitioners. For them, it’s not the complexity of the case or acuity of the case that determines access to services. Parents’ perception is that access to services is determined by the treatability of the impairment. “If you can fix it, you get your therapy. If you can’t fix it, like our kids, [you don’t]. That's our feeling.”

Education sector capability development

Parents and practitioners alike describe the need for more professional development for teachers. Participants perceive teachers as lacking the knowledge and skills necessary to meet the needs of children in school. Parent participants speak of bringing in their own specialised resources for teachers that had not been seen before by teachers or Special Education practitioners. However, parents also identify what they see as inconsistency in the quality of Special Education services. One parent noted: “The whole country is not in sync—you get pockets of really good and pockets of really bad and [it’s] the same with schools.”

A Ministry practitioner described a need for teachers to come into their roles with more training around learning strategies for supporting children with disabilities. She says,

> I guess, what is needed is, professional development for teachers around special education, but I think it should be done at tertiary teacher training level. I know that teachers are coming out—new grads—have done absolutely no special education study in their 3 or 4 years of completing their diploma or degree.

Practitioners note the importance of advanced training and professional development for educators in classroom settings. The need for more specialised training is especially important when considering the impact of resource limitations on specialist special education practitioners when there are already too few practitioners to meet growing demand for services. Special education practitioners speak of wanting more staff both in their specific disciplines as well as for their teams. Other practitioners note they are the only practitioner in their discipline for the entire region. Additionally, teachers with specialised skills could identify and implement interventions as well as assist children and parents in adjusting to the changes between Child Development Services and Special Education support services.

For parent participants, up-skilling educators would also provide an opportunity to increase the uptake of inclusive practices. Parent participants recall the deficit-oriented language commonly in use when applying for additional education support for their children. Parents report discomfort with having to use language that undercuts their children's knowledge, skills, and abilities in an effort to secure them support services. One parent notes, "We were one of the first to apply for ORS [ongoing resourcing scheme] funding and complete that horrible, horrible report. You had to write what they couldn't do." Speaking of the ORS application process, another parent participant says, "When you read the ORS report back, it wasn't from a strengths point of view at all. They're not asking the right questions. What about the questions you haven't asked?" A better prepared sector would be more readily able to identify issues of language and deficit orientation, so that even if the application and the application process are not reflecting inclusive practices, teachers and special education practitioners could assist parents through the process by reframing the questions and context for support needs.

Special education practitioners speak of making themselves available to the community and opening up the referral process so that families can have access to meet practitioners and ask questions. One practitioner says she is stopped in the grocery store by parents. She says,

> You can even get approached in the super market—when you're out of work…they'll say, "Oh I forgot to say", or "here is a meeting next week." We try to make it informal. For some people, it is really hard to allow others to be involved, to trust, and to get the consistent support. Our agency varies the way we accept referrals, it depends on how much caseload there is. Priority is the need of the family—let's make it less painless.

Developing teachers' capability in responding to families' questions about their children's needs and strengths could potentially have positive impacts on the referral process for accessing disability support services.

Building Relationships

Relationships between parents and practitioners and practitioners and their colleagues are complex. Parent and practitioner relationships are seen to change over time and practitioners and parents alike speak of the influences and outcomes of the changing nature of those relationships. Parent perceptions of their relationships with practitioners vary and individual narratives show a chasm between relationships with practitioners in early years and school entry and then again at transition out of school into adult services. Practitioners also speak of their relationships with parents and wider communities as formative and shifting over time.

Practitioners find their collegial relationships to be complex, serving multiple purposes and functions.

Parent–practitioner relationships

Parent participants speak of their relationships with Child Development Services practitioners as a source of emotional support. Speaking of connections with practitioners at her local Child Development Services, one mother says, “There’s quite an attachment there, a reliance, and a lifeline sometimes.” Parents speak of Child Development Services practitioners as having an almost familial role in their lives, especially when their children are so young and in need of acute medical care. Parents also note that their relationships with practitioners facilitates access to information and services they might not otherwise have access to. Mothers speak of having contacts within Child Development Services who share information, arrange urgent appointments, and bypass emergency-department triaging to expedite access to inpatient services. Practitioners also discuss the importance of relationships in facilitating access to services. It is interesting to note that all but one of the interview participants speak of the role of relationships in facilitating access to services for children with disabilities. One Child Development Services Practitioner said: “I think, if we don’t have this kind of trusting relationship, I can’t go anywhere with the family.”

Practitioners in both Special Education and Child Development Services discuss the importance of fostering relationships with parents. Practitioners report actively promoting positive relationships with parents. They claim to do this by taking the child’s and families’ perspectives, sharing control and decision making with families. Echoing what other team members said, one Child Development Services therapist speaks of encouraging her team to think from a parent’s perspective. She gives an example of a family they are working with that does not want their daughter to go to school. The practitioner working with the family is new in her role and feels the young girl should be in school with her peers. In conversation, the senior practitioner responds recommending the parent’s wishes are followed. Mirroring a similar perspective, a practitioner from Special Education says, “it’s about putting my own agenda, my own thoughts and wishes for this child aside, and just being there for the family.” Elevating parent perspectives is an act of sharing control in decision making by supporting parents to be in control by prioritising their knowledge of, and goals for, their children.

Practitioners note that home visits are also a way of improving access to services and establishing rapport with families. Speaking of home visits, one practitioner says, "[I use home visits] to get to know the parents. And then they meet me and understand what my role is." For other practitioners, improving relationships includes challenging traditional communication channels. Child Development Services practitioners now send text messages instead of the previous standard appointment letter to arrange meetings and joint visits. Using text messages is seen to be a more reliable and direct form of communication. Text messages are seen to prompt quick responses from families than would traditional mail. Text messaging is also seen more cost effective for families who are able to avoid paying for a call from their mobile phones.

Parent participants discuss how their role and relationships with practitioners change over time. Parents say their roles develop and change as they become more fluent in the health and educational discourses used by professionals. One of the parent participants speaks of her early experiences as a parent, where she felt dependent on the advice and suggestions of practitioners. She says, "You do rely on them [practitioners] so much, because we don't know. We are just mum at the end of the day and we really don't know." The feeling of uncertainty she describes is shared by the other parent participants in their early days of parenting. However, each mother reports developing their expertise in meeting their children's needs over time.

Parents' growing expertise in supporting their children's needs is developed through frequent interactions with familiar practitioners. Parent participants explain that the frequency of their interactions with practitioners in managing complex, and at times, life-threatening, situations forges mutually trusting relationships between parent and practitioner. Parents suggest that the consequences of non-trusting interactions between parents and practitioners have immediate consequences for the child. One parent says,

> You'd go to some doctors…like at ED one night, there was no paediatric consultant there and I said to this guy—she's had all these seizures and she's vomiting. We need to get her something to stop the vomiting, because she could aspirate. And this guy tried to convince me that she had a stomach virus, which was why she vomiting, which was why she was having the seizures. In the end, I just said, "For god['s] sake, just go and read her medical file." I couldn't be bothered with him again.

The example is familiar to the other parents. They acknowledge the challenges of dealing with unfamiliar practitioners who question their knowledge of their child and their child's medical and educational history.

Parents also find that, as they learn to be advocates for their children, they also have to harden themselves to the manner in which practitioners speak to them and of their children. The parents agree that they face language and perspectives that they find demoralizing when working with practitioners. One parent recalls,

> [We were told] her life expectancy is only so many years, she won't do this, she won't do that…You learn as a parent really quickly that things you hear, you and I wouldn't expect it, after a while it doesn't shock you.

The parents also report that practitioners would revise their claims to insist that they had only provided dire predictions in order to prompt parents and children into proving them wrong.

Parental role development

As parents develop confidence in their own expertise, they speak of adapting practitioners' suggestions to the unique needs of their individual families. One mother speaks of filtering out unhelpful advice. She says, "early on you probably think, I better follow that, they're the experts." However, some of the strategies suggested to her prove impractical, such as having extensive discussions with her children on their way home from school when all they want to do is to get home and have something to eat. Parents report that their expertise comes from just learning over time, through trial and error, what works and what does not. Parent participants also report sharing this piece of advice with new parents who were likely to follow practitioner instructions to the letter.

Practitioners describe their participation in the process of supporting parents through role changes, and in some instances facilitating those changes. Parents are aware of some of the strategies practitioners use to enhance their access to services. However, less visible to the parent participants are the ways in which practitioners fostered parental skill development. One Child Development Services practitioner speaks of working with families during children's first three years:

> I really enjoy working with families at that time of their journey. It is challenging, but it’s really important, because you're helping to form…what I hope they get out of it, is that they will become parents who can advocate for their child—for whatever it is that they need. They have to get past that feeling of my child is a bit different, but that’s ok. I’m ok with that.

Another Child Development Services practitioner recalls how she sees the team working to develop parental competence and expertise. She says that the Child Development Services team’s approach is gentle and shows “respect for the skills that are already there—the strategies that are used are being used for really good reasons.” Her perspective appears to be that families are doing the best they could with the tools available, in a way that made sense to them and fit in with other demands in their lives.

Interacting Professionally

Collegial relationships and collaborative practices are intricately intertwined. Participants discuss relationships as the foundation for collaboration, and collaboration as the method by which relationships are maintained. Collaborative practices like joint working, shared planning, and coaching colleagues enable practitioners to work effectively with professionals in other disciplines, sectors and settings.

Collegial practitioner relationships

In addition to their work with families, practitioners are found to place emphasis on relationships with colleagues. Speaking of her work with early childhood educators, one special education practitioner says, “I feel quite fortunate that I’m building quite strong relationships with families I work with and the early childhood centre staff. I think that comes from trust, and from open communication—honest communication.”

Open and honest communication allows practitioners to share ideas and issues with one another and with families, supporting reciprocity for children and families to be able to share back with practitioners. Practitioners also see their relationships with one another as a way of creating inclusive environments for children. One practitioner notes how relationships promote a climate of positive regard for practitioner, families and children which, in turn, supports people to feel good about what they’re doing and open to trying new things. One Special Education practitioner says,

> It is so important. We know, that if we can get the relationships right, and people feeling good about what they're doing and how they're doing it—then everything else will sort of fall into place in terms of our children being supported and included in education.

Coaching

Practitioners share examples of supporting the practice of other professionals. Interprofessional coaching occurs most often in educational settings, where teachers and teacher aides are supported to implement interventions provided by practitioners from Special Education or Child Development Services.

A Special Education practitioner provides an example of coaching teachers, teacher aides and children to support a girl in their class to get around their school grounds. The girl uses a wheelchair and the school grounds have level changes and various surfaces, making it difficult for her to navigate on her own. Instead of teaching the teacher or just the teacher aide how to get girl and her chair around campus, the practitioner brings the parents, educators and children together in implementing the plan. The practitioner coaches the teacher, teacher aide and children how to support the other student in navigating her wheelchair across the terrain. Through coaching, learning and working together the children, educators and practitioners got to know and develop trust in one another so they could try out new ways of peer-supported mobility and building an inclusive learning environment.

Practitioners consistently identify the need to up-skill other professionals in the consistency of their approach and modelling behaviours for others to see. One practitioner says,

> It's not the big talks, it's about the practice. It's the doing, and role modelling and coaching, over time and being consistent, and being present. With a lot of change of staff, you lose credibility. Just doing a talk for one day, that's not professional development—you need to follow up and give advice in the moment, so they can see the reaction straight away. That makes them believe in it and say, "that worked!"

Another practitioner says,

> Basically, they can take or leave it. We're not there to enforce it and say "This is how it should be done." We have to work with different philosophies and we do have to respect different centres' philosophies, because at the end of the day, the parent or child that we're there for has chosen that centre. So, we have to be

> quite respectful, but also highlighting research and theory around child development.

Practitioners use an array of collaborative practices to support consistent implementation of interventions and approaches. However, it is up to the individual to uptake and use the strategies offered.

Advocacy

Parents and practitioners speak of advocating on behalf of children. One parent recalls navigating the area between advocate and negotiator. She speaks of an instance where she disagreed with recommendations from her daughter's school and wanted to refuse their request. However, the urging of her paediatrician to reconsider led to her decision to trial the school's request.

Practitioners tell of acting as advocates and negotiating with other colleagues the care and services for the children they supported. A special education practitioner speaks of negotiating services with other practitioners on behalf of the children she works with. "[I] generally support the first moderation—work out what the hours of support will be. We usually know the child best so we can go, 'no, no, no they need more—they need more time in this area.'" Practitioners' reports of advocacy occur most frequently around supporting a child's transition into school and regarding obtaining assistive equipment.

Collaborative practices

Practitioners use collaborative practices to share information, deliver consistent messages and foster more holistic ways of viewing the needs of children and families. Collaboration between professionals occurs in various ways, including: informal discussion, joint visiting and shared planning as collaborative practices.

Practitioners working together in the same building report using informal discussions to share information and get advice on different cases. Many practitioners report having quick catch-ups with colleagues, and they identify a need to formalise these opportunities. One practitioner notes that a more structured format for discussing cases wold be useful for her. She says, "I would dearly love to hear what my colleagues are doing so I can pick it up. I have a different background…and a different perspective, so I value it I really value it."

Joint working, or joint vising, where more than one practitioner sees a child and family at the same time, occurs most often for practitioners who express a preference for that style of working; when practitioners are wanting to learn from one another and when time allows. One practitioner notes,

> Some of the clinicians are more open to that [joint working] than others—not everyone is as comfortable with that. When we visit jointly we get an opportunity to observe [the other] clinician working with a family…then I can make sure I'm delivering the same message and doing joint visits is a way of doing that.

Shared planning features more frequently when practitioners are working with colleagues in different sectors and different environments.

> Overtime we have promoted, over and over, it's a team effort. The parents do something, the early childhood does something, and we do something. But we always sit together and say—"where is the child at" from different angles, but also "what do we need to do for the next few months to make it more successful?"

However, like the practitioner notes above, some practitioners have a take-it-or-leave-it approach to collaborative working, while others maintain that collaborative practice is the foundation to working with families.

Summary

Horizontal analysis provides a way of looking across multiple, individual vertical cases to highlight themes occurring within the individual narratives. The first theme, navigating barriers, describes the way in which participants understand the challenges they face in accessing and providing care and support for children with disabilities. Parents and practitioners vary in their interpretation of the cause of these barriers. The second theme, building relationships, highlights the role of relationships for both parents and practitioners. This section shows how parents and practitioners both use relationship development as a means to accomplishing a goal. The third theme, interacting professionally, shows practitioners work outside of the hands-on therapy they are trained to provide. Much of this work seems to centre on their ability to develop relationships among peers, similar in the way they develop relationships with parents in order to facilitate the implementation of interventions when they are unable to be there doing the work themselves.

Chapter Eight: Discussion

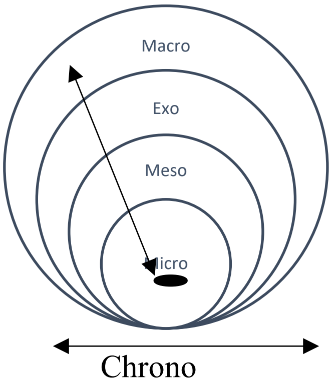
Introduction

Findings from Chapters 6 and 7 highlight the barriers, practices and relationships that parents and practitioners experience in accessing support for children with disabilities. This chapter discusses the interactions of those themes with one another and brings the themes into conversation with the conceptual and research literature. Using elements from the theories discussed in Chapter 4, I created a conceptual model of relational practices in the contexts of care and support for children with disabilities. The relational model in context helps to show how relational practices influence and are influenced by the environments where they are used.

Relational Practice in Context—Developing a New Conceptual Model

Discussed in detail in Chapters 2, 3, and 5, socioecological theory (Bronfenbrenner, 1979, 1996) provides a lens for examining differing levels of interactions. I use socioecological theory here to explain the distance between levels of interactions. The interaction's proximity to the child at the centre of the interventions impacts on the relationships between the child's parents and the practitioners delivering the intervention.

Figure 4.
Multidirectional Interactions with in the Socioecological Model.

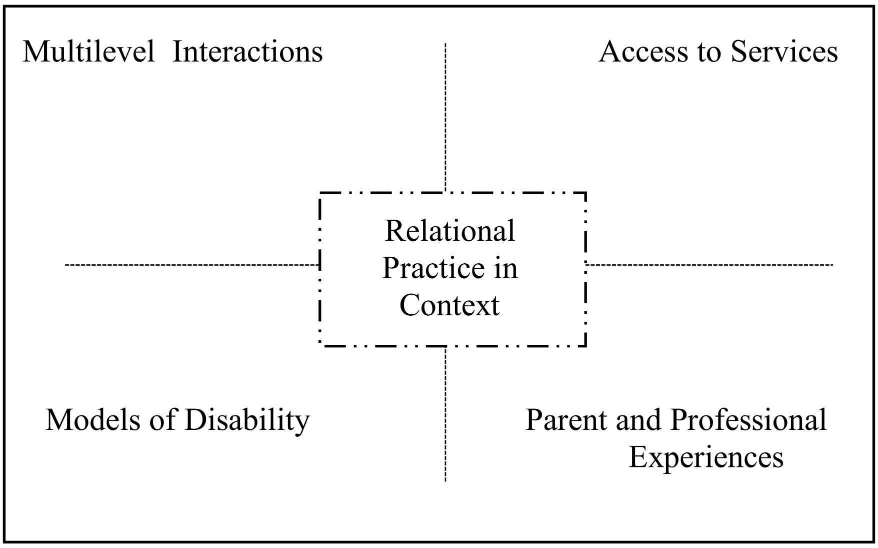


(Adapted from Bronfenbrenner, 1979)

In figure 3, the black oval represents a child. The double-sided arrow extending out from the dot represents the bidirectional influence of interactions at various levels. In addition to the influence of socioecological level, activities are also influenced by participants' conception of disability.

The phrase "conception of disability" is used in this section to encompass the various discourses, models and theories of disability that participants are seen to use and to ascribe to their organisational and practice environments. Blackburn (2016) described the practice she saw in Aotearoa New Zealand's early childhood services as *relational practice*. I have extended Blackburn's (2016) work by developing a new conceptual model. Relational Practice in Context is the new model that demonstrates how broad conceptual models of disability, multilevel interactions and relational practices influence access to services and parent and professional roles. The Relational Practice in Context model is depicted in the figure below.

Figure 5.
Relational Practice in Context



Parent and Professional Experiences of Disability Support Services

Each participant, from their different vantage point, experienced frustration at the level of services available to children with disabilities. This frustration is consistent with both grey literature (Ministry of Health, 2014; United Nations, 2011, 2015 and research literature (Bruder, 2000; Campbell & Halbert, 2002; Clark & Macarthur, 2008; Park & Turnbull, 2003; Turnbull, Summers, Turnbull, Brotherson, & Winton, 2007). In this research, parent participants express experience of service shortfalls from the earliest days of parenting their children. They report of being fearful that they did not know how to help their children and neither did some of the professionals involved in their care. However, these parents' experiences seem to relate directly to early interactions with paediatricians, medical practitioners at hospital emergency departments, and then again with educators when their children started school. These interactions did not appear in reports of interactions with allied health practitioners in child development services. Overall, parents rate highly their experiences with Child Development Services practitioners, suggesting that the relational practices in use mitigate the negative perceptions of services even where there are acknowledged service gaps.

Parents and practitioners identify that inclusive practices are stymied by system constraints. Confirming findings from other research (Hornby, 2012; Macartney, 2011), practices in the education sector are seen to be problematic. Parents take issue with the application processes for additional supports, which they report to be deficit-based. Parents also perceive teachers and other school-based practitioners to have a lack of knowledge and skills around providing supports to children with disabilities. This reinforces what we know about a lack of adequate preparation for teachers in their tertiary training (Hornby, 2012), where they have little or no compulsory exposure to special education theory and practice. Yet, education practitioners are expected to teach what are considered fully inclusive classrooms. This ties into the notion of inclusion as a rhetorical device rather than professional practices and tangible supports for student, teachers, families and communities.

The idea that Aotearoa New Zealand has an inclusive education system is misleading (Hornby, 2012; Kearney & Kane, 2006; Wills, 2006). Yes, Aotearoa New Zealand has one of the highest rates of inclusion, if measured by participation in mainstream classrooms (Hornby, 2012) where children with disabilities share the same classrooms as typically developing children. However, their learning and engagement with peers is dependent upon individual teachers, the environment, and culture of the class and the school. Inclusive practices are then stymied by system constraints due, in part, to the lack of specialised special education tertiary training and in part to the lack of resources supporting special education within the larger Education Services sector. This results in a system of support that is challenging to navigate and mirrors what Skrtic (1991a, 1991b) refers to as ad hoc and variable depending on where you live (Skoss, 2018) and who the practitioners are.

Despite language in *Te Whariki* specifically addressing the needs and provision of services for children with special educational needs, the extent to which these needs are catered to in the practice environment is disputed. Discussed in chapter 2 was evidence that demonstrated a lack of inclusive curriculum, pedagogy, environments and practices that act as barriers to full participation for children with disabilities (Foster-Cohen & van Bysterveldt, 2016; Hornby, 2012; Powell, 2012; Selvaraj, 2016; Wills et al., 2014).

Special Education Service specifications are broad, individual practice orientation varied, and there were no formal mechanisms in place to bring these into conversation let alone in concert. In both Special Education and Child Development Services there was a clear absence of collaborative clinical case review. Team meetings were focused on administrative and operational tasks, and a lack of group meetings reduced opportunities for practitioners to get feedback and learn from one another around case-related issues. Earlier reports (Ministry of Health, 2014; United Nations, 2011, 2015 exposed the variance in services and practices across the country and this research confirmed that variation. Findings from this research suggest practitioners are willing to engage in activities and practices like case reviews, joint visiting and role release that would support practitioners to build up continuity across individual sites. This indicates that practitioners recognise and acknowledge the problem, have identified the solutions, and yet do not have the means to implement them. Using these and other mechanisms, (e.g., requirements for formal group supervision) have potential to bring services into coordination without a big expenditure. However, those practices require structural support from local leadership, agency leadership and policy that mandates, supports, and resources collaborative practices.

Another issue is the handling of entry and exit criteria. A broad and general criterion for entry and exits to services, if it is “likely to continue for at least six months and limits their ability to function independently, to the extent that ongoing support is required” (Ministry of Health, 2015b, p. 6) creates a situation where individual practitioners and team leaders are tasked with determining which children receive care and which children do not. The lack of criterial specificity is a mechanism for avoiding transparency and intentionally obscuring from view what is happening. The intention might have been for localities to have freedom and flexibility to provide services appropriate and responsive to the unique needs of their area; however, without sufficient funding and other resources, practitioners are left with the responsibility of selecting which children get services and which do not. This is a problem, as it abdicates government responsibility for providing adequate services and it violates practitioners’ codes of ethics. It places practitioners at risk for violating their professional ethics. And children and families are at risk of missing out on services for perceived lack of engagement. Practitioners told of appointments scheduled by mail, when families were known to be transient. Transience, coupled with extensive wait-times means families might not learn their child has an appointment, and if they do, they might not remember why. It would be difficult then for families to assign value to meeting someone they do not know, in an unfamiliar place, usually during regular working hours and for an unspecified purpose.

A system is needed that supports individuals, their families and caretakers to identify and achieve goals that are meaningful for them. However, without a system-wide shift, what we have instead is inclusive, child- and family-centred rhetoric. This finding is supported by those of other researchers (Lee, 2015; Skrtic, 1991a; Skrtic, 1991b) and add support as another, if slightly different, version of what Lyons (2013) terms “enlightened ableism” which allows for the presentation of a world view, yet “allows the continuation of practices that marginalise people with disabilities” (p. 240). Though useful, there are limitations of what family-centred practices (Dunst, 1997; Dunst, Trivette & Hamby, 2007), like parent–professional partnerships and shared decision making can contribute when the practice takes place within services and larger support environments that are already under duress.

Relational Practice and Perceptions of Disability Constructs

Findings from this research show parent participants' perspectives of disability shift over time. In the early days of learning to respond to the needs of their children, parent participants valued the emotional support provided by practitioners. This finding supports those of Blackburn (2016) and Lyons (2013) in that parents appreciate the expertise of medical and allied health professionals (Blackburn, 2016; Lyons, 2013)**.** They are unsure of themselves and are therefore more reliant on practitioners for advice and reassurance. The paternalistic tendencies inherent in the medical model support parents in this stage—even as one parent said, if it is just to prove them wrong. The medical model in the early days provided a sense of security as well as a jumping-off point for parents developing their own sense of what is right for the child and developing a resistance mentality. Parents called this a "thick skin" that they developed. But it is more active engagement than just armour. It is a way of turning painful words and actions into something useful—a pathway forward.

Parents do not understand the difference in service between health early intervention and educational early intervention and Special Education services. This means that they see Special Education Services practitioners as being unavailable, and hands-off. While that is true, and for a variety of reasons mentioned in earlier chapters, it is also the case that these practices are part of the practice model adopted by the Ministry of Education. In education's model, Special Education Services practitioners train teachers and education assistants to implement interventions. The reasoning behind this being they are more familiar with the child, will spend more time with the child, and are a less expensive way of delivering intervention. In this model, intervention fidelity and monitoring are difficult to assess considering teacher and Special Education Services practitioner time is stretched.

Parents did not speak highly of teachers and special education services in their ability to meet the needs of their children. Findings from this research show parents more concerned with deficit-based approaches and insufficient services. Findings demonstrate that parents viewed Special Education Services as a system designed to identify their child's deficits and then fail to meet their needs in addressing those perceived deficits. They did not like the tools used to collect information, the lack of contact with Special Education practitioners or the proliferation of reports Special Education are seen to produce. Parents wanted hands-on therapy and to see their child improve.

These ideas were tacit and went undiscussed. Research into practitioners' perspectives of inclusion finds gaps between practitioner beliefs about inclusion and their actual practices (Bruns & Moghareban, 2007). Findings from this research suggest, in some circumstances, this might be the case and practitioners attributed these gaps to the policies of their agency, insufficient staffing for the service demand, increasing waitlists, and challenges posed by remote rural locations.

So, then what informed Special Education Services practitioners views? Two things seem to be going on. The first, practitioners' beliefs and practices are not well aligned. Lyons (2013) explains this phenomenon in her findings relating to inclusive believes and practices in education. She used the term "enlightened ableism" to describe their discrepancy between beliefs and practices. Ingólfsdóttir and colleagues (2013) also describe a mis-alignment between service orientation and professional practices. They attribute the tension to a change in system-level paradigms, without communicating clearly to service uses (to the extent that the paradigms and their implications are understood) and families about what these changes mean in practice, for themselves and their families.

Education appears to have adopted the social model of disability without telling parents what that means for them and their child. This finding supports that of Ingólfsdóttir and colleagues (2013) in that systems adopt new ways of working without ensuring all involved parties are aware of the changes taking place, what will be different and what will be asked of them. Access to the curriculum is an abstract idea that has little value to parents when presented with a lack of support for developing meaningful goals and strategies. Meeting Special Education practitioners only once a year at an IEP meeting was not conducive to relationship building. Parents and school-based educators would benefit from one-on-one time with Special Education Services practitioners so they could learn the specifics of the interventions they are employing but, more importantly, the reasoning behind the interventions; what they hoped to achieve and determine if these were goals relevant to the child and family. A parent who is worried about their child catching bugs from other children when being pushed around the school campus in their wheelchair by their peers is going to be problematic. Assumptions are made that parents are interested in improving peer relationships and interactions—and they may very well be—but it is impossible to know unless practitioners involve them and their children in the decision making and review processes.

Confirming the findings of others (Macarthur & Dight, 2000) Parent and practitioner relationships were in tension in times of transition. In contrast to findings in the United States, where parents and practitioners' relationships were contentious, Ballard (1994) speaks of the advocacy styles used in the United States and warns against their import to Aotearoa New Zealand where the abrasiveness of the advocacy is still ill-matched for the culture. The differences in culture, coupled with the differences in legislation make comparison between parents' experiences overseas to those of parents in Aotearoa New Zealand untenable. In this country, family involvement is not mandated through legislation. Instead it is a principle of professional practice. Parent participants expressed desires to have more influence on decisions involving support services in the education sector. This finding is especially interesting because Special Education practitioners saw themselves as being better aligned than their Child Development Services and health counterparts and more toward a family-directed conception of services.

A lack of robust transition planning is problematic. Again, supporting the findings of others, parents felt they had to leave their children in school past the age where they are gaining any benefit, because there is nowhere else for them to go. Leaving adult children in school way beyond the age of their peers because they are disabled is problematic because it assumes they have nothing else they would like to be doing, or any other ways they might be of benefit to their communities. Parents are disappointed in the lack of tertiary training options and employment support options for their children. This again supports the idea of inclusive schooling being only notional.

Children and adult children with disabilities share the same spaces as typically developing children, but the environment is not created to suit their needs, or respond to their strengths. They are instead expected to mould themselves to what is available. A strong social model of disability would look at the built environment, the pedagogical environment, the curriculum, the culture, and the community, and make modifications to suit all children.

Relational Practice and Access to Services

Parent participants describe tension with practitioners, as well as using such relationships as a means to overcome challenges and improve their access to services. The tensions between parents and practitioners are focused around the ability to access services for their children, more than with the practitioners themselves or the practices they are using. These tensions occurred when children were acutely ill and needed emergency services. In one situation a mother described how the treating Emergency Department physician did not believe her about what was needed to reduce the likelihood of continued seizures. So, while there was a tension between the mother and the physician in this instance, the larger issue is a system of care of that does not support children with acute and chronic illness to have ready access to paediatricians. The care system is not designed in such a way that facilitates access to care for children with disabilities who are more likely to have acute episodes of illness with increased risk of complications when not treated quickly.

Parents spoke of identifying people who were gatekeepers who could put them in touch with the practitioners they needed, get them in to appointments when others said there was nothing available, and get them the information they needed for accessing services in other areas. Findings from this research show parents navigating this system as part of their interactions with health and child development services, but these findings did not translate into educational contexts.

Practitioners use relationships to promote engagement with children and families and fill the gaps where services are unavailable. Practitioners said they supported these relationships and informal ways of facilitating access to services, they also spoke about the tensions they encountered in having to navigate competing demands. Child Development Services and Ministry of Education Special Education practitioners complained of insufficient resources to meet demand for their services. Feeling as though they were pulled in multiple directions—to meet the needs of children, families, the requirements set forth by their agencies, their co-working agreements with other agencies, children's rights and their own relationships with colleagues and untimely to their work, practitioners brokered relationships with families and colleagues in order to reduce the tension between competing demands. Practitioners did this using family-centred practices (Dunst, 1997; Dunst et al., 2007).

Family-centred practices have long been held as standard for early childhood service provision (Pereira & Serrano, 2014). Family-centred practices are those that recognise the interconnection between child and family, ensure family participation in decision making and build on children's and families' strengths for intervention design and delivery (Dunst, 1997; Dunst et al., 2007). Family-centred practices operate under an assumption that families and practitioners have a sufficiently robust relationship to facilitate honest communication and shared decision-making. Noddings (2010) specifies that, where there is mutual respect and exchange between practitioners and parents in these interactions, communication, trusting relationships and shared decision making can occur. Noddings (2010) refers to this interaction as reciprocity—where the recipient of the care deems their experience to be sufficiently caring.

However, the reciprocal interactions that Noddings (2010) calls for, extend the family-centred interactions Dunst and colleagues (1997, 2007) set out, because Noddings' reciprocity requires more than just involvement in decision-making, but an emotional connection that supports families in feeling cared for, rather than being solely partners and decision makers in care. Findings from this research demonstrate that it is sense of care that facilitates relationships between family and practitioner, facilitates family engagement and is projected to support families in understanding information, asking questions, participating in meetings and other aspects of decision-making processes. Without the sense of care, even when interventions, supports and services are aligned to children's and families' needs, families do not experience the service as meeting their needs.

Bronfenbrenner's chronosystem (1979, 1992) provides a useful framework for explaining how parents' confidence, and potentially their confidence to engage in reciprocal interactions, develops over time. Findings from this research demonstrate that practitioners actively participate in building this confidence. However, how much of parent's confidence development is attributed to practitioner interventions versus parents' maturation over time, the frequency with which they describe having to advocate on behalf of their children remains unanswered. And an interesting topic for further research.

Similar to the findings of others (Ballard, 1994; Macartney, 2013; Wills et al., 2014), there was some disconnect in how individual practitioners interacted with families. One practitioner made it very clear that she understood the strategies used in families to be functional and in need of respect. Where another practitioner spoke of interpreting families' unreadiness for appointments as a family being unable to organise themselves. A professional arrogance might be seen in this assumption that practitioners' time—and by extension, their appointments—ought to take priority over whatever else the family was doing. However, it is important to note that parent participants used these opportunities (where they found practitioners' behaviour or advice unsatisfactory), to develop their own strategies and seek out assistance elsewhere. Potential for professional arrogance is related to professionalism discourses (Thomas, 2007) and demonstrates that the implementation of family-centred care is likely to continue to be an issue.

Parents and practitioner participants are found to continuously vacillate between roles. Transdisciplinary practice (Watson et al., 2002) suggests this is expected under the approach. However, the literature on transdisciplinary practices says little on practitioners stepping out of their disciplinary-defined professional roles as they take on tasks in a non-professional realm. In attempting to implement family-centred practices, practitioners tried to take on parental responsibilities like creating schedules, influencing whether a child was ready to return to school, and implying practitioners do not trust parents to make the correct decisions for their families. When practitioners do not trust families, they do not have the tools necessary to explore this issue with families and to get underneath what they perceive the problem to be, so instead they make a judgment. From that judgement, practitioners determine the extent to which parents and children are able to be involved in their own and their children's treatment planning. Critical disability scholarship offers another way of looking at the practitioners working in parenting space through what (Thomas, 2007) sees as professionalisation and management of the lives of people with disabilities. Thomas's (2007) concept of the professionalisation can be applied here to the lives of parents caring for their children with disabilities, where professionals are assumed and/or actively position themselves as the source for accurate advice.

Parents and practitioners both, at times, struggled for power. Findings from this study indicate practitioners intentionally created relationships with parents in order to assert the importance of their objectives. Practitioners said things like, "We can't go anywhere without relationships." This attitude from some of the practitioners in this research suggests they have agendas from the outset, they know what is best, and if they construct relationships with families, they will be able to generate families' buy-in to their interventions. The findings, that some practitioners are more interested in ticking the box of parent participation, support Lee's (2015) findings. However, findings on the variability of practitioner perspectives, in how they attempt to engage and support family decision making, contradict those of Lee's (2015). Most practitioner participants expressed willingness to include and follow family direction, but seemed to have difficulty with implementation. Difficulty with implementation appears to come from preconceived ideas of help prior to engaging with families, a lack of organisational resources, and a lack of institutional support and flexibility. A true family-centred perspective would view relationships as the facilitator of family-directed intervention—so that practitioners could do the bidding of families through their networks of relationships instead of requiring families to do so.

Relational Practice and Multilevel Interactions

Many practitioners reported subverting agency norms to benefit the children, families and communities they work with, and doing so without calling attention to their actions. One practitioner told of keeping a child on her roster even though she knew her supervisor and her agency would deem him ready for discharge. She thought he could benefit from additional therapy that would allow him to meet his personal goals—even if they might be considered sub-threshold for Child Development Services. Gable and Peters (2004) would suggest these acts fit within a resistance paradigm, where practitioners and parents are pushing back and subverting organisational and cultural norms. In the Aotearoa New Zealand context, a resistance paradigm is used in reframing conversations around family violence (Family Violence Death Review Committee, 2017). Although the family violence context and the focus of this research are different, there are parallels that can be drawn between how actions of parents and practitioners can be seen to resist the impositions of service constraints.

Findings from this research show that practitioners sought to lessen the impact of inequities created by geographical isolation. They did this by leaving office doors unlocked when operational policy dictated they were meant to be behind locked doors. They also spoke of making themselves available outside of normal working hours knowing that oftentimes families were unable to make meetings during regular working hours. Findings also show that informal modes of communication are utilised by parents and practitioners alike when both groups make themselves more available to one another, despite agency norms restricting communication to certain channels and time periods. Parents are seen to utilise the advocacy skills strengthened through work with practitioners, against those same practitioners in creating their own intervention, adjusting medication regimens to reflect the needs of their children and creating advocacy and support systems that are outside of agency structures and are actively involved in challenging agency practices and policies.

Summary

Research into parent and professional experiences of disability support services is not new. Much has been written about the challenges both groups experience in providing care and support for children with disabilities (Blackburn, 2016; Brantlinger et al., 2005; Bruder, 2000; Campbell & Halbert, 2002; Clark & Macarthur, 2008; Lyons, 2013; Macartney, 2013; Turnbull, Summers, Turnbull, Brotherson, & Winton, 2007; Park & Turnbull, 2003; Wills et al., 2014). Yet, those challenges continue. This research generated new knowledge about how parents and practitioners use relational ways of working to bridge the gaps left by inadequate levels of support in the care and education service for children with disabilities. In the research literature, relationship building and maintenance are considered core concepts of family-centred care (Dunst, 1996; Dunst et al., 2007) and family-centred care was developed in response to the medical model of disability that pathologises the individual with an impairment. In this context, relational practices are an antidote to professional-led decision making through parent–professional reciprocity and the involvements of families in the decision-making processes. Findings from this research also suggest that parents use relational practices to create otherwise unavailable access to services for their children. Findings also demonstrate that practitioners take an active role in developing parents' advocacy skills so they are able to take full advantage of the relational interactions they have with practitioners as they continue to engage with disability support professionals.

The theoretical and conceptual framework for this research involved and overlay of structural and post-structural theoretical positions. This was attempted by bringing together elements of Bronfenbrenner's (1979, 1996) socioecological systems theory with critical social theories of disability. The conceptual framework was influenced by Ingólfsdóttir and colleagues (2012, 2018) work signalling the potential for cultural historical activity theory and other similar activity theories to inform the understating of the complex interactions taking place across multiple systems in early intervention services for children with disabilities.

The primary contribution to new knowledge is understanding of how and why relational practices are useful to both practitioners and parents involved with care and education of children with disabilities.

Chapter Nine: Conclusions and Recommendations

Introduction

This research set out to investigate parent and practitioner experiences in accessing and providing support services for children with disabilities. I did this by employing a critical constructivist paradigm and naturalistic inquiry methods to explore the experiences of parents and practitioners supporting children with disabilities in one area of Aotearoa New Zealand. As an expatriate unfamiliar with the contexts and nuances of services and service provision in Aotearoa New Zealand, using a critical constructivist paradigm allowed for exploration of concepts from a critical perspective while still maintaining the relationships necessary to progress the investigation. Using vertical analysis (Mutch, 2017, 2018), I set out to uncover the narrative inherent in the participants' experiences described in the individual case studies. I then used horizontal analysis (Mutch, 2017, 2018) to identify and cluster themes across case studies. Themes were then discussed using socioecological systems theory (Bronfenbrenner, 1979, 1996) critical social theories of disability (Oliver, 1980; Gable & Peters, 2004; Shakespeare, 2013; Tremain, 2005) and concepts from the empirical research literature.

Summary of Findings and Significance

I found that parents and practitioners use relational practices to mediate support services limitations. Parents do this through developing relationships with one another, practitioners, and others in their communities to increase access to the services they need. Practitioners also use relationships to fill gaps in support service limitations. They do this through developing parental confidence in engaging with practitioners and employing interventions, developing parental competence in advocacy, and working in partnership with their internal and cross-sector colleagues. Practitioners also used collaborative practices in up-skilling their communities, and resisted their agency policies and norms to make themselves more accessible to children and families. I found parents' conception of disability to change over time, from an early acceptance of the medical model to a moderate social construction of disability as their children aged. Practitioner conceptions of disability varied in their degree of commitment to social constructions of disability. Practitioners in this research were not found to adhere to strict medical models of disability.

I also found parent and practitioner actions and interactions were complicated by the unique challenges posed by their environments. These challenges included geographic isolation with rural services covering large areas, limited full-time staff to participate in joint visiting, clinic-based visits for more rural families when urban counterparts had more access to home visits. Parents found educational settings and educational practices to be deficit focused, and they did not appreciate the changes in service delivery between Child Development Services and Special Education Services, which represent (to varying degrees) differences in conceptual paradigms of disability and the services necessary to respond to disability-related needs.

Findings are significant in demonstrating relationships between parents and practitioners are likely to influence the outcome of interventions. This research demonstrates that relationships have become part of the intervention itself, rather than just how the intervention is delivered. These findings challenge some of the earlier work by Dunst and colleagues (2007) where family-centred practices, which include relationships between parents and practitioners, are seen as the method for employing the intervention—not necessarily the intervention itself. Findings are also significant in demonstrating the need for ongoing change within the special education support services arena— suggesting that the current environmental emphasis is not well understood or appreciated by parents or by all practitioners. Findings are also significant because they detail a need for further advocacy training for parents that does not impinge upon the therapy and support services provided to their child. Overlapping direct therapy time with parental advocacy training, administrative and other tasks place unfair burdens on parents and practitioners, and (though not investigated here) likely the child who is not receiving the level of support to optimise their environment and functioning.

The Relational Practices in Context framework I used explains the importance of what I have found by demonstrating that parents and professionals use relational ways of working to multiple ends. The conceptual framework also provides a mechanism for examining how interventions and services can have multiple orientations, and problems arise when these orientations and their justifications are not made explicit to families who are likely unaware of the changes and their intended purpose.

This research contributes to the body of knowledge on parent and professional interactions by offering a new model for understating how relationships facilitate changes in parent and professional roles and interactions, and the potential to impact intervention outcomes across socioecological levels and concepts of disability. This research builds on the findings of others in explaining how the discourse of disability (Macartney, 2013) and environmental context influence, in concert, the experiences of parents and practitioners involved in the care and support of children with disabilities.

Findings from this research might benefit policy makers by providing evidence for investment into specific areas of disability support services. Findings might benefit practitioners from seeing their own and their colleagues' practices, and having additional evidence advocating for changes within their sector. And perhaps most importantly, findings might help parents by identifying and validating the challenges they experience in accessing necessary services for their children and in creating and maintaining inclusive environments.

Recommendations

Hornby (2012) refers to many differences between special education provision in the United States and that in Aotearoa New Zealand. One major difference is the lack of a legal mandate for special education services. This lack of a legal mandate in Aotearoa New Zealand poses problems such as an inability to seek enforcement or redress. However, legal mandates create problems of their own including in the litigious culture in the US where practitioners are fearful of legal ramifications and react with allegiance to the letter, rather than the spirit, of the legislation (Skrtic,1991a; Skrtic,1991b). Aotearoa New Zealand has a unique opportunity to build on its current emphasis on inclusive education and universal health services in implementing the following policy recommendations.

- Teacher training institutions create mandatory disability studies and special education coursework of all trainee teachers, and prepare education practitioners in universal design for education, need specific intervention, universal screening
- Increase funding to special education and allocate by need
- Professional registration requires ongoing professional development in special education practices, specific learning needs, and inclusive practices

- Expansion of universal, and locally relevant, children's services in order to reach and expand access to children not hitting the threshold for specialist services (in education and health)
- Funding tied to disability prevalence rates and rates of contributing factors influencing likelihood of disability including environmental considerations, as well as social and cultural contexts.

Legislative and operational policy can provide support for professional practice. Practice related recommendations follow below.

- Increase professional development opportunities for allied health, special and general education practitioners including support for time away from work to attend professional development
- Increase use of role release to maximise the expertise of scarce specialist practitioners
- Increase face-to-face therapy with children
- Increase face-to-face time with parents to identify their needs, dreams for their children and support for their skill development.

Limitations

An important caveat is that parent participants are reporting on services provided in the past. Parents interviewed for the research had children no longer in childhood services, and arguments can be made that much has changed over the years since their children received services from Child Development Services practitioners. The research design was limiting in that it looked at one geographical area of Aotearoa New Zealand, and findings might be different in other areas of the country. In hindsight, using a critical constructivist paradigm was limiting in that it prevented a depth of exploration in either critical or constructivist positions as emphasising one element created issues for exploring the other. An example of this was the difficulties in unpacking parent and professional conceptions of disability, while also taking into account the co-construction of those narratives within the interview process.

Final Conclusion

Multiple layers of analysis were required to explore complexities of practice and the impact of multiple systems of influence on the provision of support services for children with disabilities. Moving forward, findings suggest that building upon the universal (Shakespeare, 2013; Shakespeare & Watson, 2001; Zola, 2005) and emerging Relational Practice in Context models to focus on building mutually trusting relationships, seeking out opportunities for acknowledging and supporting reciprocal and culturally relevant practices and advocating for the re-conception of service orientation and delivery could make an impact on the experiences of those who practise and those who participate in services.

This research contributed to emerging models of practice and to the operationalising social theories of disability. This research adds to the understanding relational practices in context and reciprocal approaches to service provision include and acknowledge that:

- Individuals experience impairment, but disability is a socially constructed phenomenon borne of disabling actions, attitudes, practices and environments. This is an operationalisation of the social model of disability in practice.

- Interdependence and reciprocity are necessary in practitioner/family/child interactions. Practitioners depend on service users for their profession, professional identify and income. Service users depend on practitioners for specific support, therapies, and education. These relationships are continuously built and rebuild on reciprocal exchange of information and trust. Including reciprocity an interdependence in transactions between practitioners, children, and families.

- Relationships are drivers in interventions and intervention outcomes. Taking issue with what Dunst and colleagues (2007) characterised as how things are done, the universal relational model centres both *what* is done and *how* it is done to achieve an outcome. Both intervention and practice promote and sustain relationships within systems (interpersonal to inter-political).

- Different paradigmatic models of practice and services have the ability to perpetuate or disrupt conceptions of disability by influencing physical, attitudinal, practice, interpersonal, political and economic environments.

Parents and practitioners use their roles and relationships with each other and others in the communities in which they live to navigate challenges of accessing support services for children with disabilities. Building and maintaining relationships is more than just how interventions are delivered— relationship development is an intervention in and of itself as well as a mechanism to achieving outcomes. This study demonstrates that relational practices can help parents to access Child Development and Special Education services, and can help practitioners to access parents and children to aid in therapeutic intervention uptake. However, this study also shows that relational practices are unable to bridge all service limitations. Some limitations, for example, isolated geographic location, insufficient levels of practitioners and staffing, and lack of specialised professional training and development for teachers, and routine and robust case review practices cannot be bridged through relational practice alone.

Appendix A

School of Critical Studies in Education

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PARTICIPANT INFORMATION SHEET: Education and Health Professionals
Project Title: Parent and Professional Knowledge in Relation to Children with Special Needs in Early Childhood Development
Researcher: Karen Hale

My name is Karen Hale and I am working on a PhD at the University of Auckland. This is to tell you what my research is about because you might be interested in being part of it. What I am doing is writing about how parents and practitioners think about, talk about and make decisions about children with special needs.

This can be a troublesome area with parents, educators and health practitioners often frustrated by the difficulties of communication and arriving at agreements over how we define need and provision. I want to make transparent the nature of those challenges for all involved. The aim is not to make judgments, but to make complexities transparent and to try to understand them better.

If you are reading this you may be a teacher or a health practitioner or some other person with a role to play in managing decision making processes on behalf of children. What I want to do with my research is to create a small, what we might call, a 'community of enquiry' around important issues. This means I will share insights and invite you to make sense of these experiences.

I would like to invite you to participate in two interviews lasting about 45 minutes each, as well as request your permission to sit in on an assessment, education or treatment plan meeting that you are a part of. With your permission, I will record our interviews using a digital recording device. You can stop the recording and withdraw from the research at any time. From the recording I will create a narrative summary, which I will provide for you to review and comment on. The recording and notes will be confidential and will not be seen by anyone other than the principal investigator and myself. In any reporting of the research I will maintain confidentiality of both the participant and the school or organization by the use of pseudonyms (fake names) and changing any description, however, there is always some possibility of recognition.

The audio recording file and typed notes will be stored in a locked cabinet within the University premises for the duration of this research project. The consent forms will be stored in a different office on the campus. After a six-year period the information will be destroyed.

If you are interested and wish to volunteer to take part in this research, I would appreciate if you could fill in the consent form (attached) and contact me directly to express your interest in participating. I can be reached at 0210 853 2518 (voice or text) or khal522@aucklanduni.ac.nz. Thank you very much for your time and help in making this research possible.

Warmly,
Karen Hale

Researcher: Karen Hale
Principal Supervisor: Saville Kushner, PhD
Supervisor: Robyn Dixon, PhD
Head of School: Carol Mutch, PhD

For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 ext. 83711.

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 15 May 2015 for 3 years until 15 May 2018, Reference Number 014374.

Appendix B

School of Critical Studies in Education

THE UNIVERSITY OF AUCKLAND
FACULTY OF EDUCATION
Te Kura Akoranga o Tamaki Makaurau
INCORPORATING THE AUCKLAND COLLEGE OF EDUCATION

Epsom Campus
Gate 3, 74 Epsom Avenue
Auckland, New Zealand
Telephone 64 9 623 8899
Facsimile 64 9 623 8898

www.education.auckland.ac.nz

The University of Auckland
Private Bag 92601, Symonds Street
Auckland 1035, New Zealand

CONSENT FORM: Adult
(THIS CONSENT FORM WILL BE HELD FOR A PERIOD OF SIX YEARS)

Title: Parent and Professional Knowledge in Relation to Children with Special Needs in Early Childhood Development
Researcher: Karen Hale

I have read the **Education and Health Professional** Participant Information Sheet and I understand the voluntary nature of this research. I have been given the opportunity to ask questions and they have been answered to my satisfaction.

I understand that:

- I agree to take part in two 45-minute semi-structured interviews as well as one observation lasting up to 60 minutes.
- I agree to have the interviews audio recorded.
- During the interview, I can refuse to answer any questions, stop the audio recording at any time, and because participation is voluntary, and I can withdraw data at any time.
- I understand my identity will be protected through the use of a pseudonym and any identifying features of the school or organization disguised.
- Even though all steps have been taken to protect the participant's and school or organization's identity, someone might recognize one of the participant's comments or features of the school or organization.
- The data will be used in the researcher's thesis, conference presentations and journal publications.
- The data will be securely stored at The University of Auckland for a period of six years and after that date will be destroyed.
- I wish/do not wish to have the chance to check the typed field notes developed from the interviews.
- A copy of the research findings will be made available to me upon request.

I hereby give my informed consent to participate in the research project *Parent and Professional Knowledge in Relation to Children with Special Needs in Early Childhood Development*

Signed: ___________________________

Name: ___________________________ Date: ______________________

Researcher: Karen Hale
Principal Supervisor: Saville Kushner, PhD
Supervisor: Robyn Dixon, PhD

Head of School: Carol Mutch, PhD

For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 ext. 83711.

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Appendix C

School of Critical Studies in Education

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PARTICIPANT INFORMATION SHEET: Parent
Project Title: Parent and Professional Knowledge in Relation to Children with Special Needs in Early Childhood Development
Researcher: Karen Hale

My name is Karen Hale and I am working on a PhD at the University of Auckland. This is to tell you what my research is about because you might be interested in being part of it. What I am doing is writing about how parents and practitioners think about, talk about and make decisions about children with special needs.

This can be an area of concern for parents, educators and health practitioners often frustrated by the difficulties of communication and arriving at agreements over how we define need and services. I want to make transparent the nature of those challenges for all involved. The aim is not to make judgments, but to understand them better.

What I want to do with my research is to create a comfortable space where we can look at and talk about important issues. This means I will share insights and invite you to make sense of these experiences.

I would like to invite you to participate in two interviews lasting about 45 minutes each, as well as request your permission to sit in on an assessment, education or treatment plan meeting that you are a part of.

With your permission, I will record our interviews using a digital recording device. You can stop the recording and withdraw from the research at any time. From the recording I will create a narrative summary, which I will provide for you to review and comment on.

The recording and notes will be confidential and will not be seen by anyone other than the principal investigator and myself. In any reporting of the research I will maintain confidentiality of both the participant and the school or organization by the use of pseudonyms (fake names) and changing any description, however, there is always some possibility of recognition.

The audio recording file and typed notes will be stored in a locked cabinet within the University premises for the duration of this research project. The consent forms will be stored in a different office on the campus. After a six-year period the information will be destroyed.

If you are interested and wish to volunteer to take part in this research, I would appreciate if you could fill in the consent form (attached) and contact me directly to express your interest in participating. I can be reached at 0210 853 2518 (voice or text) or khal522@aucklanduni.ac.nz. Thank you very much for your time and help in making this research possible.

Warmly,
Karen Hale

Researcher: Karen Hale
Principal Supervisor: Saville Kushner, PhD
Supervisor: Robyn Dixon, PhD
Head of School: Carol Mutch, PhD

For any concerns regarding ethical issues you may contact the Chair, the University of Auckland Human Participants Ethics Committee, at the University of Auckland, Research Office, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 ext. 83711. Email: ro-ethics@auckland.ac.nz

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 15 May 2015 for 3 years until 15 May 2018, Reference Number 014374.

Appendix D

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CONSENT FORM: Adult
(THIS CONSENT FORM WILL BE HELD FOR A PERIOD OF SIX YEARS)

Title: Parent and Professional Knowledge in Relation to Children with Special Needs in Early Childhood Development
Researcher: Karen Hale

I have read the **Parent** Participant Information Sheet and I understand the voluntary nature of this research. I have been given the opportunity to ask questions and they have been answered to my satisfaction.

I understand that:

- I agree to take part in two 45-minute semi-structured interviews as well as one observation lasting up to 60 minutes.
- I agree to have the interviews audio recorded.
- I can refuse to answer any questions, stop the audio recording at any time, and because participation is voluntary, and I can withdraw data at any time.
- I understand my identity will be protected through the use of a pseudonym (fake name) and any identifying features of the school or organization disguised.
- Even though all steps have been taken to protect the participant's and school or organization's identity, someone might recognize one of the participant's comments or features of the school or organization.
- The data will be used in the researcher's thesis, conference presentations and journal publications.
- The data will be securely stored at The University of Auckland for a period of six years and after that date will be destroyed.
- I (circle one) wish/do not wish to have the chance to check the typed field notes developed from the interviews.
- A copy of the research findings will be made available to me upon request.

I hereby give my informed consent to participate in the research project *Parent and Professional Knowledge in Relation to Children with Special Needs in Early Childhood Development*

Signed: ____________________________

Name: ____________________________ Date: ________________________

Researcher: Karen Hale

Principal Supervisor: Saville Kushner, PhD
Supervisor: Robyn Dixon, PhD
Head of School: Carol Mutch, PhD

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 15 May 2015 for 3 years until 15 May 2018, Reference Number 014374 .

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