

**BARRIERS, FACILITATORS, AND ADAPTATIONS TO AUTISM SUPPORT
SERVICES FOR LOWER INCOME AOTEAROA NEW ZEALAND FAMILIES**

BY

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ABSTRACT

Classified as a form of neurodivergence, autism is recognised as consisting of differences in sensory and cognitive processing, social interactions, and preferences for routine and structure. Research suggests that the provision of autism early support services is associated with a range of beneficial outcomes for autistic children and their whānau (family). Ideally, the needs of each individual family and child would dictate access to such support services. However, lower financially resourced families with an autistic child appear to face several barriers to receiving support services. Literature examining the adaptation of pre-existing early autism supports to address disparities in access and participation is limited. Utilisation of methods such as research-community partnerships to inform such adaptations is also rare. More research is needed to understand the barriers and facilitative factors lower financially resourced families may experience when seeking to access and/or participate in autism support services for their autistic child. Such research may then inform the adaptation of autism support services to increase accessibility, and therefore improve equity within autism service systems.

The present thesis consists of three empirical studies. Study 1 assessed the barriers and facilitators Aotearoa New Zealand parents reported experiencing when accessing and/or participating in support services for their autistic child. Study 2 utilised a research-community partnership approach to explore the experiences of five lower financially resourced Aotearoa New Zealand parents who had accessed an autism support service, the Early Start Denver Model. Results informed the development of a set of adaptations to improve the accessibility of this service. Study 3 consisted of piloting the adapted support programme with one lower financially resourced whānau (family). Study 1 results suggested that lower income families experienced a significantly greater number of barriers, and experienced those barriers to a greater extent, than families who were higher income. The

results of study 2 identified several facilitative factors and barriers to the Early Start Denver Model programme, with both parents and community partners providing a broad range of ideas for possible adaptations. Results from study 3 suggest that adaptations to support services which target the needs of lower financially resourced families may indeed be useful for improving accessibility of such services.

Collectively, the results of these studies indicate that lower financially resourced families experience a range of barriers to autism support services for their children, but also several facilitative factors. Both parents and providers have ideas of ways in which service access and participation could be improved. Through applying such ideas to the adaptation of pre-existing early autism support services, it appears as though accessibility of such programmes may be improved for lower financially resourced. Future research further examining the impacts of adapted services on autistic children and their whānau would be beneficial.

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“Ehara taku toa i te toa takitahi, engari he toa takitini: My success is not mine alone, it is the success of the collective.” (Elder, 2020, p. 145).

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GUIDING WHAKATAUKĪ

The following Whakataukī (Māori proverb) was selected at the beginning of this PhD to guide my actions, decisions, and overall approach throughout the journey: “**He aha te huarahi? – I runga, I te tika, te pono, me te aroha.** *What is the pathway? - It is doing what is right with integrity and compassion.*” (Te Puna Hauora o Te Raki Paewhenua, 2023, “Our Whakataukī” section).

PUBLICATIONS ARISING FROM THIS THESIS

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DECLARATION BY THE AUTHOR

This thesis is composed of my own original work in fulfilment of a PhD under the supervision of Dr Hannah Waddington (primary supervisor) and Professor Jeff Sigafos (secondary supervisor) from the School of Education at Victoria University of Wellington. No part of this thesis has been previously submitted for any other degree or diploma. Work by other authors has been referenced in the text and others' contributions have been clearly stated. The studies included in this thesis received ethical approval from the relevant ethics committees. All details applicable to ethical approval are reported in the corresponding study. Dr Hannah Waddington advised on the design, methodology, and data analysis of each of the studies, as well as editing of all chapters in this thesis. Professor Jeff Sigafos advised on the design and methodology of each study and provided editing suggestions for each chapter. Details of the contributions made by community partners (Chapter 4) and co-authors (Chapters 3 and 5) are detailed in the corresponding chapter note. Community partners advised on design and data analysis as part of the research-community partnership for Study 2. Dr Jessica Tupou and Mrs. Lauren van Noorden advised on the design, methodology, and data analysis for Study 3 (Chapter 5). Aside from this input, the studies presented in this thesis were designed, analysed, conducted, and written by me.

This thesis includes four original papers, two of which have been published in a peer reviewed journal and two which have been submitted for publication. Any changes made to the original versions of published works have been clearly detailed at the beginning of each chapter. The relevant publishing agreements are included in Appendix A of this thesis.

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PREFACE

Overview of Thesis

This thesis consists of six chapters. Two chapters (1 and 6) have been written in traditional thesis format. The remaining four chapters (2, 3, 4, and 5) were written and formatted to align with publication guidelines. As the methodologies are drastically different across studies, a chapter discussing overall research questions and methodological approaches has not been included. Instead, research rationale is provided at the end of Chapter 1, expanded upon in Chapter 2, and information relevant to research questions/aims are included within the relevant chapter (i.e., 2, 3, 4, and 5).

Chapter 1 introduces the thesis. An overview of autism and support service approaches are detailed followed by initial information and terminology relevant to the topic of lower financially resourced families. The chapter concludes with the rationale for the research contained within this thesis.

Chapter 2 consists of a qualitative systematic literature review exploring the barriers and facilitators experienced by underserved families when accessing autism support services. This literature review was previously published in the journal *Autism*.

Chapter 3 consists of a journal article previously published in the journal *Autism*. This article details a quantitative study exploring parent reported barriers and facilitators to autism support services within Aotearoa New Zealand.

Chapter 4 is a journal article which has been submitted for review and publication. This article consists of a qualitative study which used a research-community partnership to explore five lower financially resourced parents' experiences of a specific early autism support service. Based on parent and key stakeholder suggestions, a set of potential adaptations to improve accessibility of the service for lower financially resourced whānau and family were developed.

Chapter 5 consists of a case study written in the publication format relevant to the journal for which it has been submitted for review and possible publication. The purpose of this case study was to understand the experiences of one lower financially resourced whānau/family when receiving an adapted early autism support service. Adaptations used were those developed within the study detailed in Chapter 4.

Chapter 6 provides a general discussion in which the above research studies are summarised and limitations, implications, and recommendations for future research are explored.

There are a range of differing preferences regarding the terminology used when speaking about autism. Within this thesis, all efforts have been made to ensure that the language and terminology aligns with recommendations made within the Autism New Zealand Terminology Resource (Monk, 2022). An exception to this is the wording of the survey for Study 1, which was created prior to the publication of the Autism New Zealand terminology guide and my participation in professional development specifically on neurodiversity. It is likely language preferences will continue to evolve, to which I keep in mind the following: “I did then what I knew how to do. Now that I know better, I do better.” (Maya Angelou, as cited in Goodreads, 2023).

CHAPTER 1 INTRODUCTION

Autism

Autism, a type of neurodivergence (Pellicano & den Houting, 2022), is characterised by differences in sensory and cognitive processing, social interactions, and a predilection for routine (American Psychiatric Association, 2013). There is considerable variation in autistic experiences, with each individual having their own unique profile of strengths and challenges. Broadly, autistic people have strengths across a range of areas comparable with those of non-autistic people, such as problem-solving, academic, and technological skills (Taylor et al., 2023). Areas of challenge for autistic individuals may include difficulties with emotional regulation, sensory modulation, and/or motor skills (Beck et al., 2020; Lane et al., 2022; Licari et al., 2020).

Presently, the most commonly referenced diagnostic criteria for autism are described within the fifth edition of the Diagnostic and Statistical Manual (DSM-5-TR), a psychiatric reference text which contains criteria for a range of mental disorders (American Psychiatric Association, 2022). The DSM-5-TR refers to autism spectrum disorder (ASD; hereafter autism) as a neurodevelopmental disorder which emerges in early childhood, characterised by difficulties in social communication and interaction along with restrictive or repetitive behaviours, interests, and activities (American Psychiatric Association, 2022). Characterisations of autism within the DSM-5-TR have been criticised for being overly focused on ‘deficits’, with an emphasis placed on what an autistic person is unable to do rather than on their particular strengths (Pellicano & den Houting, 2022), with support focused on ‘treatment’ or ‘cures’ (Monk et al., 2022). Tensions between the view of autism as a form of neurodivergence and the more medicalised approach taken in the DSM-5-TR may be best understood through a review of relevant history.

A Brief History of Autism

The term autism finds its origins in the Greek word “autos” meaning “self”. The first use of the term appears to have been made by Bleuler in 1911 (as cited in Bleuler, 1952) to describe a ‘symptom’ observed in individuals with severe schizophrenia, namely their apparent withdrawal into an inaccessible ‘inner world’. Hence, autism came to be viewed as synonymous with schizophrenia and psychosis. Three decades later, an American-based psychiatrist Leo Kanner (1943), was the first to describe autism as a separate condition, using the term Early Infantile Autism to refer to a set of distinct ‘symptoms’. These symptoms had been identified based upon Kanner’s (1943) observations of 11 children who shared similar characteristics. Many of the characteristics described by Kanner (1943) still appear in current conceptualisations of autism, for example, references to social withdrawal, communication challenges, and stereotypic movements.

Only one year later, Austrian based paediatrician Hans Asperger (1944) published “Die ‘Autistischen Psychopathen’ im Kindesalter”, which translates in English to “The ‘Autistic Psychopaths’ in Childhood”. Asperger (1944) described four children with what would later be referred to as Asperger’s syndrome. There were clear similarities between the descriptions formulated by both Kanner (1943) and Asperger (1944), including the children’s difficulties with social cues and preferences for routine. Points of divergence were mainly in relation to language abilities and cognitive aptitude, specifically, individuals with Kanner’s autism were believed to experience language and cognitive delays, while those Asperger described did not (Kugler, 1998).

The timing of both Kanner’s (1943) and Asperger’s (1944) works, only a year apart, with several similarities between the two may in part be explained by a third individual, George Frankl, who worked with first Hans Asperger and then Leo Kanner (Silberman,

2015). Frankl does not appear to have used the term autism nor autistic in his published works, including one in 1943 on affective communication; however, he did reference autism in an unpublished manuscript (Frankl, 1957). Frankl's (1957) descriptions of autism as something which was not necessarily abnormal, with reference to a continuum of autistic experiences, align much more closely with present neurodivergent perspectives of autism (Muratori et al., 2021). Unfortunately, this important work was, and remains, unpublished.

Four decades on from Kanner's (1943) seminal work, autism became a diagnosis distinct from schizophrenia for the first time in the publication of the third edition of the DSM (DSM-III; American Psychiatric Association, 1980). Characterisations of autism as a form of social impairment, rather than a difficulty with emotional connection, became prominent (Evans, 2013). As did descriptions of autism as a 'triad of impairments', with reference to autistic individuals exhibiting difficulties with social interaction, social communication, and social imagination (Wing, 1981; Wing & Gould, 1979). The fifth iteration of the DSM reduced this triad to a two-domain conceptualisation of autism, marked by social communication and interaction difficulties along with restrictive and/or repetitive behaviours (American Psychiatric Association, 2013). At this same time, the DSM-5 amalgamated several conditions, including Asperger's syndrome, autistic disorder, and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), under the umbrella term of autism spectrum disorder (ASD; American Psychiatric Association, 2013).

Thirty years ago, as the internet became more accessible and brought with it new ways for people to communicate and connect, the neurodiversity movement began to emerge. In 1993, an autism rights activist, Jim Sinclair, delivered a conference presentation, "Don't mourn for us", targeted towards parents of autistic children (Sinclair, 1993). This presentation held within it several key elements which would inform the neurodiversity movement (Silberman, 2015). For example, Sinclair (1993) posited that the true challenge which came

with having an autistic child was the limited services provided to meet that child's - and their family's - needs. This view aligns understandings of neurodiversity with the social model of disability, which suggests that an individual person is not disadvantaged by their 'condition', but by the fact that the environment around them is not set up to meet their needs (M. Oliver, 1996).

Largely driven by autistic individuals, the neurodiversity movement continued to grow throughout the late 1990s and early 2000s. A combination of the terms neurological and diversity led to the development of the phrase neurodiversity (Singer, 1998, 2016). The concept of neurodiversity has grown to embrace differing forms of neurodivergence including, for example, attention-deficit/hyperactivity disorder (ADHD) and dyslexia (Silberman, 2015). Today, neurodiversity affirming approaches position autistic individuals at the centre of discussions regarding diagnostic processes and areas for research, emphasising the inherent value of being autistic and broadening conceptualisations of what constitutes quality of life (Pellicano & den Houting, 2022).

Aetiology of Autism

As characterisations of autism have shifted across time, so too have beliefs regarding potential aetiology. While Kanner's (1943) observations were centred on children, the characteristics of several of the children's parents were also discussed, including a perceived lack of emotional warmth. Despite Kanner's (1943, 1949) conclusion that autism was likely of biological origin, the parental characteristics he had noted led, in part, to the idea that the origin of autism lay in parenting approaches – particularly those of the mother (Harris & Piven, 2016). This belief was promoted by Bettelheim (1967), a proponent of the theory of psychogenesis, who acknowledged the possibility for innate origins of autism, however, he argued for an aetiology located within the family environment. The term 'refrigerator mothers' was coined to describe the perceived lack or maternal warmth deemed to be the

cause of a child's autism (Waltz, 2015). Though modern research has found no evidence that parental actions cause autism (Crowell et al., 2019), it has been hypothesised that the legacy of parental blame continues to have impacts. For example, Waltz (2015) suggested that parental blame has now simply shifted to parental pressure to seek out and co-ordinate 'treatment' for an autistic child.

Current research examining the potential aetiology for autism indicates that the causes are likely manifold, arising from a combination of both genetic and environmental factors (Lodge, 2019). Research studies focusing on twins suggest that the heritability of autism may be around 83% (Sandin et al., 2017). Given the complexity of the genetic variants and mutations which have been associated with autism, there are likely multiple genetic factors contributing to the development of the condition (Cheroni et al., 2020). In terms of possible contributing environmental factors, prenatal factors including maternal nutrition and stress have been identified, as well as maternal exposure to environmental pollutants, chemicals, and heavy metals found in seafood (Cheroni et al., 2020). Existing alongside these explorations of the aetiology of autism is the belief within neurodiversity affirming approaches that variations in human neurology are natural, and autism is simply one expression of this natural variation (Kapp et al., 2013; Pellicano & den Houting, 2022; Singer, 2016).

Terminology

With the current differences in conceptualisations of autism, it is important to note the type of language which will be used within this thesis to describe autism and supports for autistic people. Within this thesis, neurodiversity affirming, strengths-based language will be used. A strengths-based approach negates the use of terms such as 'disorder' in reference to autism. Various terms such as 'differences' or 'condition' have been suggested to replace the term 'disorder' (Barbaro & Yaari, 2020; Baron-Cohen, 2000). However, in this thesis, the

term autism will be used in accordance with some current data into the preferences of the Aotearoa New Zealand autistic community (Monk, 2022).

Studies exploring language preferences have found that some autistic people have a preference for identity-first language (i.e. autistic person; Geelhand et al., 2023; Kenny et al., 2015; Taboas et al., 2023), while others have found an overall preference for person-first language (i.e. ‘person on the autism spectrum’; Buijsman et al., 2023; Bury et al., 2023;). Within this thesis, the term autistic will be used to refer to an individual, which again is in alignment with some data exploring the preferences of the Aotearoa New Zealand autistic community (Monk, 2022). Similarly, the general term support service/s, or the name of the specific support service, will be used in place of the deficit-focused terms intervention and/or treatment (Monk, 2022).

Prevalence

Though once perceived to be relatively uncommon, the percentage of children being diagnosed as autistic has increased significantly over time. In one of the initial reports estimating rates of autism, the condition was believed to impact only around 1 in every 2,000 individuals (Lotter, 1966). In contrast, current estimates of the prevalence of autism suggest as many as 1 in 36 children may be autistic (Maenner et al., 2023). In Aotearoa, New Zealand, estimated rates of autism have increased from 1.6% in 2012 to 2% in 2022 (Ministry of Health, 2022b). While the exact reason for increases in prevalence is unknown, several factors have been proposed. These include shifts in the ways in which autism is defined and/or measured, a higher level of awareness of autism amongst the general population, and the influence of both biological and environmental factors (Rice et al., 2012). It is likely that a combination of these factors may be contributing to increases in the rates with which children are being identified as autistic, however further research on this issue is needed.

Currently, there are limited data on the prevalence of autism in Aotearoa, New Zealand (Ministries of Health and Education, 2016). Recently, Bowden et al. (2020) utilised health data contained in the Integrated Data Infrastructure (IDI)¹ to estimate a rate of occurrence of autism within Aotearoa New Zealand children. Results of this study indicated an estimated 1 in 102 Aotearoa New Zealand children had received an autism diagnosis (Bowden et al., 2020). However, the authors noted that the method of data collection, though promising, likely underestimated the true rate of autism in Aotearoa New Zealand by around 40% (Bowden et al., 2020). In comparison, data estimates from the same point in time from the Centers for Disease Control and Prevention (CDC; Maenner et al., 2021) estimated that 1 in 54 children within the United States had an autism diagnosis. This finding does lend credence to the assertion that the prevalence rate estimated by Bowden et al. (2020) is likely an underestimate of the true occurrence of autism in Aotearoa New Zealand.

Identification and Diagnosis

Across time, methods to accurately identify the potential signs of autism in young children have been developed and refined. Typically, parents of autistic children note developmental differences in their child between the ages of 1 and 2 years (Chawarska et al., 2007; Coonrod & Stone, 2004; Guinchat et al., 2012). However, recent research suggests differences in factors such as sleep and gaze may be noted by parents from as early as 6 months of age (Waddington, Macaskill, et al., 2023). Evidence suggests that a child may first be reliably diagnosed with autism between the ages of 14 months and 2 years (Chawarska et al., 2007; Kleinman et al., 2008; Pierce et al., 2019). Diagnostic tools, for example the Autism Diagnostic Observation Schedule – Toddler Module (ADOS-T; Lord et al., 2012), appear to identify autism in children under the age of two years with high short-term stability

¹ The IDI is a research database which collates information regarding households, families, and whānau in Aotearoa New Zealand from a range of government agencies, Statistics New Zealand surveys, and non-government organisations (Statistics New Zealand, 2020).

of the diagnosis (Guthrie et al., 2012). Early, accurate recognition of autism in children may allow parents to begin exploring and gaining knowledge relevant to their child's diagnosis (Rabba et al., 2019) and assist families in gaining access to evidence-based supports.

Early Support Services

Given the potential for diagnosis at or before the age of 2 years, there has been emphasis within the literature for the expedient delivery of evidence-based early support services (previously referred to as early intervention) to young children who have been diagnosed as, or who are likely to be, autistic (Zwaigenbaum et al., 2015). Some research suggests that the younger a child is when they begin participating in an early support service, the greater their outcomes may be (Gabbay-Dizdar et al., 2022; Miller et al., 2021; Reichow et al., 2012; Woods & Wetherby, 2003). However, not all research has found a difference in outcomes related to child age at initiation of support services (Trembath et al., 2023). With the current shift towards neurodiversity perspectives, what support services may look like, and which outcomes are appropriate to target, is currently under debate (G. Dawson et al., 2022; Leadbitter et al., 2021; Waddington, Minnell, et al., 2023).

Autistic advocates along with some parents and professionals are beginning to question particular aspects of certain support services for autistic children. A need for services which focus on an autistic child's wellbeing and on strengthening their individual ways of communicating is emerging (G. Dawson et al., 2022; M. Dawson & Fletcher-Watson, 2022). Recent research posits that autistic adults who ascribe to neurodiversity affirming perspectives exhibit greater levels of self-esteem than those who do not (Ferenc et al., 2022). This may provide further justification for neurodiversity affirming supports; however the directionality of this relationship is unclear and further research is needed. It is important to note that a neurodiversity affirming and strengths-based approach does not preclude the provision of support, either to the child or their parent/caregiver (Brown et al.,

2021; Kapp et al., 2013). Where services are carefully matched with needs, this can lead to overall improvements in quality of life for an entire family (S. Jones et al., 2017).

Currently, there are a variety of support services available for young children who are diagnosed as, or who are likely to be, autistic. Within Aotearoa New Zealand, examples of these support services include speech and language therapy, occupational therapy, play-based therapy, and educational supports (Kasilingam et al., 2021). A support programme may be delivered by a trained professional, a child's parents and family, educators, or some combination of all three (Zwaigenbaum et al., 2015). Regardless of the role a parent may play in the delivery of a support programme to their child, collaboration between teachers, therapists and families is considered an important part of providing effective support (Burrell & Borrego, 2012; Hume et al., 2005; Meadan et al., 2009; Zwaigenbaum et al., 2015).

Direct Support Services

The delivery of an early support programme directly to a child by a trained therapist or educator may be referred to as a direct support service. Research suggests that parents may anticipate their child will primarily receive services via this method of delivery (Watts Pappas & McLeod, 2008). In Aotearoa New Zealand, this approach to support service delivery appears to be both the most frequently utilised, as well as the most desired, by parents (Wallace-Watkin et al., 2021). Direct service providers may work within multidisciplinary teams which can include speech and language therapists, psychologists, and/or occupational therapists (Strunk et al., 2017). This allows opportunities for providers to continually upskill, gaining skills and education across a range of disciplines (Luskin-Saxby et al., 2023).

The way in which direct autism support services are delivered may also be referred to in terms of intensity. Generally, support services which are delivered for more than 10 hours per week (e.g., G. Dawson et al., 2010) may be considered to be of higher intensity (Rogers,

Estes, Lord et al., 2019). Evidence regarding the potential benefits of higher versus lower intensity support services is currently limited (Trembath et al., 2023). However, consideration of the intensity of a service may be important when adapting programmes to the needs of a specific group of individuals. For example, consideration of the time commitment a lower financially resourced family is expected to make to participate in an autism support service may be a useful strategy employed to assist attendance and adherence (Carr & Lord, 2016).

Delivery of support directly to a child by a trained therapist may be associated with several potential benefits. For example, the delivery of early supports, such as the Early Start Denver Model (ESDM) and the Joint Attention, Symbolic Play, Engagement and Regulation (JASPER) programme by a trained therapist have been associated with increases in a child's daily living skills, engagement levels, imitation, and/or verbal and/or nonverbal communication skills (Colombi et al., 2018; G. Dawson et al., 2010; Geoffray et al., 2019; Goods et al., 2013; Waddington et al., 2019). Despite the potential benefits of direct therapy, not all parents or children will experience 'improvements' to the same extent. Indeed, research suggests that for some families, there is a potential for a support service to result in few, or no, changes in measured outcomes (Landa, 2018; Waddington et al., 2016, 2021). Additionally, the cost of direct therapy may be prohibitively expensive for some families (Clasquin-Johnson & Clasquin-Johnson, 2018).

Parent-Mediated Support Services

The ways in which parents or caregivers (herein referred to as parents) are included in early support services for their autistic child can differ. Teaching parents to work with their own children (parent training/coaching or parent-mediated support) has emerged as one potentially beneficial approach (Nevill et al., 2018). Bearss et al. (2015) and Bearss (2019) have proposed two categories to broadly define parent training: (a) parent support programmes which disseminate information and education on autism to families, and (b)

parent-mediated support (also referred to as parent-mediated intervention) in which parents are taught specific techniques to work directly with their child. Parent-mediated supports provide parents with strategies and skills to support their child's learning in one of two areas: (a) across developmental domains typically associated with areas of challenge for autistic children (e.g., social communication) or (b) in areas specific to adaptive behaviours (e.g. feeding or sleeping difficulties; Bearss, 2019; Bearss et al., 2015).

Reviews of the current literature examining parent-mediated support have found that individual, also referred to as one-on-one, parent training within the family home was the most common method of delivery, followed by parent training within clinic settings (Beaudoin et al., 2014; Nevill et al., 2018; Oono et al., 2013). Typically, this training occurred with the child present to allow therapists to model support strategies (Brookman-Frazer et al., 2006). Sessions were reported to typically be between 30-60 minutes (Nevill et al., 2018). The least utilised approach to parent training was group delivery, which targeted small groups of four to five parents (Nevill et al., 2018). This aligns with parental desire for receiving such services one-on-one (Wallace-Watkin et al., 2021).

There are several factors which provide a strong rationale for utilising parent-mediated supports. It has been suggested, for example, that parents are often in a strong position to support the development of their child (Crowell et al., 2019) as parents tend to spend more time with their child than a therapist would. This means parents may be able to incorporate strategies and supports into the everyday routines and activities of the home environment. This in turn would increase opportunities for parents to practice and support their child in the learning of new skills as well as supporting the maintenance and generalisation of those skills (Meadan et al., 2009; Zwaigenbaum et al., 2015). Additionally, parent-mediated supports may contribute to an increase in parental self-efficacy, empowering

parents in their roles as supporters and advocates for their autistic child (Pellecchia et al., 2020).

Several beneficial outcomes have been associated with the use of parent-mediated supports. For autistic children, increases in skills across several developmental domains have been observed (Kasari, Kaiser, et al., 2014; Rogers et al., 2012; Stadnick et al., 2015), while for parents, improvements in family quality of life and/or parental mental health have been found (Estes et al., 2014; Tonge et al., 2006). The possibility of empowering parents and providing autism-related education is a further potential benefit of parent-mediated supports (Jurek et al., 2022). When compared to more typical therapist-led support services, parent-mediated supports may provide a more cost-effective approach to delivering support to young autistic children (Bearss et al., 2015; Shalev et al., 2020). Therefore, this approach may be potentially more sustainable for lower income families and communities.

There is, however, evidence of the potential limitations to parent-mediated supports. In a meta-analysis of randomised control trials (RCTs) examining 17 parent-mediated support services, Oono et al. (2013) assessed the efficacy of this approach in relation to potential outcomes for both autistic children and their parents. Results were variable across studies, with only limited evidence that parent-mediated supports led to gains in child language, communication, or adaptive behaviours. Barriers to implementing support strategies have been highlighted by parents including time restraints, lack of confidence in parenting skills, and a sense of feeling overwhelmed by the implementation of strategies (Jurek et al., 2022). There is also variation in the outcomes of such services, depending upon who is reporting them – parents or providers (Nevill et al., 2018). Overall, given the high amount of variation in reported outcomes across studies, further research examining which outcomes are most appropriate to focus on, and by who, is needed.

Naturalistic Developmental Behavioural Supports

Naturalistic Developmental Behavioural Interventions (Herein referred to as Naturalistic Developmental Behavioural Supports [NDBSs]) are a group of support services which have garnered research attention in recent years. NDBSs focus on delivering support services within natural contexts and settings, targeted to a child's developmental level, while utilising behavioural strategies (Schreibman et al., 2015). These support services are often organised so that there are increased opportunities for child-led, as opposed to only adult-led, learning opportunities. NDBSs also tend to provide support across a range of developmental domains, such as cognition, language and communication, joint attention, and imitation (Schreibman et al., 2015). NDBSs may be further categorised dependent upon the number of skills targeted for support. Focused NDBSs tend to target one or a few specific skills (e.g. social skills and communication skills), whereas more comprehensive support programmes tend to focus on a wider range of skills across multiple developmental domains (Schreibman et al., 2015).

Several NDBS have been developed including Joint Attention, Symbolic Play, Engagement, and Regulation (JASPER; Kasari et al., 2006, 2010), the Early Start Denver Model (ESDM; Rogers & Dawson, 2010), and Pivotal Response Treatment (PRT; R. I. Koegel & Frea, 1993; Stahmer, 1995). In general, NDBSs share common elements including an emphasis on adult positioning when working with a child, following the child's lead, the use of positive affect, and the modelling of language (Frost et al., 2020). While NDBSs may be delivered directly to a child by a trained therapist, several have been adapted to be implemented by parents (parent-mediated NDBSs) including JASPER (Kasari, Lawton, et al., 2014) and the Parent-ESDM (P-ESDM; Rogers et al., 2012; Rogers & Vismara, 2015).

Results of a meta-analysis of 27 group-design studies examining NDBS conducted by Tiede and Walton (2019) suggested that the NDBS approach is associated with clinically

modest, but statistically significant improvements for autistic children in the areas of expressive language and play skills. Larger/moderate effects were evident for social engagement and overall cognitive development. Other outcomes, such as a reduction in autism-related characteristics were reported by Tiede and Walton (2019). However, there is some debate as to whether targeting the reduction of a child's autism-related characteristics (e.g., increasing eye contact, reducing intense interests) is appropriate (M. Dawson & Fletcher-Watson, 2022; Waddington, Minnell, et al., 2023).

At present, there is not full alignment between the approaches taken in NDBSs and the neurodiversity movement. One of the concerns autistic self-advocates and some parents and professionals have regarding NDBSs relate back to goals which prioritise 'neurotypical' ways of being, such as making eye contact (Schuck et al., 2022). Instead, goals which focus on promoting change in the environment around a child, rather than changing the child themselves, are increasingly indicated to be a preferred priority among surveyed stakeholders (Waddington, Minnell, et al., 2023). Recommendations for improving the fit of NDBSs with neurodiversity affirming views have included: ensuring the views and experiences of autistic people are placed at the centre of discussions around programme delivery and parent education, reviewing the appropriateness of goals, taking a strengths-based approach, and focusing simultaneously on autism acceptance and ways to best support an autistic child's development (Schuck et al., 2022).

Though it is beyond the scope of this thesis to explore in-depth the areas of disconnect between the neurodiversity movement and several NDBS approaches, it is important to note that behavioural strategies are a particular point of contention. The use of behavioural strategies based on applied behaviour analysis (ABA) have been viewed by some as prioritising modifications of a child's behaviour over their autonomy and wellbeing (Wilkenfeld & McCarthy, 2020). There appears to be very little research which has examined

the ways in which autistic adults reflect on their childhood experience of ABA-based approaches. One qualitative study with 10 autistic adults indicated that experiences with physical prompting, feelings of being misunderstood, not accepted, and/or perceiving the repetition of tasks until success was reached as a form of punishment, were areas of particular concern (McGill & Robinson, 2021). ABA-based approaches have garnered decades of research with results suggesting this approach may be effective for supporting learning in a range of areas including communication and daily living skills (Ivy & Schreck, 2016). It is currently unclear whether it may be possible to bring alignment between the neurodiversity movement and approaches which respectfully utilise behavioural strategies. Further research which positions autistic people at the centre of such research and conversations would be valuable.

Early Start Denver Model

One comprehensive NDBS which has a rapidly expanding evidence base is the Early Start Denver Model (ESDM; Rogers & Dawson, 2010). The ESDM is a manualised comprehensive support programme designed for children between the ages of 12 and 60 months who are, or may be, autistic. The ESDM incorporates aspects of several support services as well as theoretical conceptualisations of autism characteristics (Rogers & Dawson, 2010). These include the Denver model, a play-based relational approach (Rogers et al., 2006); Pivotal Response Treatment (PRT) which focuses on teaching ‘pivotal skills’ such as initiation (L. K. Koegel et al., 2016); and theories of interpersonal development (Rogers & Pennington, 1991) and social motivation (G. Dawson et al., 2005). The ESDM may be delivered directly to an individual child or within group settings, by a trained therapist, teacher and/or the child’s parent/s (Rogers & Dawson, 2010; Rogers & Vismara, 2015; Vivanti et al., 2017). Research suggests that the ESDM may be successfully delivered at either higher or lower intensity (G. Dawson et al., 2010)

The ESDM consists of four core features related to teaching approach, therapist fidelity, child goals, and assessment of progress (Rogers & Dawson, 2010). Teaching occurs within 'joint activity routines' which are typically play-based activities where joint engagement and collaboration are key goals (Rogers & Dawson, 2010). Individuals delivering the ESDM are expected to exhibit a high degree of accuracy when implementing ESDM techniques, which is measured using the ESDM teaching fidelity rating system (Rogers & Dawson, 2010). Child goals are set across multiple domains such as expressive and receptive communication, fine and gross motor skills, and imitation, based upon assessment with the ESDM curriculum checklist (Rogers & Dawson, 2010). Child goals are broken down into incremental learning steps which are used to monitor the child's progress through the programme (Rogers & Dawson, 2010). Underpinning the core features of the ESDM is a focus on positive, supportive relationships and child choice (Rogers & Dawson, 2010).

As well as being delivered by trained therapists, teachers and/or parents may also be taught how to implement support strategies. The Parent Early Start Denver Model (P-ESDM) for example, supports parents to learn and implement ESDM strategies (e.g., following their child's lead, creating opportunities for communication) in their child's play and regular daily routines (Rogers & Vismara, 2015). Outcomes measured across P-ESDM studies have varied dependent upon the aims of the research, with mixed results reported. Parents generally exhibit increases in fidelity in their implementation of ESDM techniques, however not all parents reach full fidelity (Abouzeid et al., 2020; Grogan et al., 2023; Hernandez Ruiz & Braden, 2021; Kim et al., 2022; van Noorden et al., 2022; Waddington, van der Meer, Sigafos & Whitehouse, 2020). Child outcomes have also been diverse, with selected studies reporting improvement in some children in engagement, motor skills, and language (See the review by Jhuo & Chu, 2022), while other research has located more mixed outcomes (e.g.,

Rogers, Estes, Vismara, et al., 2019; Waddington et al., 2019). More research is required to further examine the appropriateness, acceptability, and efficacy of the P-ESDM, and the associated goals. Additionally, it would be helpful to explore how to improve or adapt the parent coaching approach to increase the probability of providing effective support for all parents and children.

Currently, it appears as though there have been three systematic reviews (Baril & Humphreys, 2017; Ryberg, 2015; Waddington et al., 2016) into the efficacy of the ESDM. At least one further review has focused explicitly on a systematic review of the P-ESDM literature (Jhuo & Chu, 2022). The broad consensus of these reviews suggested that the ESDM appears to be a potentially efficacious approach, however, concerns regarding research quality, variability in outcomes, and/or parent fidelity of implementation, indicated the need for further research (Baril & Humphreys, 2017; Jhuo & Chu, 2022; Ryberg, 2015; Waddington et al., 2016).

At least two meta-analyses have been conducted examining the impact of ESDM on child outcomes (Fuller et al., 2020; Wang et al., 2022). Both studies concluded children receiving the ESDM exhibited significantly greater improvements in cognition and language when compared to children in control groups (Fuller et al., 2020; Wang et al., 2022). However, while Wang et al. (2022) found that children receiving the ESDM exhibited significant ‘improvements’ in autism characteristics, Fuller et al. (2020) did not. This difference may be due to the inclusion of publications in both Chinese and Malay within the study conducted by Wang et al., (2022), or differences in the items selected to measure change in autism characteristics. For example, both meta-analyses included an article by Vivanti et al., (2014), however, Fuller et al., (2020) appears to have based effect size calculations on scores from the Autism Diagnostic Observation Schedule (ADOS) whereas Wang et al., (2022) appear to have used the results of the Mullen Scales of Early Learning

(MSEL). Neither study found that the children receiving ESDM experienced significantly different outcomes related to social communication (Fuller et al., 2020; Wang et al., 2022). Furthermore, Fuller et al. (2020) reported on the results of measures examining adaptive behaviours as well as restrictive and repetitive behaviours, for which there was no greater change in children who received ESDM compared to those in control groups.

Lower Financially Resourced Families

Despite the number of promising evidence-based early support services designed for young autistic children access to these services does not currently appear to be equitable. A family's available economic resources may impact upon support service access and/or participation (Nguyen et al., 2016; Pickard & Ingersoll, 2016). In studies which have examined the impact of limited financial resources on a family with an autistic child, several terms have been utilised to describe the population. These include underserved (Stahmer et al., 2019), under-resourced (Carr & Lord, 2016; Pickard, Kilgore, & Ingersoll, 2016), low-resourced (Carr et al., 2016; Divan et al., 2015; Karp et al., 2018; Kasari & Lawton et al., 2014; Lee & Meadan, 2021b) and, collectively, underrepresented (Iadarola et al., 2017; Pellecchia et al., 2018).

While the term low-resourced appears to have been used most consistently across the research literature, it is important to note that there are numerous ways in which a family may be 'resourced'. For example, a family may have limited financial income while being richly resourced in other areas of their life, such as culturally, emotionally, or spiritually. Research does suggest however, that being in financial hardship may also impact upon both social and spiritual needs (Madden, 2015), as well as the ability to access stable housing. A combination of these difficulties may lead to a cumulative effect, leading to further inequity (Tømmerås & Kjøbli, 2017). Within this thesis, the terms lower financially resourced and lower income will be used interchangeably to describe the population of interest.

In Aotearoa New Zealand, systemic inequalities, and the impacts of colonisation has led to Māori being more likely to fit the criteria for being lower financially resourced. In recent data released by Statistics New Zealand (2022), it was found that those from ethnic minority backgrounds, specifically Māori and Pasifika children, were more likely to reside in lower-income households than children from European backgrounds. Though this clearly does not mean that all families from traditionally under-represented racial or ethnic groups will be lower financially resourced, it is important to recognise the importance of cultural sensitivity and cultural fit of any early support service for an autistic child which may be targeted to supporting lower resourced families.

In broadly examining factors which may be impeding access and engagement in autism support services for lower financially resourced families, it is also useful to consider research emerging from low-to-middle income countries. Though contextual differences exist, certain challenges faced by families in such countries are similar to those faced by lower financially resourced families in higher income countries. For example, families in both settings have reported the influences of cultural beliefs as well as logistical and/or systems-based challenges including long waiting lists, shortages of qualified professionals, challenges accessing and/or affording transport as barriers to accessing autism support services (Birkin et al., 2008; Dababnah & Bulson, 2015; Guler et al., 2018; Iadarola et al., 2017; Pearson & Meadan, 2018; Stahmer et al., 2019). Research which has examined the adaptation of support services for families in low-to-middle income countries have included considerations of both cultural values as well as practical issues such as accessibility (Blake et al., 2017; Divan et al., 2015; Sengupta et al., 2020). Both concepts are highly relevant to lower financially resourced and multicultural families from higher-income countries such as Aotearoa New Zealand (Birkin et al., 2008).

Ideally, the support requirements of an autistic child and their family would dictate access to support services. However, though research suggests that certain difficulties faced by autistic children, for example conditions impacting mood, may be more common in those from lower income backgrounds (Mayes & Calhoun, 2011), it appears as though lower income families are accessing services at a reduced rate (Carr et al., 2016; Nguyen et al., 2016; Smith et al., 2020). This suggests that there may be barriers faced by these families when seeking to access and/or participate in services. Presently, literature examining how to best support lower financially resourced or ethnically diverse families has only begun to emerge (Davenport et al., 2018; Durkin et al., 2015; Fannin, 2017). Therefore, understanding of how to best engage and work with these families is limited, further compounding the challenges they face.

Research Rationale

Barriers to autism support services

Whilst parents generally may experience obstacles to accessing support for their autistic child, research suggests that the combination and accumulation of barriers faced by lower financially resourced families may create a unique set of challenges for this group (Stahmer et al., 2019). For example, due to the current way in which some autism service systems are constructed, it has been estimated that raising an autistic child may be associated with costs twice that of raising a child with no developmental or medical needs (Montes & Cianca, 2014). In combination with this, the cost of an autism support service may itself be prohibitive (Clasquin-Johnson & Clasquin-Johnson, 2018). Additionally, research suggests that parents of autistic children often earn less than parents of children who are not autistic (Cidav et al., 2012).

It is imperative to understand the possible barriers and facilitators experienced by lower resourced families to ensure equitability in autism support service access and

participation. Prior to the research undertaken in this thesis, a broad review of the research literature examining both barriers and facilitators to autism support services experienced by underrepresented families had yet to be conducted. However, in a qualitative review of literature from studies conducted in the United States of America, Singh and Bunyak (2019) located the presence of several barriers impacting the accessibility of both autism diagnostic and support services. Results of this review were broadly categorised into themes of familial, cultural, and structural barriers (Singh & Bunyak, 2019). A broader review of the literature exploring research undertaken outside of the United States of America, inclusive of factors which are both barriers and facilitative of support service access and/or participation, was needed.

Presently, there does not appear to be research directly examining the experiences of Aotearoa New Zealand lower financially resourced families when accessing early autism support services for their child. However, one study was located which examined experiences of families from underrepresented ethnic groups. Birkin et al. (2008) explore the reported barriers faced by a small number of Māori, Pasifika, and Korean families with a young autistic child which had impacted their ability to attend the Early Bird Programme, an early support service. The study revealed that both cultural and socioeconomic barriers were impacting families.

Comparative research examining sociodemographic differences in the types and amounts of barriers experienced by families when accessing and/or participating in autism support services is limited. There appears to be only one study which has examined the differences experienced between lower and higher socioeconomic status (SES) families. This study was conducted within the United States of America with 244 parents of an autistic child/ren (Pickard & Ingersoll, 2016). Barriers were assessed in this study within a

questionnaire using a single open-ended question, with the resultant reported barriers coded, then reported qualitatively and tallied for quantitative analysis.

The results of the research by Pickard and Ingersoll (2016) suggested that parents' knowledge of support services in part mediated the relationship between parental SES and service use. Additionally, lower SES parents reported a desire for greater information regarding services, a need for in-home services, and a high number of experienced structural barriers to support services. Comparatively, higher SES parents were more likely to report a desire for higher quality support services. Results were not analysed for any other sociodemographic variables (Pickard & Ingersoll, 2016). Exploration of additional potentially mitigating factors (i.e. ethnicity, child age) may provide greater information as to how to best support a range of lower financially resourced families. Approaching such an analysis from a quantitative perspective would allow for additional statistical analyses of significance to also be conducted on the data.

Adapting Early Autism Support Services

One approach which has been utilised to improve access to, and participation in, autism support services for specific populations, including lower financially resourced families, is through adaptation of pre-existing support services. Several studies have examined the outcomes of adapting pre-existing services, particularly parent-mediated supports, to the needs of lower financially resourced and/or culturally diverse families with an autistic child (Blake et al., 2017; Carr & Lord, 2016; Kasari, Lawton, et al., 2014; Rogers et al., 2022; Sengupta et al., 2020). The core elements of each support service were retained while various adaptations, including use of culturally relevant materials and/or increased choice in scheduling, length of the service, or location of delivery (Blake et al., 2017; Carr & Lord, 2016; Kasari, Lawton, et al., 2014; Rogers et al., 2022; Sengupta et al., 2020). Whilst a review of the literature specific to the adaptation of autism support services is yet to be

conducted, Pellecchia et al. (2018) examined research related to engagement strategies which have been used with underrepresented families with a child with social, emotional, or behavioural difficulty. This review noted that, as engagement strategies are generally used in conjunction, it was difficult to identify which specific strategies had the greatest impact.

Within the literature regarding the adaptation of early autism support services, a number of parent-mediated NDBSs have been adapted to suit the needs of lower financially resourced families. The majority of these studies have been undertaken within the United States (Carr & Lord, 2016; Kasari, Lawton, et al., 2014; Pickard et al., 2019; Rogers et al., 2022), with one taking place in India (Sengupta et al., 2020). However, there are still several gaps to address in this area. For example, each study has focused on the adaptation of a different NDBS with results not yet replicated, mixed outcomes have been reported, and it appears as though one intervention (Pickard et al., 2019) has yet to be piloted. Differences in rates of attrition were also reported. It appears as though studies which utilised a research-community partnership to develop adaptations (Rogers et al., 2022; Sengupta et al., 2020) reported lower rates of attrition than studies which did not use this approach (Carr & Lord, 2016; Kasari, Lawton, et al., 2014).

There does not presently appear to be research conducted seeking and/or utilising community input to adapt an autism support service directly targeting lower financially resourced Aotearoa New Zealand families. There are several early support services which could potentially be adapted to support access and engagement by such families. Developing adaptations alongside those who will potentially benefit from them, may ensure such adaptations are acceptable, appropriate, and feasible for this population.

Research-Community Partnerships

Research-community partnerships provide an approach through which to adapt a specific autism support service to the needs of a particular population. The term research-

community partnership, as used within the context of this thesis, refers to a formalised collaborative partnership between researcher/s and community stakeholders to achieve shared goals (Brookman-Frazer et al., 2016). Such an approach provides a meaningful way to engage with, gain the perspectives of, and reciprocally share knowledge with, a target population (Barrera et al., 2011; Baumann et al., 2015; Brookman-Frazer et al., 2012; Trickett, 2011). Differing models and approaches have emerged by which to guide research-community partnerships, all of which exist along a wide continuum of anticipated individual input. For example, Community-Partnered Participatory Research (CPPR) has emerged as an approach to assist the implementation of evidence-based practices within mental health settings. CPPR places researchers and community providers in an equal position, with each having input into all areas of the research project (L. Jones & Wells., 2007; Wells et al., 2013).

The use of research-community partnerships has been perceived to increase both the relevance and contextual acceptability of support services while also increasing quality of the research (Brookman-Frazer et al., 2016). Therefore, the use of a research-community partnership in adapting an autism support service to the Aotearoa New Zealand context, for lower financially resourced families, is likely to be beneficial. Presently, there does not yet appear to be research examining the adaptation of an autism support programme within Aotearoa New Zealand, nor research examining the utilisation of a research-community partnership for this purpose. Research of this nature would add further evidence to the international research literature examining such partnerships.

In summary, access to autism supports is likely to be inequitable particularly for families who are lower financially resourced (Carr et al., 2016; Nguyen et al., 2016; Smith et al., 2020). Though research indicates that such families may encounter several barriers to autism support services (Singh & Bunyak, 2019), little is known regarding the degree and

extent of these barriers. Additionally, very few studies have explored potential differences in barriers and/or facilitators to autism support services between lower and higher income families (Pickard & Ingersoll, 2016).

Understanding both the barriers and facilitators experienced by lower financially resourced families may be useful in the development of adaptations to increase the accessibility of, and to support participation in, autism support services. Taking a research community partnership approach to designing such adaptations may be particularly useful as it includes the very people who stand to potentially benefit from the process. Few studies have examined the effects of utilising a research community partnership to adapt a programme through to the implementation and piloting phase. Therefore, little is presently known regarding the efficacy of this approach, either internationally or within the unique Aotearoa New Zealand context.

General Overview

Presently, there appears to be issues of inequity within support service access and participation. This indicates that lower financially resourced families may need additional support to access services for their autistic child. In the following chapter (Chapter 2), a review of the qualitative literature exploring potential barriers to and facilitative factors for support service access and/or participation for lower financially resourced families will be presented. This thesis will then describe three studies. The first quantitatively examines barriers and facilitative factors to support services experienced by Aotearoa New Zealand parents of autistic children (Chapter 3). The second qualitatively explores the experiences of lower income Aotearoa New Zealand parents when accessing a specific early support programme (ESDM). This study utilises a research-community partnership and includes the development of adaptations to increase accessibility and participation in the support service for lower income families/whānau (Chapter 4). The third investigates the experience of one

lower financially resourced family receiving an adapted form of the early support programme (Chapter 5). As aforementioned, the methodology and research questions related to each study appears within the appropriate chapter. The final chapter (Chapter 6) is a general discussion of findings across all studies within this thesis.

CHAPTER 2

Barriers and Facilitators for Obtaining Support Services Among Underserved Families with an Autistic Child: A Systematic Qualitative Review

Chapter Note

This chapter is based on a journal article published in the peer-reviewed journal, *Autism*. Dr. Hannah Waddington provided input into design and data analysis, editing, and performed checks for a portion of the study quality ratings and coding of the thematic analysis. Professor Jeff Sigafos provided input into design and editing. Aside from this input, this review was designed, conducted, and written by me. The original published review is included in its entirety, with minor changes to formatting and spelling (e.g., changed from American English to New Zealand/United Kingdom English) to ensure consistency with the rest of this thesis. The full citation for this article is: Wallace-Watkin, C., Sigafos, J., and Waddington, H. (2023). Barriers and facilitators for obtaining support services among underserved families with an autistic child: A systematic qualitative review. *Autism*, 27(3), 588-601. <https://doi.org/10.1177/13623613221123712>

Abstract

Families of autistic children from underserved populations participate in support services at lower rates than other families. To better understand possible reasons for this inequity, we reviewed qualitative studies examining parent reported barriers and facilitators to accessing and participating in support services. A systematic search identified 18 articles that met inclusion criteria. Resulting thematic analysis located three themes: (a) support service accessibility, (b) diversity of support services, and (c) community. Parents reported that financial pressures, geographic location, and service flexibility influenced their ability to obtain support services. Implications for service delivery and areas for future research are discussed.

Introduction

Autism is characterized by difficulties in social communication, a restricted range of interests and repetitive behaviour (American Psychiatric Association, 2013). Autistic children are likely to benefit from a range of diverse and long-term support services (Hyman et al., 2020; Sandbank et al., 2021; Wong et al., 2015). Research indicates that the provision of a range of support services (For definition of this term see Table 2.1) such as developmental interventions, positive behaviour support, speech and language or occupational therapy, can lead to improved social communication, motor skills, and/or emotional regulation (Fuller & Kaiser, 2020; Ruggeri et al., 2020; Sandbank et al., 2020; Weiss et al., 2018). Parent-mediated support services also appear to be helpful in increasing parenting confidence and improving parent mental health (MacKenzie & Eack, 2022; Pellecchia et al., 2020). However, improvements in outcomes such as stress levels may not occur for all parents (Bendixen et al., 2011; van Noorden et al., 2022).

Table 2.1*Definition and Examples of Support Services*

Support service definition	Inclusion	Exclusion
<p>The term support service refers to those services provided to children and/or their parents to support a child in an area in which they may experience difficulties. Traditionally, the terms intervention or therapy were used to identify these services.</p>	<p>Support services include but are not limited to:</p> <ul style="list-style-type: none"> – Speech and language therapy – Occupational therapy – Psychologist support – Naturalistic Developmental Behavioural Interventions (NDBIs) – Parent education/coaching – Cognitive behavioural therapy – Art therapy 	<p>The term support services as used in this review excludes:</p> <ul style="list-style-type: none"> – Funding providers – School specific approaches (e.g., IEP's) – Social-based support groups with no educational component – Respite services

Ideally, autistic children and their families should have equitable access to a range of support services. However, Singh and Bunyak (2019) note that there is often “unequal access to diagnosis, treatment, and services related to [autism] experienced by groups that are otherwise disadvantaged due to economic status, racial bias, or other forms of discrimination” (p. 796). Families from underrepresented racial or ethnic groups and families with lower financial resources are reported to have greater difficulty accessing and/or participating in support services (Nguyen et al., 2016; Smith et al., 2020). Collectively, families who are impacted by such disparities in autism services have been referred to as ‘underrepresented’ (Iadarola et al., 2017; Pellecchia et al., 2018) or ‘underserved’ (Janvier et al., 2018; Stahmer et al., 2019; Wagner et al., 2022).

In terms of accessing specific services, several researchers have reported that underserved families appear more likely to experience delays in receiving an autism diagnosis for their child in comparison to children from families who are not underserved (Dickerson et al., 2017; Mandell et al., 2009; Nowell et al., 2015). Financial, cultural, and/or structural barriers are potential factors influencing such diagnostic delays (Kelly et al., 2019; Khowaja et al., 2015; M. D. King & Bearman, 2011; Sritharan & Koola, 2019). Research also suggests that parents of autistic children exhibit higher levels of stress, which may inhibit support-seeking behaviours (Benson, 2006; Davis & Carter, 2008; Hayes & Watson, 2013; Keenan et al., 2016; Shepherd et al., 2021). Certain barriers faced by underserved families (e.g., cultural, financial, and service pathway challenges) could exacerbate stress and further inhibit the process of obtaining and participating in support services (Stahmer et al., 2019).

Lim et al. (2021) identified and reviewed eight qualitative studies that focused on barriers to care services experienced by immigrant parents of autistic children. Key barriers included lengthy wait lists, language barriers, and difficult to comprehend information about services. These barriers reportedly created considerable stress for families. Lim et al.

recommended expanding support services to include access to translators and immigrant-friendly information about the supports available and how parents can access services. While many of these issues identified in the Lim et al. review are similar to those reported more generally in the literature, it is possible that immigrant families may have certain unique support needs (e.g., need for translators) that would be less relevant to other types of underserved families, such as families with limited financial resources.

In another relevant review, Singh and Bunyak (2019) identified 24 studies that sought to identify service barriers among US-based families who were likely marginalized due to “race, ethnicity, social class, health insurance status, and/or immigration status.” (p. 797). They identified three classes of barriers affecting the underserved families. Familial barriers included limited resources and the demands of family life. Cultural barriers included cultural beliefs and language barriers. Structural barriers included health care systems and policies and experiences with clinicians. The authors’ suggestions for addressing these types of barriers included offering non-print materials to parents with limited English literacy, reducing service cost, such as reducing travel requirements, and offering more flexible (e.g., weekend) service options.

In a third relevant study, Smith et al. (2020) examined disparities in service access experienced by underserved US-based families with an autistic child. They found disparities with respect to amount and type of supports received. Specifically, children from underrepresented racial or ethnic groups and lower-income families had less access to educational, community-based, and specialist services. In addition, African American, Hispanic, and lower-income families reported lower quality services. The authors concluded there is a need to reach out and provide better coordination of intervention services to underserved families.

Within current literature, there does not appear to be a review which has examined barriers and facilitators to autism support (rather than support and diagnostic) services experienced by underserved parent populations internationally. A review in this area would inform knowledge of the experiences such parents have after their child has received a diagnosis. Additionally, differences and similarities between underserved groups have yet to be explored, including those factors which act as facilitators. Synthesizing such information may be useful in understanding how to improve access and/or participation in autism support services.

The primary aim of the present review was to explore the perceptions and experiences of barriers and facilitators to support services experienced by underserved families with an autistic child. The term ‘underserved families’ refers to (a) underrepresented ethnic or racial groups, (b) families from lower resourced settings, (c) families who are lower financially resourced, or (d) families from immigrant populations (Pellecchia et al., 2018; Singh & Bunyak, 2019; Smith et al., 2020; Wagner et al., 2022). We also sought to explore differences and/or similarities between the types of underserved families. To this end, we elected to review qualitative literature given the strength of this approach in providing insight into individual and group beliefs, experiences, and perspectives (Choy, 2014).

Method

Protocol Registration and PRISMA Guidelines

Prior to conducting database searches, the study protocol was submitted to the International Register of Systematic Reviews (Prospero; CRD42021261775). Submission occurred on 20 June 2021 and was automatically registered on 18 July 2021 (https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021261775). An update outlining changes to the protocol (i.e., refinement of inclusion criteria, addition of exclusion criteria, change of quality assessment tool to one which best suited our data set)

was submitted on 6 December 2021. Further variations to the protocol made during completion of the review are detailed in Appendix B, Table S1. The review was conducted in accordance with the procedures outlined in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Page et al., 2021) as indicated in Appendix B, Table S2.

Search Strategies

An initial search of electronic databases and grey literature was conducted by the first author on 23 June 2021. The databases searched were CINAHL, PubMed, Scopus, MEDLINE, and PsycINFO. Search terms were based on those used in the study conducted by Pellecchia et al. (2018). Terms included: (Parent* OR Mother* OR Father* OR Caregiver* OR Famil*) AND (Underserve* OR “Under resource*” OR “Under rep*” OR “Low resource*” OR Poor OR Poverty OR “Ethnic minorit*” OR “Low SES” or “Low Socioeconomic Status” OR Medicaid) AND (Autis* OR ASD OR Autism Spectrum Disorder OR Asperger* OR PDD*) AND (Intervention* OR Programme* OR Service*) AND (Barrier* OR Disparit* OR Obstacle* OR Facilitat* OR Engag*). Database searches were limited to peer-reviewed articles published in English, article titles, abstracts, and keywords on each of the four databases.

The first author searched for grey literature using Google Chrome and the Prospero database. Keywords used were the same as those listed for the database searches, and the searches were limited to the first 100 results written in English. Further database searches were then conducted for the primary authors of eligible studies. Ancestral searches were also conducted using the reference lists of each eligible study and relevant systematic reviews and meta-analyses. The above searches were repeated as described above on May 23, 2022, with the following additional search terms: “racial minorit*”, “immigrant*”, and “Support Service*”.

Inclusion Criteria

English language studies focused on documenting the perceptions and/or experiences of parents of autistic children with respects to the barriers and/or facilitators of accessing support services for their autistic child were sought. To be included, the participants had to be parents or caregivers of an autistic child and had to be identified as underserved (i.e., from lower financially resourced backgrounds or settings, from an underrepresented racial or ethnic group, were immigrants). Studies that included various representative groups (e.g., lower versus higher financially resourced parents) were included if the data for each group could be isolated. Lower financially resourced was defined as: (a) participants received an income-tested form of government assistance (e.g., Medicaid), and/or (b) participants were identified as being from low socioeconomic households/backgrounds and/or resided in a location defined within the original study as a lower resourced setting or as a low and/or middle-income country as defined by The World Bank (2022). Studies that included other multiple participant groups (e.g., providers and parents) were also included if the data for the parents/caregivers could be isolated. The children referred to in the studies had to have received a clinical diagnosis of autism spectrum disorder. Studies which utilized mixed methods were included if it was possible to extract [qualitative] data on parent/caregiver perceptions and experiences.

Study Selection

The first author conducted all database searches and imported the results into EndNote reference management software. Duplicates were removed prior to uploading the titles and abstracts to Covidence, an online systematic review management system. The first author independently screened all articles against the inclusion criteria. The third author independently screened the titles and abstracts of 20% of the studies and the full text of 20% of the articles. The percentage of agreement on the inclusion of articles was calculated using

the following formula: $\text{Agreements} / (\text{Disagreements} + \text{Agreements}) \times 100$. Agreement for the title and abstract screening was 94% and agreement on the full-text screening was 100%.

Disagreements were resolved via consensus.

Data Extraction

The following data were extracted from each study: (a) bibliographic details (author, year, title, journal), (b) study aim, (c) data collection method, (d) approach to data analysis, (e) geographic location, (f) number of parent/caregiver participants, (g) parent/caregiver gender and/or relationship to the child, (h) ethnicity of participants, (i) child characteristics (i.e. number of, age, gender), (j) underserved category, (k) type of support service, and (l) name of support service where stated. The extracted outcomes, determined a priori, were qualitative results regarding parent experiences and/or perceptions of barriers and/or facilitators to support services.

The first author independently extracted relevant data for all studies. Training in, and practice with, the data extraction template was conducted collaboratively between the first and third author using two of the included articles. The third author then independently extracted data for 20% of the studies. Agreement on data extraction was 95% with disagreements resolved via consensus.

Quality Assessment

Included studies were rated for quality using the first nine items of the Critical Appraisal Skills Programme qualitative checklist (CASP; 2019). The CASP includes 10 items relating to the presence and/or appropriateness of (a) research aims, (b) methodology, (c) research design, (d) recruitment strategy, (e) data collection method, (f) researcher relationship with participants, (g) ethical considerations, (h) rigor of data analysis, (i) statement of findings, and (j) the value of the research (Majid & Vanstone, 2018). The tenth item, the value of the research, is not reported due to the subjective nature of this factor.

Ratings for all included articles were made by the first author. The third author independently rated 20% of the included studies and agreement was 97%.

Thematic Analysis

The three stages of thematic synthesis, as described by Thomas and Harden (2008), were used to analyse the data. This approach focuses on maintaining elements of the original studies through initial descriptive coding, followed by the development of deeper analytical themes (Thomas & Harden, 2008). To ensure trustworthiness and credibility were maintained, elements of reflexive thematic analysis were also utilized. This included conducting multiple reviews of themes throughout the synthesis process, collaboration between the first and third author in the development of codes, maintaining reflexive notes, and keeping a research journal (Braun & Clarke, 2019).

The relevant data extracted from the results section of each article were imported into NVivo data analysis software. The initial synthesis of the data was conducted by the first author, who first familiarized herself with the data through reading each text three times and checking to ensure any remaining ineligible data was removed (e.g., findings related to providers). Following this, data were coded line by line. This occurred first using descriptive codes which were later reviewed and developed into descriptive themes. The data was reviewed again to ensure all relevant concepts had been captured and appropriately assigned to the descriptive themes. For the final stage of thematic synthesis, which was to develop analytical themes, the first author formulated the initial analytical themes using the mind map tool available in NVivo. The resulting themes were defined within the NVivo codebook and shared with the third author to check for meaning. Coded references for each theme were exported from NVivo and sorted by underserved group type (i.e., immigrant population, lower financially resourced families, racial/ethnic underrepresented groups, families located in lower resourced area). References from articles which included participants identified as

being from more than one underserved group type (i.e., lower financially resourced *and* racial/ethnic underrepresented groups, racial/ethnic underrepresented group *and* a lower resourced setting) were sorted into each relevant group. Themes, both descriptive and analytical, were further refined and/or grouped following discussion between the two reviewers. The coding of two of the articles (11%) was reviewed by the third author, leading to further collaborative discussions and the finalization of themes.

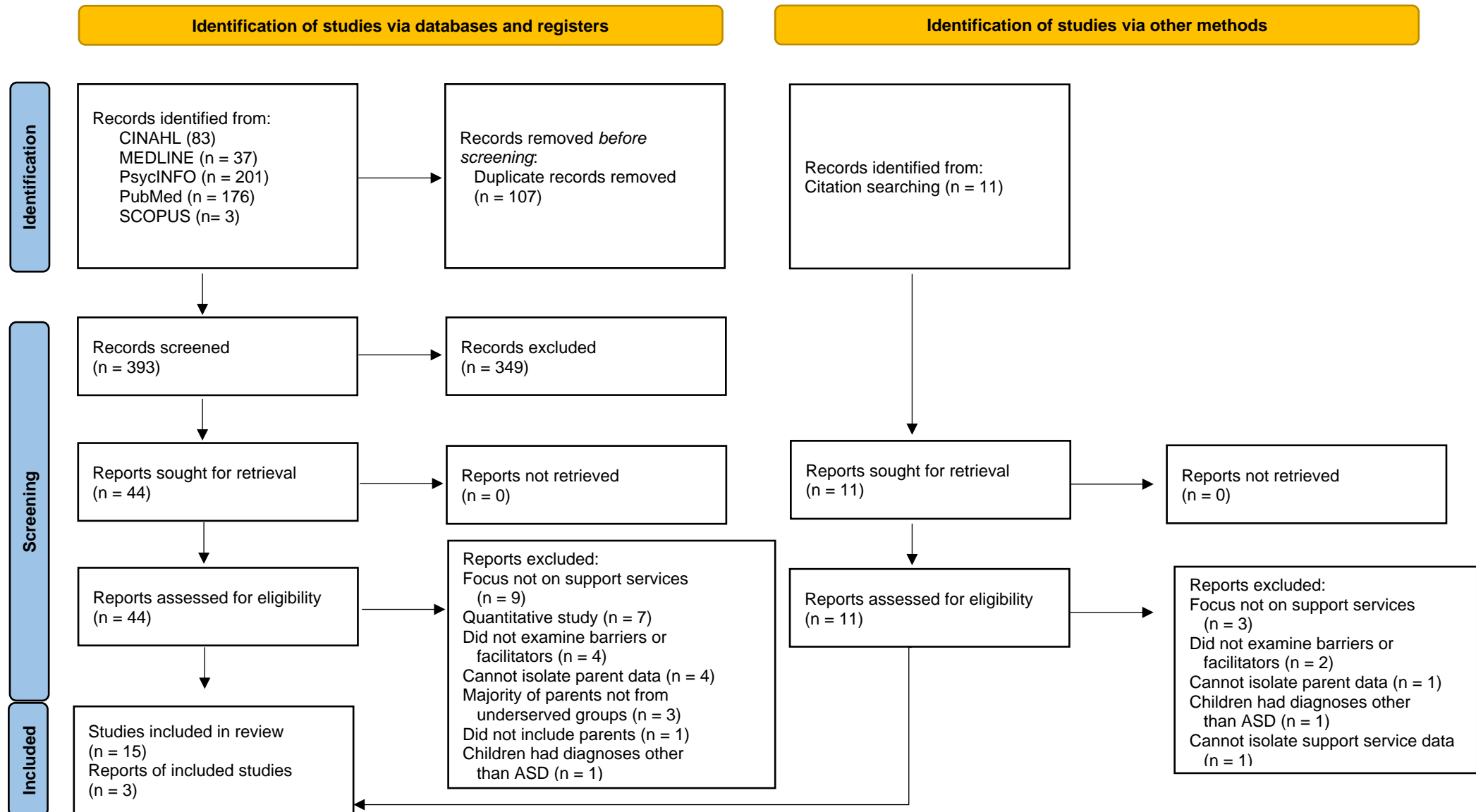
Results

Search Outcome

The database search returned 500 records. Once duplicates were removed there were 393 records remaining for the title and abstract screen, of which 349 records were excluded. Of the remaining 44 records, 29 were excluded during the full-text screening (see Appendix B, Table S3). Author and reference list searches resulted in 11 records for review, of which three were eligible for inclusion. The grey literature search resulted in no new records. In total, 18 studies were eligible for inclusion in the qualitative synthesis. Figure 2.1 provides a PRISMA flow diagram (Page et al., 2021) of the search and screening process.

Figure 2.1

PRISMA Flow Diagram Demonstrating the Results of the Systematic Literature Search (Page et al., 2021)



Study Characteristics

The 18 included studies provided data on parent reported barriers and facilitators to accessing and participating in support services from eight different countries/regions: USA, Canada, South Africa, the West Bank, Aotearoa New Zealand, England, Mongolia, and Sweden. Six of the studies reported experiences of families from immigrant populations, two were conducted with families from lower resourced settings, one involved parents who were from both a racial or ethnic underrepresented group and a lower resourced setting, two included parents who were lower financially resourced, three included families from racial or ethnic underrepresented groups, and four examined perspectives of families who were both lower financially resourced and were from a racial or ethnic underrepresented group/s. Of the eligible articles, 13 included parent reports of barriers and facilitators to support services and 5 examined barriers only. No study explored only facilitators. The majority of articles were published in 2015 or later. Full details of study characteristics are provided in the supplementary material (Appendix B, Table S4).

Quality Assessment

Results of the quality appraisal are provided in Appendix B, Table S5. Generally, the studies met CASP (2019) criteria, however, the majority (83%) did not include a positionality statement or researcher reflection on their relationship to participants.

Thematic Analysis

The thematic analysis focused on identifying both barriers to and facilitators for accessing and participating in support services. Barriers were defined as those factors which parents identified as causing difficulty for them with respect to gaining and/or participating in support services for their autistic child. Facilitators were defined as factors that parents said were helpful for gaining and/or participating in support services. All the underserved groups as defined in this review were represented within each theme, the number of times a code was

used per underserved group (i.e., immigrant population, lower financially resourced etc.) is detailed in Table 2.2. Figure 2.2 provides an overview of the analytic themes with relevant associated subthemes. Table 2.3 provides example quotes from the literature for each subtheme. For full definitions of codes, along with additional illustrative quotes, please see Appendix B, Table S6. Appendix B, Table S7 provides an overview of which studies appeared within each theme/subtheme. While the majority of themes below include some form of parent reported barrier along with relevant facilitator/s, it was not possible to align all barriers with a facilitator.

Table 2.2*Number of Times a Thematic Code was Applied for Each Group*

Code	Underserved group			Immigrant group	Totals
	Racial or ethnic underrepresented group	Lower financially resourced	Lower resourced setting		
1a. Knowledge	51	26	23	25	109
1b. Service Pathways	33	21	14	37	93
1d. Financial Pressures	32	20	16	16	73
1c. Geographic location	39	24	30	4	81
1e. Providers	59	40	21	20	125
2a. *C&L Considerations	45	24	13	30	111
2b. Service diversity	30	35	13	23	98
3a. Stigma	33	9	23	13	61
3b. Social Support	58	29	22	37	129
Totals	272	228	175	205	

Note. *Cultural and Linguistic considerations

Most frequently applied code/s per group*Least frequently applied code/s per group*

Figure 2.2

Resulting Themes from the Analytic Process: Barriers and Facilitators to Support Services

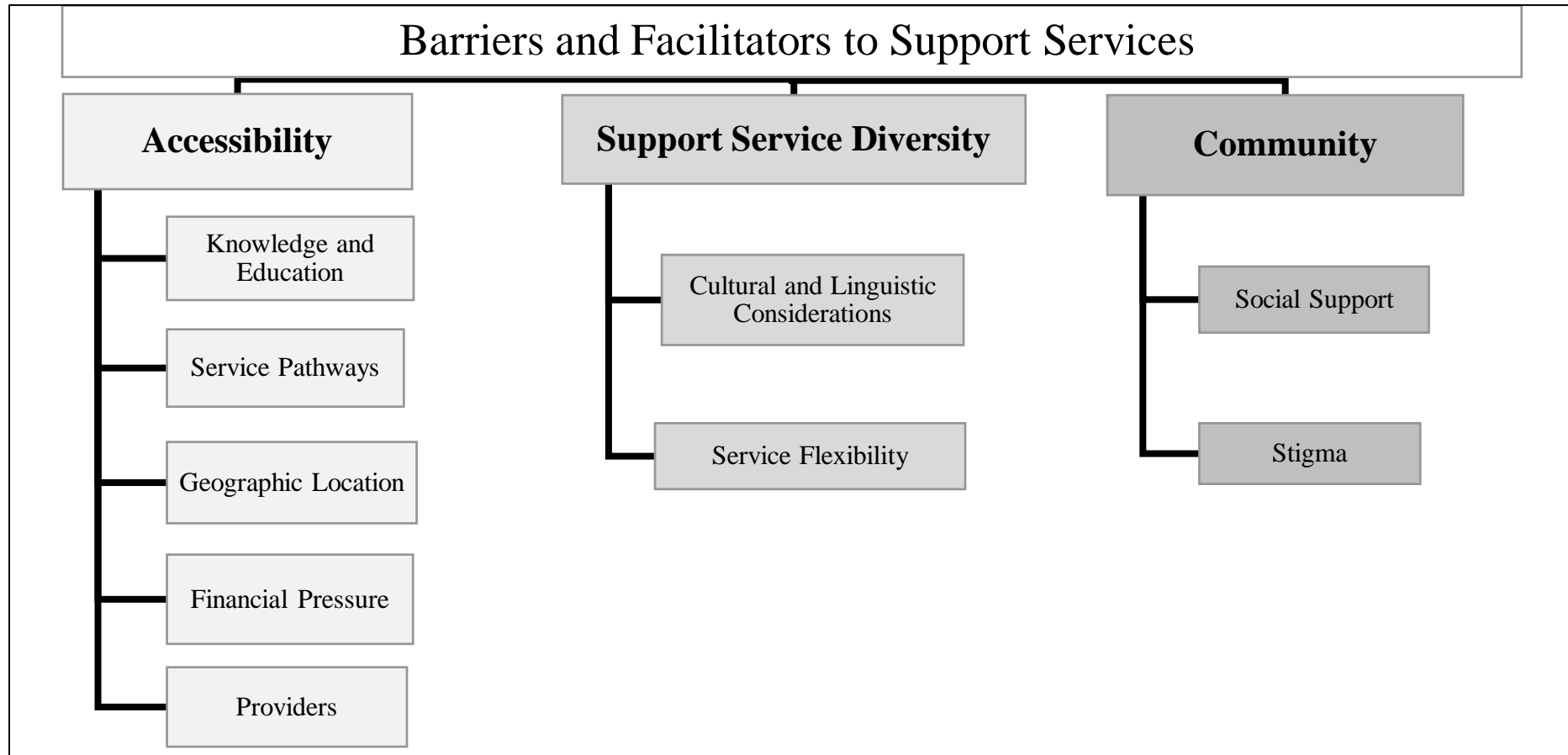


Table 2.3*Supporting Quotes from the Literature for Each Subtheme*

Theme/Subtheme Name	Example Quote from Text
Theme 1: Support service accessibility	
1a. Knowledge and education	<p><i>... it's because of a lack of information from the parents not knowing, and when the therapist starts saying things, the people get confused because they do not know. So, then it's about going back to the beginning, it's to make the parents understand, give them an explanation... (Chlebowski et al., 2018; p. 557)</i></p>
1b. Service Pathways	<p><i>Services are scattered everywhere. It took me 3 or 4 months to figure out what to do. I don't knowso many services ... I don't know if they designed it this way to serve only a few people at a time. (Khanlou et al., 2017; p. 246)</i></p>
1c. Financial Pressure	<p><i>"One of us doesn't bring in income [due to childrearing] ... To ensure a satisfying life for our children, there is financial hardship." (Lee & Meadan, 2021a; p. 3599)</i></p>
1d. Geographic Location	<p><i>[Families of children with ASD] are on the sidelines and forgotten. Our suffering with our kids is not our country's or our government's business. Nothing is available for our kids. (Dababnah & Bulson, 2015; p. 4130)</i></p>
1e. Providers	<p><i>When I saw their [provider's] willingness to tell me certain things then I just put my guard down...And that's when I was okay, I let everything go, humbled myself. Then I could be open. I was ready to be</i></p>

taught. And so, they showed me things. They opened up a whole new world for me (Stahmer et al., 2019; p. 762).

Theme 2: Diversity of Support Services

2a. Cultural and Linguistic Considerations

... I mean people will just think that 'that kid is cursed.' That kid doesn't even get that information ... the sharing that we are doing now. So—then maybe we have to do more awareness so that it doesn't impact the kids because our beliefs can actually make those kids never get an opportunity. (Guler et al., 2018; pp. 1009-1010)

2b. Service Flexibility

I noticed that when we felt things were going too fast, we told them, that this is too fast for X. Then they adjusted the schedule ... (Nilses et al., 2019; p. 3403)

Theme 3: Community

3a. Stigma

There are a few people who think that I have got a child who is mentally ill, and that I shouldn't go near them. I don't like to go to certain people's houses because I don't feel they sympathize, or I don't feel confident enough to go to their houses (Fox et al., 2017; p. 308)

3b. Social Support

Blessedly we had his [child's father] mom because she was babysitting for us. The early intervention really sucks if you are not the one at home. So, she became our stay-at-home parent. The services were happening in her house, and she was very good. (Pearson & Meadan, 2018; p. 26)

Theme 1: Support Service Accessibility

Knowledge and Education

The theme of knowledge and a desire for education was identified in 17 of the 18 included studies. Parents reported that a limited knowledge of support services, autism, and child development, created barriers to support services. Immigrant parents identified concerns about their children's futures due to unfamiliarity with the concept of autism (Nilses et al., 2019). Parents from lower resourced settings, immigrant populations, and underrepresented racial or ethnic groups also identified challenges posed by differing forms of knowledge and understandings of autism (Birkin et al., 2008; Chlebowski et al., 2018; Fox et al., 2017; Lee & Meadan, 2021a; Luelmo et al., 2020; Sakai et al., 2019; Stahmer et al., 2019). These included a lack of belief in autism as a diagnosis, believing the diagnosis was temporary, and/or recommendations from family members to use alternative or more traditional forms of healing rather than support services (Blanche et al., 2015; Fox et al., 2017; Sakai et al., 2019; Shanmugarajah et al., 2022; Stahmer et al., 2019). Conversely, parents reported that the provision of parent education, specifically education which increased an understanding of autism, facilitated their participation within support services and/or informed the way they parented their child (Chlebowski et al., 2018; Fox et al., 2017; Lee & Meadan, 2021a; Nilses et al., 2019; Pearson & Meadan, 2018; Stahmer et al., 2019).

Limited availability of relevant information also hampered parents' efforts to gain support services for their child. Parents broadly reported a lack of information on autism as well as on relevant services (Dababnah & Bulson, 2015; Fox et al., 2017; Hong & Singh, 2019; Khanlou et al., 2017; Luelmo et al., 2020; Nilses et al., 2019; Pickard & Ingersoll, 2016; Stahmer et al., 2019). Eager to understand how to best support their child, parents reported actively seeking knowledge and education, including attending parenting classes and/or using the internet to fill the gaps in their knowledge (Fox et al., 2017; Lee & Meadan,

2021a; Nilses et al., 2019; Pearson & Meadan, 2018; Pickard & Ingersoll, 2016; Stahmer et al., 2019). Parents also often reported feeling more able to advocate for their child upon receiving relevant education (Blanche et al., 2015; Lee & Meadan, 2021a; Pearson & Meadan, 2018; Shanmugarajah et al., 2022; Stahmer et al., 2019), suggesting an increased understanding of autism and their child was empowering.

Service Pathways

Though the articles reviewed represent a wide range of countries and differing service systems, the barriers created by such systems were discussed in 12 of the articles. Whilst all underserved parents discussed the complexity of service pathways, this theme was most frequently coded within parents from immigrant populations (see Table 2.2). Parents across groups regularly described service pathways which were ambiguous and confusing. Parents also reported needing to ‘fight’ for their child to receive services and/or schooling, with children regularly missing out due to system criteria, difficulty in accessing the service, and/or their diagnosis (Dababnah & Bulson, 2015; Hong & Singh, 2019; Khanlou et al., 2017; Lee & Meadan, 2021a; Pickard & Ingersoll, 2016; Stahmer et al., 2019).

Service system challenges also seemed to be exacerbated by lengthy waiting lists and a lack of follow-up (Blanche et al., 2015; Dababnah & Bulson, 2015; Khanlou et al., 2017; Lee & Meadan, 2021a; Luelmo et al., 2020; Pickard & Ingersoll, 2016; Sakai et al., 2019; Stahmer et al., 2019). Two specific factors were present for parents from immigrant populations. Firstly, such parents were more likely to favourably compare the service system within their current location to what had been available in their prior location (Shanmugarajah et al., 2022). Secondly, a specific barrier to parents from immigrant populations who did not hold legal status in the United States was the fear of deportation if they were to apply for financial or support services (Luelmo et al., 2020). Generally, parents who received support and/or guidance from professionals with service system knowledge

indicated this was a significant facilitative factor in overcoming the challenges of a complex system (Lee & Meadan, 2021a; Luelmo et al., 2020; Pearson & Meadan, 2018; Pickard & Ingersoll, 2016; Stahmer et al., 2019).

Financial Pressure

Financial barriers were identified as a theme in 13 studies. Parents often stated that the cost of accessing support services was prohibitive, which led to both inaccessibility and limitations to how long a service could be accessed. For families who were lower financially resourced, this barrier appeared to be complicated by broader financial challenges related to unmet basic needs and/or being a single parent household (Guler et al., 2018; Pearson & Meadan, 2018; Pickard & Ingersoll, 2016). For families who qualified for government supported health insurance, for example Medicaid in the United States, co-occurring costs (e.g., transport), age limits, and/or limited availability of providers continued to pose barriers (Hong & Singh, 2019; Pearson & Meadan, 2018; Pickard & Ingersoll, 2016; Pickard, Kilgore, & Ingersoll, 2016; Pickard et al., 2019; Shanmugarajah et al., 2022).

Often, challenges caused by costly services were exacerbated by reduced family incomes due to employment challenges. Several parents reported difficulty in balancing a work schedule with trying to access services for their child, with some parents reportedly giving up employment despite the resultant reduction in family income (Birkin et al., 2008; Blanche et al., 2015; Dababnah & Bulson, 2015; Hong & Singh, 2019; Khanlou et al., 2017; Lee & Meadan, 2021a; Luelmo et al., 2020; Pearson & Meadan, 2018; Stahmer et al., 2019).

Four studies discussed factors which would decrease financial pressure. Providing all-inclusive services in which all costs were stated upfront, the provision of subsidies, and understanding employers were all mentioned (Guler et al., 2018; Stahmer et al., 2019). Specific to immigrant families were the suggestions for job workshops specific to immigrant

mothers (Khanlou et al., 2017) and the helpfulness of the child's elder sibling in financially contributing to the child's services (Shanmugarajah et al., 2022).

Geographic Location

Challenges posed by geographic location were explored in 10 of the reviewed studies, with parents from lower resourced settings mentioning this theme more frequently (Dababnah & Bulson, 2015; Lee & Meadan, 2021a). A lack of trained providers and services was a barrier both for those parents in lower resourced settings as well as those underserved parents who lived rurally (Dababnah & Bulson, 2015; Lee & Meadan, 2021a; Pearson & Meadan, 2018; Pickard, Kilgore, & Ingersoll, 2016; Stahmer et al., 2019).

Parents also reported barriers posed by limited public transport, high transport costs, and/or long travel times to access services (Dababnah & Bulson, 2015; Hong & Singh, 2019; Khanlou et al., 2017; Pickard & Ingersoll, 2016; Stahmer et al., 2019). In the study by Hong and Singh (2019) with parents from underrepresented racial and ethnic groups who were also identified to be lower financially resourced, the challenges of taking public transport with an autistic child were also discussed. Parents from immigrant populations were the only ones to note the benefits of their geographic location, mentioning facilitative factors such as locally available services (Nilses et al., 2019) and the range of support available (Luelmo et al., 2020).

Providers

In all 18 studies, parents mentioned that providers could either facilitate or create barriers to accessing and/or participating in support services. This theme was most frequently mentioned by parents from lower financially resourced families and underrepresented racial or ethnic families. Limitations in providers' understanding of autism, dismissal of parent concerns or questions, breaking confidentiality, unclear communication, and/or relationships which lacked warmth and trust all negatively impacted parents' attempts to gain and/or

participate in support services. Providers who took the time to build warm, culturally aware, respectful relationships and those willing to advocate for families facilitated parental participation in an autistic child's services (Birkin et al., 2008; Chlebowski et al., 2018; Guler et al., 2018; Lee & Meadan, 2021a; Luelmo et al., 2020; Nilses et al., 2019; Pearson & Meadan, 2018; Pickard, Kilgore, & Ingersoll, 2016; Sakai et al., 2019; Stahmer et al., 2019).

Service providers appeared to be uniquely placed to provide families with information and education. Parents from immigrant populations, underrepresented racial or ethnic groups and those who were lower financially resourced particularly reported valuing those providers who were able to empathetically provide clear information, support, and who took the time to follow-up regarding any further questions a family may have (Blanche et al., 2015; Chlebowski et al., 2018; Luelmo et al., 2020; Nilses et al., 2019; Pearson & Meadan, 2018; Stahmer et al., 2019).

Theme 2: Diversity of Support Services

Cultural and Linguistic Considerations

Cultural and linguistic barriers to services were discussed in 10 of the included studies for review. Whilst underserved parents in general mentioned this factor, it was most frequently discussed by parents from racial or ethnic underrepresented groups (See Table 2.2). Across a range of cultural groups and geographic locations, parents spoke of the ways traditional cultural beliefs impacted upon their understanding of autism and/or of appropriate supports for their child (Birkin et al., 2008; Blanche et al., 2015; Chlebowski et al., 2018; Fox et al., 2017; Guler et al., 2018; Sakai et al., 2019; Stahmer et al., 2019). Beliefs were diverse and included that autism was the result of a curse (Birkin et al., 2008; Guler et al., 2018), that parenting approaches were the cause of a child's behaviours (Birkin et al., 2008; Stahmer et al., 2019), that autism could be reversed or 'grown out of' (Fox et al., 2017; Sakai et al., 2019), and that autism is a Westernized concept (Blanche et al., 2015). Sensitivity, respect,

and empathy were desired when discussing traditional beliefs (Birkin et al., 2008; Guler et al., 2018).

Language barriers were prominent amongst parents from linguistically diverse populations. Barriers included the limited availability of bilingual providers, confusion over which language a child should be taught in (i.e., English or their primary language), concerns regarding translation of key terminology, and/or the lack of services offered in diverse languages other than English. In the study conducted by Stahmer et al. (2019) within the United States with parents from racial and ethnic underrepresented groups who were also identified to be lower financially resourced, parents reported feeling as though they had few options in providers due to language barriers and felt ‘stuck’ with costly or lower quality providers. Parents also reported feeling left to overcome language barriers on their own (Birkin et al., 2008; Blanche et al., 2015; Fox et al., 2017; Guler et al., 2018; Stahmer et al., 2019). Services which provided access to interpreters, as well as educators within the school system who were willing to spend additional time with a child, were both facilitative in accessing and participating in services (Fox et al., 2017; Khanlou et al., 2017; Sakai et al., 2019; Stahmer et al., 2019)

Service Flexibility

In 14 of the included studies respondents indicated a need for flexible, inclusive services. Flexibility in scheduling, including offering appointments outside of work hours, consideration of work obligations, flexibility in session length and frequency, and/or consideration of individual family needs, were all perceived to be facilitative factors (Birkin et al., 2008; Dababnah & Bulson, 2015; Hong & Singh, 2019; Nilses et al., 2019; Pickard et al., 2019). Additionally, in lower resourced settings, the importance of considering the materials used within support services was highlighted (Dababnah & Bulson, 2015). Further highlighting the need for flexibility within support services were the presence of differing

preferences. For example, where a proportion of parents reported a preference for receiving services within a group setting (Pickard, Kilgore, & Ingersoll, 2016; Sakai et al., 2019), for others this approach created anxiety (Birkin et al., 2008). For some, delivery of a service within the home was most ideal, whilst for other parents whose living situations may be ‘chaotic’ this posed a barrier (Guler et al., 2018; Pickard, Kilgore, & Ingersoll, 2016).

A range of factors posed challenges to accessing or participating in services. Restraints on time, limited session times, perceived usefulness of a service, and childcare challenges may be possible to address through service modification. However stressful life events, long work hours, inability to take time off work, ill family members, unstable housing, family inability to have basic needs met, and/or limited parental energy are factors which likely go beyond what a support service is able to address.

One parent-reported facilitating factor was the inclusion of family in support services. This included training parents to work with their child, educating extended family members on autism and how to relate with the child, and/or involving siblings in support (Guler et al., 2018; Hong & Singh, 2019; Lee & Meadan, 2021a; Nilses et al., 2019; Pickard, Kilgore, & Ingersoll, 2016; Pickard et al., 2019). Parents who were lower financially resourced specifically reported that being taught strategies to work with their own child was both empowering and a way to bond with their child.

Theme 3: Community

Stigma

Half of the studies included parental references to stigma as a barrier to support services. Experiences of stigma (e.g., labelling the child as naughty, judging parenting approach, disbelief of the child’s diagnosis; withdrawal of social support and exclusion) occurred within families, with friends, providers, and/or the wider community. Parental response to stigma was to keep the child’s diagnosis a secret, to withdraw from the

community, and/or to isolate themselves and their child, limiting support seeking behaviour (Blanche et al., 2015; Guler et al., 2018; Lee & Meadan, 2021a; Nilses et al., 2019; Stahmer et al., 2019):

Social Support

Thirteen studies included reference to social support. Pearson and Meadan (2018), for example, noted that social support appeared to be linked with parental resilience and confidence to advocate for their child. Responses from parents often pointed simply to a desire for general acceptance and understanding of their child (Blanche et al., 2015; Guler et al., 2018; Pearson & Meadan, 2018; Pickard, Kilgore, & Ingersoll, 2016). While support of immediate and extended family members, friends, and providers was important, relationships with fellow parents of autistic children played a significant role in accessing services as parents were able to share personal experiences, advice, and support (Dababnah & Bulson, 2015; Fox et al., 2017; Guler et al., 2018; Khanlou et al., 2017; Lee & Meadan, 2021a; Sakai et al., 2019). The child's grandparents were common supports, assisting parents with daily routines, babysitting, emotional support, and transport (Blanche et al., 2015; Dababnah & Bulson, 2015; Hong & Singh, 2019; Pearson & Meadan, 2018; Stahmer et al., 2019):

Discussion

Our review highlights three major themes related to the perceptions and experiences of under-served families with respect to accessing and participating in autism support services. These were (a) system-based challenges, (b) limited diversity of support services, and (c) community. The results suggest that underserved families are likely to experience multiple barriers to accessing and participating in support services.

The results of this review align with previous literature reviews that examined both diagnostic and support service disparities (Lim et al., 2021; Singh & Bunyak, 2019; Smith et al., 2020). Previous reviews have also found parents reporting multiple familial, cultural,

language, informational, and structural barriers concurrently. Indeed, underserved families often report being faced with multiple barriers (Singh & Bunyak, 2019; Stahmer et al., 2019). There thus appears to be some generality across studies regarding the numerous types of barriers experienced by underserved families.

Across the 18 studies, parents reported feeling left to overcome potential barriers on their own or face not receiving services. This seemed to be particularly reported for language and literacy barriers (Birkin et al., 2008; Blanche et al., 2015; Fox et al., 2017; Guler et al., 2018; Stahmer et al., 2019). This result aligns with those found in the study conducted by Tomczuk et al. (2021) in which providers reported believing linguistically diverse parents were unsuitable for parent coaching and therefore did not offer it to them. Furthermore, in a study conducted with both parents and service providers, parents faced with a high number of barriers were often perceived by providers as lacking engagement and/or undervaluing the support service (Stahmer et al., 2019).

Thirteen studies explored facilitative factors to support services. Generally, underserved parents highlighted the helpfulness of targeted education, particularly on the nature of autism; supportive professionals willing to guide service access; inclusion of close and extended family members within support services; and/or the support of other parents with autistic children as being facilitative in accessing and/or participating in support services. For those parents who were linguistically diverse (e.g., those from immigrant or underrepresented racial or ethnic backgrounds), access to interpreters was deemed to be beneficial (Fox et al., 2017; Khanlou et al., 2017; Sakai et al., 2019; Stahmer et al., 2019). Specific facilitators reported by parents from immigrant groups included support with locating family friendly employment, and/or the benefits of their new geographic location (Khanlou et al., 2017; Luelmo et al., 2020; Nilses et al., 2019). The presence of parent reported facilitative factors provides insight into the aspects of service provision which are

appreciated by parents. Understanding these factors may provide a starting point in further improving service delivery to underserved families.

Most of the parent participants in these 18 studies were mothers of younger (less than 10 years of age) children. The perceptions and experiences of fathers may differ and the facilitators and barriers for children older than 10 may also differ. This indicates the need for additional research to address the gender and age homogeneity of the current literature base. Regarding experiences of stigma, there appears to be very little within the current literature examining the impact on autistic children and/or teenagers. Additionally, there is a lack of literature, specifically reviews, exploring autistic adult experiences of gaining access to support services. Each of these areas represents a potential focus for future research.

The present thematic analysis extends previous reviews by explicit analysis of facilitators to accessing and participating in services globally. Our analysis of such facilitators indicated that, when asked, parents did perceive there to be facilitators to support services. Based on the results of our analysis, we offer the following tentative recommendations as possible ways for reducing some barriers to support services for underserved families. First, it may be helpful to develop a community-wide promotional programme to increase autism knowledge and awareness. This could include disseminating parent-friendly and culturally appropriate informational booklets and educational materials. Second, it might be helpful for service providers to consider how access to services could be streamlined to enable easier parental navigation of the service system. Additional service-related changes that might be helpful to easing access and participation by under-represented families would be to (a) clarify all service costs, (b) better training of providers in the area of collaborative consultation with parents, and (c) increasing the number of available providers from culturally and geographically diverse backgrounds. This recommendation aligns with previous research noting the need for an increase in trained providers from underrepresented

racial or ethnic groups along with services which are both culturally informed and appropriate (DuBay et al., 2018; Iadarola et al., 2020; Tupou et al., 2021). It would also seem important to address the issue of service flexibility by, for example, enabling parents to participate outside of usual work hours and by enabling participation by the larger family unit. Many families indicated they valued the inclusion of their child's sibling, grandparents, and other extended family members in support services (Guler et al., 2018; Hong & Singh, 2019; Lee & Meadan, 2021a; Nilses et al., 2019; Pickard, Kilgore, & Ingersoll, 2016; Pickard et al., 2019).

There were a few limitations to this qualitative systematic review. First, the authors acknowledge that reviews of qualitative research may lack generalizability, given that, by nature, such research is context dependent (Denny & Weckesser, 2019). While quantitative research may provide more generalizable information, it would not have provided the deeper level of understanding regarding parent experiences which was the aim of this study (Choy, 2014). The lack of evidence of researcher reflexivity in the majority of studies made it difficult to assess whether researcher bias may have had an impact on the reported results. Additionally, the conflation of the terms race and ethnicity within the majority of the original studies may mean differences in parental experiences between the two have not been captured. The search was restricted to English-language studies due to the authors being monolingual and lacking funding for translation services. Given this, the results of this review should be interpreted with caution as the conclusions may only apply to the English-language literature on this topic.

Finally, by exploring all families who fit within our definition of 'underserved' in one review, nuanced information relative to specific groups (i.e., racial or ethnic underrepresented families, lower financially resourced families) may have been lost. We aimed to reduce this risk by providing details of the similarities and differences between groups in the results

section. Additionally, where relevant, we have highlighted which barriers or facilitators may be most relevant to a specific group. Many factors were shared amongst underserved families, suggesting the experience of barriers, as well as facilitators, to autism support services is a global experience.

Conclusion

This qualitative review highlighted several barriers facing underserved parents with respect to obtaining support services for their autistic child. Potential methods for reducing such challenges were considered through concurrent analysis of facilitative factors. Future research which continues to examine barriers and facilitators to support services will be an important means of improving equity in service access and participation.

Declaration of conflicting interests

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Community involvement statement

The first author is a parent of an autistic child. Otherwise, autistic individuals were not involved in this article.

CHAPTER 3

Study 1: Parent Reported Barriers and Facilitators to Support Services for Autistic Children in Aotearoa New Zealand

Chapter Note

This chapter has been published as a journal article in the peer-reviewed journal *Autism*. Dr. Hannah Waddington provided input into design and assistance with data analysis, interpretation of results, and editing. Professor Jeff Sigafos provided input into design and assistance with editing. Dr. Lisa Wood provided assistance with data analysis, interpretation of results, and editing. Aside from this input, this study was designed, conducted, and written by me. Other than minor changes made to ensure consistency in formatting and spelling (i.e., changing spelling from American English to New Zealand/United Kingdom English), this chapter is identical to the published article. Full citation details for this article are as follows: Wallace-Watkin, C., Sigafos, J., Woods, L., and Waddington, H. (2023). Parent reported barriers and facilitators to support services for autistic children in Aotearoa New Zealand. *Autism*, 27(8), 2542-2554. <https://doi.org/10.1177/13623613231168240>

Abstract

We surveyed Aotearoa New Zealand parents of autistic children to identify their perceived barriers and facilitators to accessing support services, including the influence of a family's level of financial resourcing. A total of 173 completed surveys were analysed. Service pathway factors were the greatest barrier experienced by participants, whereas facilitators related to providers tended to be most helpful. Lower family income was associated with a higher number of reported barriers. Both lower family income and having a child who identified their gender as non-binary were predictive of rating the extent of barriers higher.

Parents of younger or of non-speaking autistic children on average reported a greater number of facilitators. Implications of these results for support service delivery and potential areas for future research are discussed.

Introduction

Research into the efficacy of support services for autistic children and their families suggests that a range of diverse support services are likely to have beneficial effects on expressive language, motor skills, emotional regulation, anxiety, daily living skills, and/or social functioning (Duncan et al., 2018; Hyman et al., 2020; Perihan et al., 2019; Ruggeri et al., 2020; Sandbank et al., 2021; Sissons et al., 2022; Tiede & Walton, 2019; Weiss et al., 2018).

Unfortunately, many families with an autistic child report experiencing barriers that prevent or restrict their ability to access and/or participate in support services (Fong et al., 2022; Pickard & Ingersoll, 2016; Shepherd et al., 2018).

The types of barriers reported by parents/caregivers (herein referred to as parents) of autistic children include fractured service systems, lengthy wait lists, knowledge limitations, and/or financial pressures along with societal stigma and/or limited diversity in support services (Fong et al., 2022; Luelmo et al., 2020; Pickard & Ingersoll, 2016; Stahmer et al., 2019). Barriers experienced by Aotearoa New Zealand parents of autistic children appear to be similar to those reported globally, including financial, geographic, time, and service system barriers (Birkin et al., 2008; Stahmer et al., 2019). Though such barriers may also be faced by parents of children with other developmental differences, parents of autistic children comparatively appear to exhibit higher levels of parenting stress and/or decreased satisfaction with aspects of received support services (Amireh, 2019; Bitterman et al., 2008; Hayes & Watson, 2013; Picardi et al., 2018).

Parents also report factors that facilitate their access and participation in autism support services (referred to herein as facilitators), including easily accessible information and education on autism and/or support services, trusting relationships with providers, assistance with navigating service systems, peer support, and/or transparency of support service cost (Birkin et al., 2008; Lee & Meadan, 2021a; Pearson & Meadan, 2018; Stahmer et al., 2019; Wilson et al., 2021). Currently, there does not appear to be any research that has quantified parent reported facilitators to autism support services.

Barriers and facilitators to support services are likely not experienced to the same degree amongst all families who have an autistic child/ren. Pickard and Ingersoll (2016), for example, found that parents with lower incomes reported less knowledge of autism support services, which in turn was associated with receiving a reduced number of such services. Several studies have found that lower income families access and participate in support services at a reduced rate (Carr et al., 2016; Nguyen et al., 2016; Smith et al., 2020). These data suggest there are likely additional challenges to accessing support services experienced by lower income families.

This study was conducted within Aotearoa, New Zealand. New Zealand has a multicultural population of over 5 million people (Statistics New Zealand, 2023). The most common ethnicities include European (70.2%), Māori (the indigenous peoples of Aotearoa New Zealand; 16.5%), Asian (15.1%) and Pacific (8.1%). The majority of the population speak English (95.4%), followed by Te Reo Māori (4%) and Samoan (2.2%; Statistics New Zealand, 2020a). Rates of child poverty in Aotearoa New Zealand pose numerous challenges, including issues of inequity. Approximately 16.3% or 187,300 Aotearoa New Zealand children are deemed to live in poverty (Gage et al., 2022; Statistics New Zealand, 2022). Additionally, disabled

children are slightly more likely to live in poverty compared to non-disabled children (Statistics New Zealand, 2022).

Autism diagnostic and support services are available in Aotearoa New Zealand through the government funded public system or the user-pays private sector. The majority of autistic children in Aotearoa New Zealand (72%) gain a diagnosis through the public system with the process on average taking 10.9 months (van der Meer & Evans, 2021). Post-diagnosis, autism support services are scattered across multiple government agencies (Htut et al., 2020). Whilst parents can elect to pay for private support services, this can be prohibitively expensive (Shepherd et al., 2018). Based on two recent Aotearoa New Zealand surveys, less than a quarter of parents reported satisfaction with autism support services (Eggleston et al., 2019; van der Meer & Evans, 2021).

Presently, there does not appear to be research which has explored the number and range of barriers or facilitators parents face, the degree to which those barriers/facilitators are experienced, nor the potential influence of certain sociodemographic variables, such as family income levels. An understanding of the factors that positively and negatively impact support service access and participation could be useful for developing more inclusive and effective support services for autistic children and their families.

Towards this end, the present study involved a quantitative survey (see Appendix C) to examine the types, number, and extent of barriers and facilitators to accessing and participating in support services as reported by Aotearoa New Zealand parents of autistic children. Principles of equity and the importance of equal access to services informed the development of the study questions. The concept of access, within this study, is not limited to the availability of services. Based on previous research examining healthcare equity, factors such as affordability, quality,

and availability of information are also included (Goddard & Smith, 2001; Gulliford et al., 2002; A. Oliver & Mossialos, 2004). The aims of this study were to (a) quantify the total number and extent of barriers and facilitators to support services as reported generally by Aotearoa New Zealand parents of an autistic child/ren, and (b) to identify if there were any significant differences based upon sociodemographic factors in general and family level of financial resourcing specifically due to the relatively high rates of income inequality and child poverty within Aotearoa New Zealand (OECD, 2022).

Method

Ethics and Informed Consent

Ethical approval was obtained from Victoria University of Wellington Human Ethics Committee (#29469). Participation in the study was voluntary and anonymous. Parents were provided with information relevant to the study (see Appendix D) and provided informed consent prior to starting the survey. Parents were asked not to include identifiable information on themselves or their child. Where identifying information was provided, it was removed.

Participants

Screening questions were used at the start of the survey to ensure respondents currently resided in Aotearoa New Zealand and were the parent or primary caregiver of a child who (a) was 18 years of age or younger, and (b) had a diagnosis of autism. At the end of the two-month data collection period, 195 surveys had been submitted through Qualtrics. Surveys with incomplete demographic information and no further responses ($n = 22$) were removed, resulting in a total of 173 surveys for analysis. Of this total, 173 parents completed the demographic and barriers sections of the survey and 143 completed the full survey. Depending upon the normality of the data, the relevant statistical tests (i.e., t-test, Mann Whitney U, Chi square) were used to

determine whether there were any significant differences between those who only completed the barriers section and those who completed the full survey. No significant differences were found on any demographic variable. Descriptive statistical analysis was conducted to examine demographic characteristics of parent participants (see Appendix E Table S8). Parents reported that their autistic children's current ages ranged from 2 years 6 months through to 18 years 7 months. Child age at the time of diagnosis ranged from 1 year 10 months through to 18 years 6 months. For those children who had a diagnosis in addition to autism (83.24%), the median number of additional diagnoses was two, with a range of one to eight. The most common additional diagnosis was anxiety. Child demographic characteristics are presented in Appendix E Table S9.

Distribution

A website was constructed to assist with dissemination of the survey. Information provided on this website included an outline of the survey content, participant eligibility as listed in the previous section, the process of consent, contact details of the first and fourth authors, a brief profile introducing the first author (e.g., information about her role and research interests), and embedded links to the online survey hosted by Qualtrics. The survey was distributed mainly online via email and/or Facebook pages through health and autism specific organisations (e.g., Autism New Zealand, New Zealand Paediatrics Society, Wellington Early Intervention Trust). To ensure those who did not have reliable internet access could participate, paper copies of the survey were available and distributed by mail to providers and potential participants upon request. Twenty paper copies were mailed out in equal amounts to two Aotearoa New Zealand based providers. The questionnaire was open for responses between 22 September and 22

November 2021. Electronic responses were downloaded from the Qualtrics database onto a secure password protected USB drive. No paper-based surveys were returned.

Materials

Survey Development

The survey used in this study was based on the results of a qualitative systematic literature review (Wallace-Watkin et al., 2023b). This review, conducted collectively by the authors, examined parent reported barriers and facilitators for accessing and/or participating in support services for autistic children from underserved families. Main themes identified within this review included support service accessibility, diversity of support services, and community (for subthemes see Appendix E Table S10). Using the themes identified within the review as a guide, a list of brief barrier and facilitator statements was created. Upon completion of these written statements, the Barriers to Treatment Participation Scale (BTPS; Colonna-Pydyn et al., 2007; Kazdin et al., 1997) was reviewed to determine whether any relevant factors remained which had not yet been included in the survey. This resulted in the addition of a statement regarding parent/child illness as a barrier to support services. In total, 76 statements, split evenly between the barrier and facilitator sections, were placed into tables (see Appendix E Table S10), and configured with Likert-type rating scales. Statements were then removed from thematic categories and randomly listed to create the final version of the survey.

Survey Content

The questionnaire was divided into four sections: (a) informed consent and screening questions, (b) parent and child demographic information, (c) barriers to accessing and participating in professional support services, and (d) facilitators for accessing and participating in professional support services. The survey ended with an optional opportunity to list current

support services and number of service hours received. The first section included four screening questions designed to check eligibility. In addition to the requirements that the child be 18 years of age or younger and diagnosed with autism, the respondent was asked to confirm that (a) they were one of the child's parents/primary caregivers, and (b) the family currently resided in Aotearoa New Zealand.

Questions relevant to parent demographic information included the respondent's relationship to their child, the number and type (e.g., child's siblings, father) of individuals within the household, whether the respondent was the one who usually co-ordinated their child's support services, ethnicity, location (i.e., urban/suburban or rural), highest education level held by respondent and/or by any individual within the household, and family level of financial resourcing. The term "lower income" as used in this study refers to families who currently had, or were eligible for, a community services card² and/or income tested benefit. Child demographic information included current age and age at diagnosis, additional diagnoses, gender, ethnicity, and expressive language. Parents who had more than one autistic child were asked to fill in the survey with one child in mind and then repeat the process for any additional children if they wished.

In the 'barriers' section, respondents were asked to rate potential barriers to any support service which they wanted to access, had accessed, and/or had participated in over the previous 12 months. Each possible rating (i.e., 'not applicable', 'not at all a barrier', 'somewhat a barrier', 'a barrier', and 'very much a barrier') was defined (see Appendix E Table S11) before the list of 38 statements were provided in table format. Participants could then optionally add up to two

² A community services card (CSC) assists families with the costs of healthcare in Aotearoa New Zealand. This initiative is income-based and targets lower income New Zealand families/whānau (Ministry of Health, 2022a)

additional barriers that had not been listed and/or provide further qualitative information regarding barriers.

In the ‘facilitators’ (listed as ‘helpers’) section, respondents were asked to rate helpful factors experienced within any support service which they wished to, or had, accessed and/or participated in during the previous 12 months. Each possible rating on the Likert-type scale (i.e., ‘I did not experience this’, ‘not helpful’, ‘somewhat helpful’, ‘helpful’ and ‘very helpful’) was defined (see Appendix E Table S11) before the list of 38 statements were presented. Participants could then optionally add up to two additional facilitators that had not been listed and/or provide further qualitative information regarding facilitators. Finally, parents could choose to list any support services their child currently received, including number of hours per week those services were received.

Data Management and Analysis

Quantitative analyses were conducted using IBM SPSS Statistics (Version 28.0.1) and R (Version 4.2.0). Descriptive statistics were calculated for both parent and child demographic information. Participants were able to select more than one ethnicity. For statistical analysis (e.g., regression models), participants were grouped into one of three groups: (1) European/Pākehā, (2) Māori, or (3) other ethnic group/s (i.e., those who were not Pākehā or Māori). A participant was categorised as ‘Māori’ if one of their stated ethnicities was Māori.

Cronbach’s alpha was calculated for the barrier/facilitator scales. The total number of barriers/facilitators experienced by participants was calculated and the resulting dataset checked for normality through visual inspection of QQ plots and calculation of Kolmogorov-Smirnov tests. The mean total number of barriers/facilitators experienced, both overall and by participant level of financial resourcing (i.e., lower versus higher income) were calculated. As data were

normally distributed, to locate any significant differences in total number of barriers/facilitators between lower and higher income participants, *t*-tests were conducted.

To calculate an extent score for barrier/facilitator statements, numeric values were assigned to the Likert-type scale responses (see Appendix E Table S11). For each participant, an overall extent score was calculated for both barriers and facilitators. To ensure all values were represented in these extent scores, the mean Likert-type score was calculated across all statements. Co-occurrence of barriers and/or facilitators was examined through analysing percentage overlap. Statements were paired and the percentage of participants selecting both statements within a pair was calculated.

Responses to barrier/facilitator statements were grouped into original subthemes. The total number and percentage of participants who selected a barrier/facilitator statement within each subtheme was calculated. A score for extent of barriers/facilitators per subtheme was calculated as the mean Likert-type rating per participant across statements within each subtheme. Results are reported both overall and by level of financial resourcing (i.e., lower income versus higher income based on eligibility for a Community Services Card and/or income tested benefit). Prior to determining if any significant differences were present between barrier/facilitator subthemes, extent data were checked for normality. As the data were non-parametric, Friedman's test and pairwise comparisons, corrected for multiple comparisons, were calculated. Thematic categories were ranked based on the results, with median and interquartile ranges reported.

Simultaneous multiple linear regressions were used to examine the predictors of (a) the total number and (b) the extent severity/helpfulness of parent reported barriers and facilitators. Prior to conducting analyses, the normality of the datasets (i.e., the mean total number and extent of barriers/facilitators) was checked through visual inspection of QQ plots and calculation of

Kolmogorov-Smirnov tests. As only one measure of financial resourcing was required, two variables (parent education level, relationship status) were excluded as these have been used as proxies and/or have previously been shown to be related to, socio-economic status (Durkin et al., 2017; Härkönen, 2018; Pickard & Ingersoll, 2016; Statistics New Zealand, 2020b). The age at which a child had been diagnosed as autistic was also excluded as this variable was highly correlated with the child's current age. All excluded variables have been reported descriptively in Appendix E Tables S8 and S9. The final set of included parent variables were: (a) ethnicity, (b) level of financial resourcing (i.e., lower income versus higher income), (c) household location, (d) number of child's siblings. Child characteristics included: (a) current child age, (b) presence versus absence of additional diagnoses, (c) gender and (d) language. A check for influential cases was conducted for all four resultant regression models using Cook's distance, standardized DFBeta, and leverage values (Cook, 1977). Plots of residual values versus predicted values were also analysed ensuring the constant variance assumption was met in all models.

Additional barriers/facilitators noted by parents were collated into a table and reviewed by the first author. Where these aligned with a pre-defined statement within the main body of the survey, they were added to the count and rating of the most appropriate statement. Where new barriers and/or facilitators were identified, these were again collated, organised into the relevant theme, and re-written into barrier/facilitator statements. Totals and mean ratings were then calculated for each. The fourth author performed a check of 20% of the additional barriers and facilitators, with 92.6% agreement on the assigned theme. Disagreements were resolved via consensus. Due to there being too few responses to the questions regarding currently received support services and total hours of services received, these two variables were not included in the data analysis.

Community Involvement

Feedback on the initial version of the survey was sought from autistic adults, parents of autistic children, community providers, a university-based statistician, and experienced researchers in the field of autism including a Māori post-doctoral researcher. Feedback was generally positive, with suggestions for improvements mainly regarding terminology. The majority of suggestions were incorporated into the survey. In the write-up of this study, preferences in terms of terminology have followed the feedback and guidance provided by autistic adults in Aotearoa, New Zealand (Monk, 2022).

Results

Barriers

Overall Total and Extent

A total of 173 parents selected and rated the barriers they had experienced when accessing and/or participating in support services for their autistic child. Cronbach's Alpha across all barriers was 0.91, indicating strong internal consistency across scale items. The mean total number of barriers experienced across participants was 17.54 ($SD = 7.74$). There was a statistically significant difference between lower income and higher income parents on the total number of barriers experienced ($t(169) = 3.17, p < 0.001$). Lower income parents experienced a significantly higher total number of barriers ($M = 19.52, SD = 7.72$) than parents who were higher income ($M = 15.85, SD = 7.39$).

Results of Friedman's test indicated that the extent to which participants experienced individual barriers was significantly different between statements ($X^2(37) = 1495.572, p < .001$). Post hoc analysis using pairwise comparisons with Bonferroni correction for multiple tests revealed statistically significant differences between subthemes. Based on median scores per

statement, lengthy waiting lists were experienced to a significantly greater extent than the majority of other barriers to support services (all $p < .01$; except B27 and B28 both $p > .05$). There were no significant differences between barrier statements based on family level of financial resourcing.

The extent to which participants experienced barriers was also significantly different across the different barrier subthemes ($X^2(8) = 484.011, p < .001$). Post hoc analysis using pairwise comparisons revealed statistically significant differences in severity between subthemes (for full results see Appendix E Table S12). Based on median scores per subtheme, Service pathway related barriers were experienced to a significantly greater extent than culture, geographic location, social support, providers, service flexibility, and stigma related barriers (all $p < .05$). Culture was experienced to a significantly lesser extent than all other barriers (all $p < .05$). There were no significant differences between subthemes based on family level of financial resourcing. Median extent scores, interquartile range, and the percentage of participants experiencing at least one barrier per subtheme are presented in Table 3.1.

Table 3.1

Median and Interquartile Range of the Extent to Which Each Barrier Theme/Subtheme Were Experienced, Rank of each Subtheme, and Percentage of Participants Selecting at Least One Barrier Per Theme/Subtheme*

Barrier Theme or Subtheme	Group									Missing (n)
	All			Lower Income			Higher Income			
	Mdn (IQR)	Rank	%	Mdn (IQR)	Rank	%	Mdn (IQR)	Rank	%	
Across all themes	1.55 (0.48)	-	98.84	1.64 (0.59)	-	100	1.48 (0.44)	-	98.60	2
Support service accessibility	1.89 (0.61)	-	98.84	2 (0.68)	-	100.0	1.79 (0.63)	-	97.83	2
Knowledge and education	2.33 (1.33)	2	91.33	2.33 (1.33)	2	93.67	2.33 (1.33)	1	90.22	2
Service pathways	2.50 (1.25)	1	95.38	2.50 (1.25)	1	98.73	2.25 (1.0)	2	92.39	2
Financial pressure	2.0 (1.0)	3=	86.71	2.0 (1.5)	3=	88.61	2.0 (1.0)	3=	85.87	2
Geographic location	1.40 (0.40)	8	79.77	1.6 (0.6)	8	84.81	1.4 (0.6)	7	73.91	2
Providers	1.60 (0.80)	5	80.12	1.8 (1.0)	5	86.08	1.4 (0.75)	8	75	2
Diversity of support services	1.50 (0.67)	-	89.60	1.58 (0.67)	-	93.67	1.38 (0.56)	-	86.96	2

Cultural and linguistic considerations	1.0 (0.17)	9	25.00	1.0 (0.33)	9	32.05	1.0 (0.0)	9	19.57	2
Service flexibility	1.56 (0.89)	6	89.02	1.67 (0.89)	6=	92.41	1.5 (0.67)	5=	86.96	2
Community	1.57 (0.71)	-	87.86	1.71 (1.0)	-	91.14	1.43 (0.57)	-	85.87	2
Stigma	2.0 (2.0)	3=	64.16	2.0 (2.0)	3=	73.42	2.0 (1.0)	3=	57.61	2
Social support	1.50 (0.83)	7	83.24	1.67 (1.0)	6=	86.08	1.5 (0.67)	5=	83.70	2

Note. *Extent is based on Numeric conversion of Likert-type scale ratings, where 1 = Not at all a barrier/Not applicable, 2 = somewhat

a barrier, 3 = a barrier, 4 = very much a barrier.

Percentage Overlap between Statements

The percentage overlap between participants who selected each possible pair of barriers was calculated. The five most commonly selected co-occurring barriers were as follows: Not being sure what kinds of support services were available occurred alongside lengthy waiting lists (76%), not being sure which services were best for a child (76%), and not being able to find information on how to access support services (72%). Not being sure which support services were best for a child also occurred alongside length waiting lists (72%) and not being able to find information on how to access support services (67%). Full results of this analysis are available in Appendix E Table S13.

Simultaneous Multiple Regressions

To evaluate what factors predicted parent reported total number and rating of barriers, two simultaneous multiple linear regressions were conducted. Data was approximately normally distributed, and all cases were retained. For the total number of barriers, the model was significant, $R^2 = 0.124$, $F(10, 157) = 2.219$, $p = 0.019$. This suggests that the model explained 12.4% of the variation in the total number of barriers. The results indicated no significant effects other than for family level of financial resourcing. Specifically, a lower family income was associated with a higher total number of barriers reported. For the overall mean rating across all barriers, the model was significant $R^2 = 0.112$, $F(10, 157) = 1.987$, $p = 0.038$. This indicates that the model explained 11.2% of the variation in mean rating of the extent of barriers. The results indicated that lower income families and child gender (non-binary) were significantly associated with a higher mean rating of barriers reported (both $p < .05$). Full results are presented in Table 3.2.

Table 3.2*Simultaneous Linear Regression Predicting Total Number and Overall Mean Rating of Barriers and Facilitators*

Predictors	Overall total number of barriers		Overall mean rating across all barriers		Overall total number of facilitators		Overall mean rating across all facilitators	
	β	<i>p</i>	β	<i>p</i>	β	<i>p</i>	β	<i>p</i>
Parent characteristics								
Ethnicity								
Māori vs. European	0.105	0.188	0.029	0.720	-0.013	0.879	-0.046	0.610
Other vs. European	0.54	0.483	0.042	0.589	-0.002	0.979	0.011	0.899
Financial resourcing								
Lower income vs. Higher income	0.179	0.023*	0.169	0.033*	-0.107	0.210	-0.82	0.348
Household location								
Rural vs. non-rural	0.082	0.304	0.106	0.186	-0.019	0.826	-0.021	0.809
Child's siblings								
Number of siblings	0.119	0.125	0.107	0.171	-0.065	0.443	-0.056	0.519
Child characteristics								
Current child age								
Presence vs. absence of additional diagnoses	-0.120	0.156	-0.001	0.988	-0.251	0.007**	-0.185	0.052
Gender								
Female vs. Male/Non-binary	-0.025	0.748	0.022	0.779	-0.094	0.266	-0.087	0.312
Non-binary vs. Male/female	0.149	0.064	0.167	0.040*	-0.128	0.153	-0.101	0.272
Language								
Non-speaking vs. speaking	-0.084	0.295	-0.122	0.130	0.180	0.043*	0.176	0.053

Note. * $p \leq 0.05$, ** $p \leq 0.01$. Other ethnicity refers to parents who were from an underrepresented ethnic group other than Māori.

Other Reported Barriers

In total, 83 parents provided 118 responses (maximum of two per parent) to the optional question regarding additional experienced barriers. Of these responses, 19 were removed due to being: (a) a one-word or ambiguous response, (b) a general comment, (c) related to diagnosis, or (d) related to funding. A further 47 comments were responses which fit within one of the pre-existing barrier statements. The remaining 52 comments (from 43 parents) were collated and re-written into new barrier statements. This resulted in an additional 10 barrier statements which are presented, along with the mean rating of extent and total number of participants who had experienced each factor, within Appendix E Table S14.

Facilitators

Overall Total and Extent

A total of 143 parents (82.7%) selected and rated the facilitators they reported experiencing when accessing and/or participating in support services for their autistic child. Cronbach's Alpha across all facilitators was 0.95 indicating strong internal consistency across scale items. The mean total number of facilitators experienced across participants was 17.94 ($SD = 9.46$). Though lower income parents experienced slightly fewer facilitators ($M = 16.54$, $SD = 9.19$) compared to higher income parents ($M = 19.05$, $SD = 9.58$), this difference was not significant, ($t(140) = 1.58$, $p = 0.058$).

The results of Friedman's test indicated that the extent to which participants experienced individual facilitators was significantly different between statements ($X^2(37) = 867.176$, $p < .001$). Post hoc analysis using pairwise comparisons with Bonferroni correction for multiple tests revealed statistically significant differences between subthemes. Based on median scores per statement, parent ability to advocate for their child was experienced as significantly most helpful

compared to the majority of other facilitators to support services (all $p < .01$; except F26, F13, F6, F21, F25, F10, F9, F12, F11, and F2, all $p > .05$). There were no significant differences between facilitators statements based on family level of financial resourcing.

The extent to which participants found facilitators to be helpful was also significantly different across the different facilitator subthemes ($X^2(8) = 229.863$, $p < .001$). Post hoc analysis with Bonferroni correction for multiple tests revealed statistically significant differences in helpfulness between subthemes (for full results see Appendix E Table S12). Based on median scores per subtheme, Provider related facilitators were experienced as significantly more helpful than the majority of subthemes (all $p < .001$) except financial pressure ($p > .05$). Culture was significantly lower than service flexibility, stigma, geographic location, knowledge and education, financial pressure, and providers (all $p < .05$). There were no significant differences between subthemes based on family level of financial resourcing. Median helpfulness scores, interquartile range, and the percentage of participants experiencing at least one facilitator per subtheme are presented in Table 3.3.

Table 3.3

Median and Interquartile Range of the Helpfulness of Each Facilitator Theme/Subtheme, Rank of each Subtheme, and Percentage of Participants Selecting at Least One Facilitator Per Theme/Subtheme*

Facilitator group or subgroup	Group									Missing (n)
	All			Lower Income			Higher Income			
	Mdn (IQR)	Rank	%	Mdn (IQR)	Rank	%	Mdn (IQR)	Rank	%	
Across all themes	1.56 (0.59)	-	95.1	1.49 (0.56)	-	95.2	1.61 (0.72)	-	94.9	1
Support service accessibility	1.87 (0.65)	-	95.07	1.74 (0.69)	-	95.24	2.0 (1.74)	-	94.94	1
Knowledge and education	1.8 (0.8)	5	86.01	1.8 (0.8)	4	80.95	1.8 (1.0)	6	89.87	1
Service pathways	1.40 (0.6)	7	76.22	1.4 (0.4)	7	76.19	1.6 (1.0)	7	75.95	1
Financial pressure	2.0 (1.5)	2=	82.52	2.0 (1.0)	1=	82.54	2.5 (1.5)	1	83.54	1
Geographic location	1.83 (0.83)	4	88.11	1.67 (0.67)	5	87.30	2.0 (0.83)	3=	88.61	1
Providers	2.4 (1.4)	1	88.81	2.0 (1.4)	1=	87.30	2.4 (1.2)	2	89.87	1
Diversity of support services	1.64 (1.0)	-	86.01	1.64 (0.91)	-	82.54	1.64 (1.18)	-	88.61	1

Cultural and linguistic considerations	1 (0.67)	9	37.06	1.0 (1.0)	9	41.27	1.0 (0.33)	9	32.91	1
Service flexibility	1.75 (1.38)	6	85.31	1.63 (1.25)	6	82.54	1.88 (1.38)	5	87.34	1
Community	1.50 (1.0)	-	73.43	1.5 (1.0)	-	74.60	1.5 (1.25)	-	72.15	1
Stigma	2.0 (2.0)	2=	53.85	2.0 (2.0)	1=	53.97	2.0 (2.0)	3=	53.16	1
Social support	1.33 (1.0)	8	56.64	1.33 (1.0)	8	57.14	1.33 (1.0)	8	56.96	1

Note. *Helpfulness is based on Numeric conversion of Likert-type scale ratings, where 1 = Not helpful/I did not experience this, 2 = somewhat helpful, 3 = helpful, 4 = very helpful.

Percentage Overlap between Statements

The percentage overlap between participants who selected each possible pair of facilitators was calculated. The five most commonly selected co-occurring facilitators were as follows: Easy communication with providers during sessions co-occurred frequently with providers responding to parent calls and texts (69%), having a good relationship with the provider (68%), parent ability to advocate for their child (66%). The provider responding to parent calls and texts also frequently co-occurred alongside having a good relationship with the provider (65%). The fifth rated frequently co-occurring facilitators was tied between three statements. This included parent ability to advocate for their child being experienced alongside having a good relationship with providers (64%) and providers responding to calls and texts (64%); and ease of communication with the providers occurring alongside the provider understanding the child and/or family's needs (64%). Full results are available in Appendix E Table S15.

Simultaneous Multiple Regressions

To evaluate what factors predicted parent reported total number and rating of facilitators, two simultaneous multiple linear regressions were conducted, the results of which are presented in Table 3.2. The model predicting the mean rating of facilitators was skewed to the right. The mean rating data for this model only were log-transformed. The linear regression model predicting total number of facilitators had three high leverage values. Removal of these values had a limited impact on the model, therefore results reported here are inclusive of these values.

The regression model for total number of facilitators was significant, $R^2 = 0.138$, $F(10,128) = 2.047$, $p = 0.034$. This indicates that the model explained 13.8% of the variance in total number of facilitators selected. Results indicated that current child age (the younger a

child was) and a child's level of expressive communication (non-speaking) were significantly associated with parents selecting a higher total number of facilitators. Transformed data were used in the conduction of the simultaneous regression for overall mean rating of facilitators. The resulting model was not significant, $R^2 = 0.095$, $F(10,128) = 1.337$, $p = 0.218$. No predictors significantly affect the mean rating of facilitators (see Table 3.2).

Other Reported Facilitators

A total of 14 parents listed additional facilitators resulting in 19 comments. Thirteen of these comments were excluded due to being one-word responses or unrelated to support services. A further two comments fit within one of the pre-existing facilitator statements. This resulted in four facilitator statements, which are presented along with the mean rating and total number of participants who had experienced each factor, in Appendix E Table S16.

Barriers and Facilitators

Percentage overlap between statements

The percentage overlap between participants who selected each possible pair of barriers and facilitators was calculated. The five most commonly selected co-occurring barriers and facilitators were located, with lengthy waiting lists found to be the barrier in each pair. Lengthy waiting lists commonly co-occurred with the facilitative factors of easy communication with providers during sessions (69%), parent ability to advocate for their child (69%), affordable or free support services (68%), the provider responding to parent calls, texts, and emails (68%), and having a good relationship with the provider (67%). Full results of this analysis are available in Appendix E Table S17.

Discussion

This sample of Aotearoa New Zealand parents reported several barriers and facilitators to autism support services with waiting lists reported as the greatest barrier and parental ability to advocate the greatest facilitator. Barriers related to the theme of service

pathways were experienced to a significantly greater extent, whereas facilitators related to the theme of providers were rated as significantly most helpful. Lower income families reported significantly more barriers and reportedly experienced those barriers to a significantly greater extent than higher income families. Parents of non-binary gendered children experienced barriers to a significantly greater extent than parents of children who did not identify as non-binary. Parents of younger children, and of non-speaking children, reported a significantly higher number of facilitators, however there were no significant differences in the mean rating (i.e., the rating of *how helpful* each factor was) based on any sociodemographic factor.

Almost all parents experienced barriers to autism support services. These barriers were selected from across a range of areas aligning with recent research which suggests parents experience multiple differing barriers to accessing and participating in support services for their autistic child (Fong et al., 2022; Wallace-Watkin et al., 2023b). Previous research results suggest that parents of autistic children exhibit higher rates of stress, report limited coordination of autism services, and/or have lower rates of satisfaction with aspects of those services (Amireh, 2019; Bitterman et al., 2008; Eggleston et al., 2019; Hayes & Watson, 2013). The results of this study provide further evidence that parents of autistic children face multiple challenges in this area.

The present study appears to be the first to compare the extent to which differing barriers impact parents, with waiting lists indicated to be the single greatest barrier. Wait lists have been identified as a barrier to support services across several studies (Birkin et al., 2008; Lim et al., 2021; Sun et al., 2013). While shorter wait times for support services have been associated with improved adaptive behaviour skills in young autistic children (Aishworiya et al., 2021), lengthy wait lists have been associated with higher levels of parental stress and/or lower ratings of parental emotional wellbeing (Rivard et al., 2014; Tait et al., 2016). Anecdotally, waiting lists for services, particularly government funded services, may be up to

1 year (Connor, 2021). However there does not appear to be Aotearoa New Zealand based research clarifying the average length of waiting lists generally or by service type. This would be an obvious area for future research.

Lower family income predicted a greater number and larger negative impact of reported barriers. A recent literature review conducted by Smith et al. (2020) examining autism support service disparities found that lower income families accessed services at a lower rate, experienced greater challenges in gaining referrals, and reported receiving a lower quality of care compared to families from higher socioeconomic backgrounds. The findings of the present study, specifically those which indicate that lower income families experience significantly more barriers, and experienced those barriers to a greater extent, may partially explain the causes behind service use disparities. Overall, service pathway barriers such as difficulty gaining referrals and lengthy waiting lists tended to be experienced by parents to a significantly greater extent. This indicates families need greater support in navigating service systems.

In the present study, parents of non-binary autistic children reported experiencing barriers to a greater extent. Though research suggests autistic individuals are more likely to identify as non-binary or gender diverse (Cooper et al., 2018; Corbett et al., 2023) very little is known regarding the experiences of this group when accessing and/or participating in support services. Carlile (2020) examined the experiences of gender diverse children and their families when accessing healthcare and found that the challenges faced by this group, including limited provider knowledge of gender diversity and long waiting lists, were experienced to a greater degree when the child was also autistic. Further research is needed to explore the experiences of gender diverse autistic youth when accessing autism services.

Most parents experienced at least one facilitator to support services. Overall, facilitators which related to the theme providers such as having a good relationship with a

provider, easy communication, and providers understanding the family's and child's needs, were rated as most helpful. The reported facilitators are consistent with other reports which have highlighted the importance of certain provider traits, such as showing respect, having a willingness to advocate on behalf of families, and prioritising warm relationships (Birkin et al., 2008; Chlebowski et al., 2018; Stahmer et al., 2019).

The single most helpful factor reported by parents was the ability to advocate for their child. Learning to advocate for an autistic child is likely to be a process which necessitates parents increase their personal knowledge of autism and learn advocacy skills (Blanche et al., 2015; Pearson & Meadan, 2018; Smith-Young et al., 2022). Within qualitative research, parents have reported seeking out information, both online and from other parents of autistic children to advocate for their autistic child (Lee & Meadan, 2021a; Pearson & Meadan, 2018; Stahmer et al., 2019). Given that service pathway barriers were found to be experienced to a significantly greater extent than other barriers, the effect of imparting knowledge and education which empowers parents to navigate such systems and advocate for their child is an important area for future research.

Within the present study, significant predictors of experiencing a greater number of facilitators included having a younger child or a child who was non-speaking. One potential reason for the difference between age groups may be the present focus on early support (Noyes-Grosser et al., 2018; Rojas-Torres et al., 2020). Additionally, younger children may have higher communication needs, with speech and language services highly utilised within Aotearoa New Zealand (Kasilingam et al., 2021).

The five most commonly co-occurring barrier/facilitator pairs all included lengthy waiting lists as the barrier. The greatest overlap was between lengthy waiting lists as a barrier, and the helpfulness of parental advocacy. Previous research has also found that parents utilise advocacy skills to overcome barriers faced when accessing services (Smith-

Young et al., 2022). An important issue is whether effective advocacy could in fact help to overcome the barrier of long waiting lists.

The study aimed to recruit parents from a wide range of differing sociodemographic backgrounds. According to results of the most recent census, the two largest ethnic groups within Aotearoa New Zealand are Pākehā (New Zealand European/European) and Māori (Statistics New Zealand, 2020a). The number of Māori whānau who participated (17.9%) was representative of the Aotearoa New Zealand population (16.5%; Statistics New Zealand, 2020a). The same was true for the number of Pākehā participants, with 72.8% of survey participants selecting this ethnicity compared to the general population estimate for this group of 70.2% (Statistics New Zealand, 2020a). Therefore, the recommendations discussed are likely to be fairly representative of the two largest ethnic groups in Aotearoa New Zealand.

Implications

The results of this study suggest the value of increasing parent advocacy skills, increasing knowledge of autism in parents and the public, and reducing waiting times. Ensuring all providers have the skills, tools, personnel, and knowledge to appropriately support families with autistic children would assist families in gaining and participating in support services for their autistic child. Dissemination of strengths-based information regarding autism and support services could also be beneficial. Additional supports likely need to be put in place to assist lower income families given the findings of the present study which indicate such families experience a comparatively greater number and extent of barriers, and comparatively fewer facilitators. By doing so, we may begin to address the current inequality faced by families when accessing and participating in autism support services. It is also essential that appropriate levels of funding are provided to meet these goals.

Limitations and Future Directions

As only a small number of participants provided information regarding the support services they were receiving, it was not possible to explore connections between barriers/facilitators and specific services. Though the number of participants from Pākehā and Māori backgrounds were representative of the Aotearoa New Zealand population, the number of participants from other cultural groups, such as Pacific peoples, was much lower than the Aotearoa New Zealand population estimates (Statistics New Zealand, 2020a). Future research specifically exploring barriers and facilitators for differing ethnic and/or cultural groups is strongly recommended. It is important to understand the experiences of Aotearoa New Zealand parents who have little or no knowledge of the English language. Due to funding limitations, the survey used in this study was only available in English, therefore the results may not be representative of Aotearoa New Zealand parents who primarily speak other languages. Although the number of Māori participants was representative of the Aotearoa New Zealand population in general, future research which follows Kaupapa Māori³ principles which is offered in Te Reo Māori would be beneficial in future explorations of barriers/facilitators specifically for Māori.

Due to the survey being based on self-report, the potential for recall bias also needs to be considered. Finally, though paper-based surveys were made available, and a range of agencies were contacted, all responses were provided online. There is potential that participants without internet access may have had less opportunity to learn of, and therefore participate in, the study.

Future research could seek to explore the potential reasons parents of older autistic children experience fewer facilitative factors to support services, how to reduce long

³ Kaupapa Māori, in reference to research, refers to the embedding of Māori values, practices, and beliefs as the center of the research process. There is emphasis on the collective sharing of knowledge (Rolleston et al., 2022).

waitlists, and how to enable lower income families to access and participate in services that meet their needs and those of their autistic child. Examining the ways in which families with an autistic child may be supported whilst on waiting lists for support services would also be a useful direction for future research. Finally, Aotearoa New Zealand based research which explores how barriers and facilitators may intersect and influence service use would be useful. A qualitative approach may be helpful in further understanding how families may be utilising facilitators to overcome barriers to autism support services.

Conclusion

Aotearoa New Zealand parents reported several barriers and facilitators to accessing and participating in autism support services. Differences based on sociodemographic factors, with a specific focus on level of family financial resourcing, were identified. Results suggest steps need to be taken to address the number of barriers parents face, increase facilitative factors, and improve equitable access to, and participation in, support services for autistic children.

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Declaration of conflicting interests

The authors declare no conflicts of interest with respect to this research, authorship, and/or publication of this article.

Ethical Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent

Informed consent was obtained for all individual participants included in the study.

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Community involvement statement

Autistic adults provided feedback on all aspects of the survey prior to dissemination and provided input regarding terminology. The first author is a parent of an autistic child.

CHAPTER 4

Study 2: Adapting a Support Service for Lower Income Aotearoa New Zealand

Families with an Autistic Child

Chapter Note

This chapter has been submitted for publication in a peer reviewed journal. Dr. Hannah Waddington provided input into design and assistance with data analysis, interpretation of results, and editing. Professor Jeff Sigafoos provided input into design and assistance with editing. Community partners provided feedback and suggestions pertinent to research design and data analysis, as described in the study. Aside from this input, this study was designed conducted, and written by me. The original submitted article is included here in its entirety and only minor grammatical changes have been made. For example, American English spelling has been changed to New Zealand English. Full citation details for this article are as follows: Wallace-Watkin, C., Sigafoos, J., and Waddington, H. (2023). *Adapting a support service for lower income Aotearoa New Zealand families with an autistic child*. [Manuscript submitted for publication]. School of Education, Victoria University of Wellington.

Abstract

Research indicates that lower-income families encounter barriers when accessing early support services for their autistic children. However, limited research explores parental suggestions to reduce these barriers. This study used a research-community partnership to examine parent's experiences of an early autism support service and identify potential adaptations for improving parent access and participation. Five lower-income parents in Aotearoa New Zealand, whose children had participated in the service, participated in semi-structured interviews. These interviews were analysed using template analysis. Additionally, five community partners with experience working with families of autistic children

contributed to study design and analysis. Themes derived from semi-structured parent interviews reflected a journey from parents seeking support for their children to their participation in, and transition out, of the support service. An overarching theme, *differing needs and priorities*, highlighted the necessity for greater flexibility within early support services. Collectively, suggestions from parents and community partners informed the development of potential adaptations aimed at enhancing support service accessibility. Implications and future research directions are discussed.

Introduction

Parents often express a desire to engage in early support services⁴ for their young autistic children (Bent et al., 2022). Such programmes are proposed to support autistic children's learning in several areas, including language development, motor skills, and/or daily living skills (Daniolou et al., 2022; Sandbank et al., 2020; Tiede & Walton, 2019). Despite this focus on evidence-based early autism supports, access to such services may not currently be equitable. Lower-income families, for example, experience significantly more barriers to autism support services, and experience those barriers to a greater extent, than higher income families (Wallace-Watkin, Sigafos, Woods, & Waddington, 2023).

Adapting pre-existing autism services to better suit a particular population and/or context could improve accessibility of such services. Typically, studies examining ways of adapting early autism supports for lower-income and/or culturally diverse families have focused on parent-mediated services (e.g., Blake et al., 2017; Carr & Lord, 2016; Kasari, Lawton, et al., 2014; Rogers et al., 2022). While some of these studies have reported reductions in parental stress (Sengupta et al., 2020), improved accessibility (Pickard et al., 2019), and improvements in child outcomes such as joint attention (e.g., Kasari, Lawton, et al., 2014),

⁴ Also referred to as early intervention, early support is designed for children between the ages of 0-5 years (Ministry of Education, 2022).

outcome measures used across studies have been inconsistent. Additionally, few studies have sought parental input when developing adaptations to these support services.

Research-community partnerships are a collaborative approach aimed at ensuring the voices of key stakeholders are taken into consideration throughout the research process. At the core of research-community partnerships are values of inclusivity and engagement with the community for whom the research proposes to benefit (Cargo & Mercer, 2008; Jull et al., 2017). Such partnerships help to ensure that research undertaken with vulnerable populations are in no way harmful (McDonald, 2017). Including key stakeholders in the research process means the skills and knowledge of both community members and researchers are honoured (Key et al., 2019). The collaborative nature of research-community partnerships may make this approach particularly useful when seeking to adapt an early autism support service to a specific population (Baumann et al., 2015; Brookman-Frazer et al., 2012). Such an approach would ensure adaptations are informed by the very families who would stand to benefit from them.

Consideration of parent perceptions and experiences are also important when adapting an early support service. Presently, there appears to be limited research describing the processes followed when adapting a pre-existing early autism support service to meet the needs of lower-income families. Pickard, Kilgore, and Ingersoll (2016) employed a community partnership approach to eliciting parent and provider feedback on proposed adaptations improving the fit of Project ImPACT to the Medicaid system. Although parents generally reported positive perceptions of the adapted service based upon a 15-minute video clip, parents had not previously participated in the original programme (Pickard, Kilgore, & Ingersoll, 2016).

In a second relevant study, Rogers et al. (2022) established a community-academic partnership to adapt the Early Start Denver Model (ESDM) for use within lower-income

communities. Although parents, providers, and funding agency representatives were all involved in the adaptation of the service, there were few details provided regarding the processes followed to adapt the programme. The resultant Community ESDM (C-ESDM) appeared to improve parent and provider fidelity of ESDM implementation, however no differences in child outcomes were found between the C-ESDM group and an active treatment group (i.e., those receiving the All About Young Children support programme). Additionally, data on parent perceptions of the adapted service and/or suggestions for further improvements were not collected (Rogers et al., 2022).

Adaptations to a pre-existing autism support service should also take context into consideration. Within Aotearoa New Zealand, an estimated 16.5% of children are living in poverty (Gage et al., 2022; Statistics New Zealand, 2022). Recent data from Statistics New Zealand (2022, 2023) suggests that Māori (indigenous people of Aotearoa New Zealand) children are more likely than children from European backgrounds to reside in lower-income households. Additionally, Māori people generally appear to experience both health and income-related inequity (Hobbs et al., 2019). Of course, not all whānau Māori (Māori families) or Māori children come from lower financially resourced households. The results of a recent scoping review of the literature undertaken by Tupou et al. (2022) suggested a need for more culturally responsive services to better meet the needs of all whānau Māori (Māori families). Therefore, autism support services should be adapted to the Aotearoa New Zealand context by taking cultural considerations into account.

Presently, there does not appear to be research examining the potential of using parent feedback alongside community provider input to adapt an early autism support service. To address this gap in the literature, the present study explored lower-income parents' experiences and perceptions of an early autism support service. A research-community partnership was developed to elicit feedback regarding study procedures and analysis of

results. Collectively, suggestions from parents, community partners, and the research team were used to develop a set of potential adaptations to improve accessibility of an early autism support service. Broadly, the aims of this study included: (a) exploring the potential barriers/challenges lower-income families experienced while receiving an early autism support service for their child, (b) exploring the potential advantages or positives of the early support service, and (c) identifying modifications and/or adaptations which would enhance the fit of the early support service to lower-income families.

Method

Ethical Considerations

Ethical approval was obtained from Victoria University of Wellington's Human Ethics Committee (#30539). Participation in the study was voluntary for parents and community partners. Parents were provided with information relevant to the study (see Appendix F) and a consent form (see Appendix G) prior to giving informed consent to participate in a recorded semi-structured interview. Identifying information was removed from interview data during the transcription process and each parent chose or was assigned a pseudonym. Community partners received information relevant to the study, including details regarding the phases of the study (see Appendix H), proposed timeframes, an information sheet (see Appendix I), and a consent form (see Appendix J). All community partners gave informed consent prior to participating. Identifiable information in communications with community providers (i.e., emails, documents) was also removed and each provider chose an identifier based on their role or title.

Research-Community Partnership

This study was informed by a Research-Community partnership. Five community partners participated, including a registered social worker, an autistic person, a service manager, a senior therapist/clinic manager, and an early childhood therapist/lecturer.

Providers had experience working with lower-income families, families with an autistic child, and/or lived experience as an autistic person. The partnership in this study fell to the middle of the continuum outlined by Key et al. (2019), with a mixture of full community input (i.e. during methodological, data collection, and adaptation phases) and researcher led (i.e. data analysis) stages. To assist community partners to participate, the study was organized into four phases: (a) research design, (b) consultation regarding interview techniques, (c) data analysis, and (d) suggestions for potential adaptations to the early support service.

Community partners received an overview of the four study phases and were asked to commit to participate in at least one. All five community partners participated in phase one (research design), three participated in phase two (interview techniques), and four (all except the service manager) participated in phases three (data analysis feedback) and four (adaptations).

Early Support Service

Parents interviewed for this study all had at least one autistic child who had participated in Early Start Denver Model (ESDM) services through an Aotearoa New Zealand university affiliated research clinic (hereafter referred to as ‘the clinic’). ESDM is a comprehensive, naturalistic, manualised approach to early support designed for children who have been diagnosed as, or who may be, autistic and are between the ages of 12 and 48 months (Rogers & Dawson, 2010). With a focus on positive, reciprocal interactions between a child and therapist, the ESDM uses teaching strategies to support a child’s learning and development within the context of play and daily activities (Rogers & Dawson, 2010). The clinic provides a variety of ESDM-based services including direct therapy (i.e., trained therapist works directly with a child) and parent coaching. These services may take place in the clinic, family home, or via telehealth (parent coaching only). Initial services (10 weeks) are subsidized. Continuing support cost families approximately \$845NZD per term, consisting of one therapy session per week for 10 weeks.

Parent Participants

Parents were recruited through emails sent via the university affiliated research clinic database. Five parents including two fathers and three mothers of six diagnosed autistic children participated. One mother (Rose) was a single parent of two autistic children who had both received ESDM services. Though demographic information was only collected for Rose's youngest child who had most recently received services, Rose spoke about both children's experiences during the interview. All parents were classified as lower-income due to their eligibility for a Community Services Card, an income tested initiative supporting lower-income Aotearoa New Zealand families with costs of healthcare (Ministry of Health, 2022a). Two parents were also receiving an income tested benefit (Aaden and Rose). All parents lived in suburban areas at variable distances from the clinic, reporting travel times of between 10 and 60 minutes to access services. The majority of parents received a mixture of both direct therapy and parent coaching. Two families were receiving services at the time of the interview, while three had completed therapy between 6 and 18 months prior. Participant demographic characteristics are presented in Table 4.1.

Table 4.1*Parent demographic information*

Pseudonym	Age range	Ethnicity	Number of languages spoken in the home	Service/s received	Time since service/s received	Child characteristics		
						Age*	Child ethnicity	Other diagnoses
Aaden	35-40	African	2	DT, PC	Current	3y7m	Somali	None
Grace	35-40	African	2	DT, PC, PG, Workshops	18 months	7y	African	Global Development Delay
Lyla	25-29	Tongan	3	DT, PC	Current	3y11m	Tongan & Samoan	None
Liam	30-34	Japanese	1	PC	6 months	4y	Japanese	Eczema
Rose	25-29	NZ European & NZ Māori	1	DT	12 months	5y3m	NZ European & NZ Māori	Global Development Delay, Traumatic Brain Injury, ADHD

Note. DT=Direct therapy, PC= Parent Coaching, PG= Playgroup

*Child's age at the time of the interview

Materials

Semi-structured in-depth interviews were conducted with parents using an interview guide which had been developed specifically for this study in collaboration between community partners and the first author. Topics included within the guide were: (a) overall experience with the service, (b) fit of the service to various areas of family life, (c) factors which facilitated access, (d) factors which acted as barriers to access, and (e) suggestions for adaptations to the service.

Procedure

Each parent participated in a semi-structured interview in their chosen location, on a date and time they had selected. Two in-person interviews took place at the clinic and three were conducted over the phone. Interviews lasted between thirty and sixty minutes. The interviewer (first author) began each of the five interviews by introducing herself, explaining the project, and confirming consent. Using the semi-structured interview guide (see Appendix K) the interviewer spoke to each parent regarding their experiences with ESDM services, before concluding the interview by thanking the parent for their time and providing a koha (gift) to acknowledge their expertise. After each interview the interviewer wrote reflective interview summaries. Parents were given the option to receive and review copies of their transcribed interview, a summary of the thematic results, and a copy of the final manuscript.

Data Analysis

Data were analysed using template analysis (N. King, 1998; N. King & Brooks, 2017) taking a critical realist approach (Willig, 2013). Critical realism purports the existence of an objectively knowable reality, though each individual's perception of this reality is subjective to varying degrees (Willig, 2013). Template analysis, a form of thematic analysis, was selected as it provides a means to examine overarching connections and relationships between themes across a dataset (N. King & Brooks, 2017). This allowed for identification of potential service adaptations which were relevant across themes. Recordings of interviews

were uploaded to an online transcription service (otter.io) with resultant transcripts downloaded, deidentified, and checked for accuracy. Parents who had chosen to receive a copy of their transcript (n=3) were given an opportunity to provide feedback prior to transcripts being imported into NVivo data analysis software for the analytic process. The first author conducted initial coding of the dataset and development of themes. As the positionality of a researcher may impact each stage of the research process (Holmes, 2020), a positionality statement for the first author is provided in Appendix L.

Template analysis was conducted by the first author following the six steps outlined by N. King and Brooks (2017). Prior to coding, the first author familiarised herself with the full dataset through editing and re-reading each transcript. Preliminary coding was undertaken on the transcripts of the first two completed interviews using an inductive coding approach, in which codes were generated directly through analysis of the data (Johnson & Christensen, 2019). Resultant themes were organized into meaning-based clusters and an initial template was developed. This template was then applied to the three remaining transcripts with modifications made to the template (i.e. redefining, adding, and/or removal of themes) as needed. The third author then reviewed the updated template and coded data, providing feedback and suggestions regarding the grouping and defining of themes. The template, including definitions of each theme, was then sent to parents for member checking, and to community providers for feedback. Parents who provided feedback on this template (n=3) reported themes were representative of their experiences, while community partners reported resonating with the themes in their professional experience. Based on suggestions regarding terminology from community partners, the template was updated, and the results finalised. The data analysis process concluded with the sixth and final version of the template. The first author then re-applied this coding template to the entire dataset.

Throughout the template analysis process, parent suggestions for improvement to the service, both those which were directly stated and those formulated based on researcher interpretation, were coded to the relevant theme, and added to a word document table. The resulting tabulated list of adaptations were arranged per theme and sent to parents for member checking, revision, and additional comment. Three parents provided feedback on this list stating the ideas accurately reflected strategies which would have improved their experiences. Parents had no further suggestions or changes. Community partners were then provided with the tabulated list of adaptations. Four community partners provided feedback on this list, either via email (n=3) or during an online (Zoom) meeting with the first author (n=1). Feedback from community partners consisted of additional suggestions for adaptations. The first and third authors along with a senior clinic staff member reviewed the collated feedback from both parents and community partners and added to the list of suggested adaptations based upon their research and practical experiences.

Community Involvement

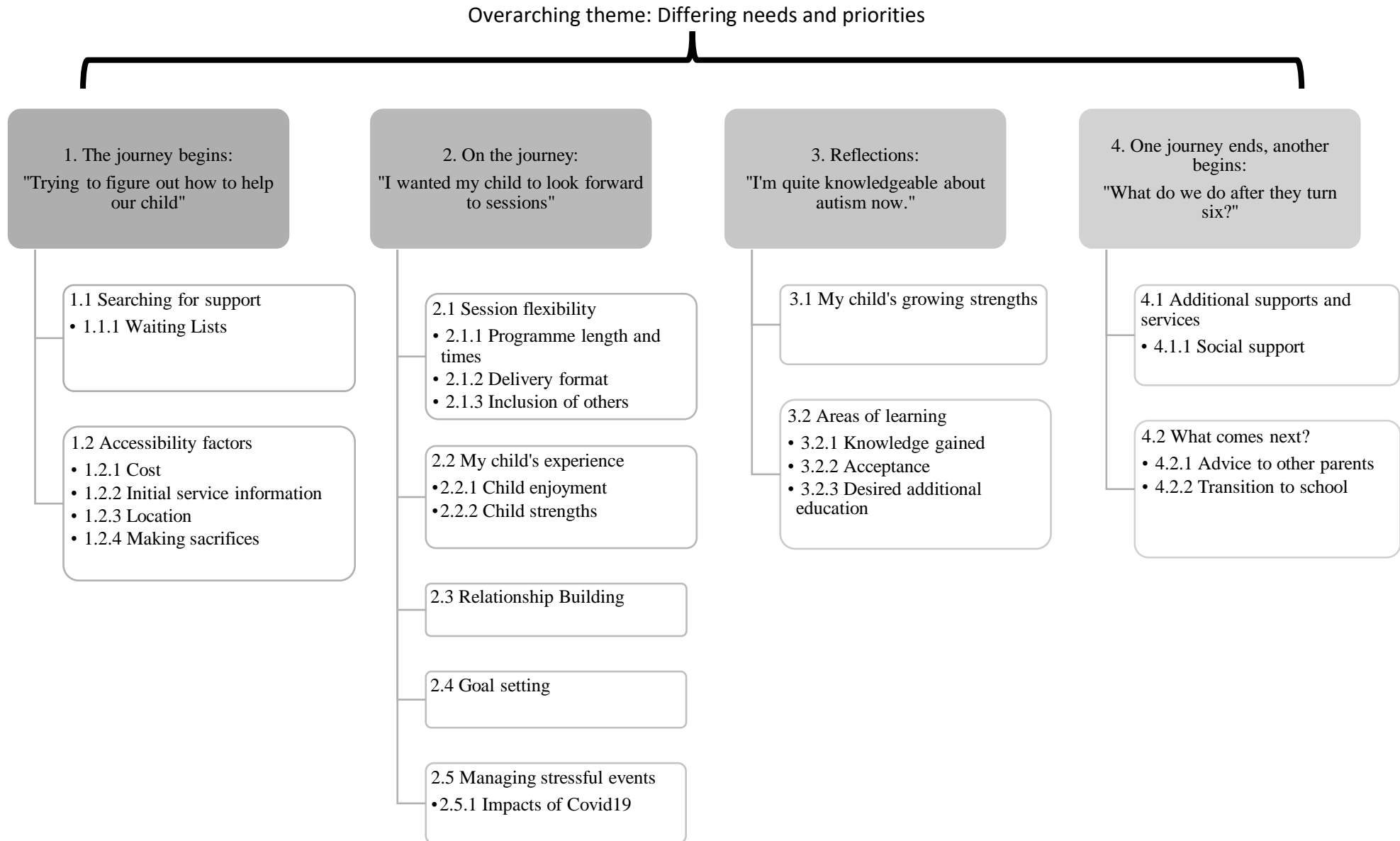
Community stakeholders were involved in all stages of this study. This included an autistic person, individuals who were experienced in working with autistic children and their families, and parents of autistic children. Both the first and third authors have autistic family members. Terminology used in the interview guide, demographic survey, and throughout the write-up of this study follow preferences outlined in the Autism New Zealand autism terminology guidelines (Monk, 2022).

Findings

Themes were structured hierarchically. One overarching theme, four top-level themes, 11 second level themes and 17 third level themes (see Figure 4.1) were identified. Themes are explored below.

Figure 4.1

Resulting themes of the template analysis: Template 6



Overarching theme: Differing needs and priorities

A common thread connecting themes was the diversity of needs and priorities expressed by each parent. What was important for one parent's situation, family, and/or child did not necessarily align with the needs of other parents. For instance, while some parents wanted to receive more "...information about neurodiversity" (Rose), others prioritised practical strategies: "I always think of what is the most practical way to do it and is it necessary to understand all the basics, sorry, all the theory behind it? ... We want to get to the outcome" (Liam). These disparities extended to logistics with Lyla advocating for telehealth service delivery as it would be 'perfect', while Rose "preferred to come in because I know [the clinic]". The variation of parental preferences throughout the dataset underscored a wider necessity for flexibility and individualisation of services.

Theme 1: The Journey begins: "Trying to figure out how to help our child"

Parents discussed *searching for support* once their child had received an autism diagnosis. The initial period directly after receiving their child's diagnosis was described as "overwhelming" (Lyla) and a "struggle" (Rose). This period was marked by parents feeling they were responsible for "figur[ing] out how to help" (Grace) their child. Four parents mentioned that ensuring a support service had a strong research base was important, with one adding this was part of doing her "due diligence" (Grace). One parent (Rose) noted the search for support was complicated by a lack of advertisement of services, stating she "...would really love if there was more advertising about this [ESDM services]".

Lengthy *waiting lists* for support services meant that even when parents located a desired service, the search for more expedient support continued: "It's pretty hard at the beginning. When you just got the diagnosis, then you ask for help, they tell you six months, eight months, one year? I need help now." (Aaden). Waiting lists were less of a problem for ESDM services, with one parent describing her experience accessing the service as "quite

easy... I didn't go on any waiting list. I was lucky." (Rose). However, another parent noted that though she had not been on a waiting list, she had family members who "want to join as well, but there's a long waiting list [now]. It's sad because [their child] will be starting primary [school] soon and they won't get a chance to join the programme..." (Lyla).

Once parents gained access to ESDM support services, *accessibility factors* became a consideration. The decision by parents to participate in ESDM services appeared to be directly impacted by factors of *cost*. Lyla shared that accessing a service at no cost meant it was "...the best option to take". Parents expressed gratitude (Aaden) and feelings of luck (Rose) for having had the opportunity to take part in a free service. For two parents whose children were currently receiving services, concern was expressed as to whether they could afford full-cost sessions. Whilst Lyla had recently accessed alternate funding "to help pay for sessions", Aaden stated that though he wished to continue, he also wanted to "give other families a chance" to access a free or lower cost service.

Initial service information parents received during their search for support and prior to beginning ESDM services was limited. Information parents did receive post their child's diagnosis often went unread, was misplaced, did not directly relate to autism, or was ill-timed due to parents feeling overwhelmed. Specific to the ESDM service, a desire for greater process-related knowledge (e.g., how long the waiting list was, other parents' experiences of the service) was expressed. General information familiarising parents with how ESDM sessions worked may have been helpful for two parents who described feeling 'really awkward...' (Lyla) or "...quite nervous" (Aaden) when starting sessions.

Factors related to *location* of service delivery such as travel, cost of petrol, time restraints, and being outside of the service delivery area impacted upon accessibility of the ESDM service. Four parents (all except Aaden) lived at least a 20-min drive from the clinic. Commuting to attend sessions was described as a barrier (Rose), a challenge (Grace), and a

downfall (Lyla) of ESDM services. Distance was particularly problematic for Lyla, who lived the furthest from the clinic:

When I was doing the parent coaching, they would only do home visits. So, because we weren't living close enough for them to come out, we've had to do it at a different family member's house. Which was kind of hard because it's not our place...".

Lyla went on to add that she would increase the number of direct therapy sessions her child was receiving "...if it was more local". Nonetheless, most parents enjoyed aspects of coming into the clinic, particularly their child's enjoyment of the centre (Grace, Rose, Lyla).

Location-based suggestions for adaptations to ESDM services included providing opportunities for therapy in outdoor settings (Grace), providing home and preschool visits across a wider region (Lyla), and the development of online modules which parents could access in their own time at (Liam).

Two parents described *making sacrifices* for their child to participate in ESDM services. For Aaden, being available to participate in the care of his son, including attending ESDM services, led to limited opportunities to work outside the home. This further challenged the family's finances: "We have to come to this. We both have to sacrifice our work." For Liam, attending sessions "Definitely... took priority, so it doesn't really matter other routines", reasoning that "It's a force multiplier. If you don't do it, it would be shooting yourself in the foot".

Theme 2: On the journey: "I wanted my child to look forward to the sessions"

Once parents were engaged and participating in ESDM services, factors which related to *session flexibility* became a consideration. Parents generally reported being happy with the length of ESDM sessions sharing it was "exactly enough" (Lyla) or "perfect" (Aaden and Rose). Parents were in less agreement on other factors related to *programme length and times*. For example, Aaden felt having direct therapy sessions "...once a week" was

preferable as "...two or three [sessions] every week, sometimes can be a bit much...". In contrast, Liam stated "Three times a week, that's actually very intensive and that's what makes it work". Aaden preferred sessions which were within school hours due to having other school aged children, whereas Grace stated "Weekends would have been really, really helpful" as this would have fit within her work schedule. Liam was the only parent to mention missing several sessions due to illness and stated he would have found greater flexibility to extend programme participation "very" helpful. Aaden discussed a preference for the overall length of the ESDM programme to be longer, suggesting six months to one year would be preferable as: "...you plant the fruits. It's nice to actually see the fruits, and pick the fruits, and eat the fruits".

Parents reported mixed preferences for both *delivery format* and the *inclusion of others*. Parents reported that parent coaching increased their understanding of their child (Lyla) and was both enjoyable (Grace) and helpful (Aaden, Liam): "I did the first [parent coaching] session and I can see the results straight away" (Liam). While Grace had enjoyed group sessions as she "...appreciated meeting other parents", both Liam and Lyla, who had not received group services, expressed concern for this approach. Lyla felt her child did "...much better when it's one on one". All parents spoke of how helpful observing a therapist work with their child was, with Rose sharing the experience showed her "...how play really helped my child learn".

When it came to including extended family members or other people from the child's life in ESDM services, Grace mentioned the benefits of including her child's preschool teachers, while Lyla mentioned she would "...love to include family" suggesting "...a family day for all families that attend the clinic". Conversely, Aaden and Liam preferred not to include extended family members, with Aaden further clarifying that his other children would be "...really tired" from school and may be disruptive.

Their *child's experience* was a key consideration for parents. *Child enjoyment* was measured by parents as their child's desire to attend and remain in sessions. Grace wanted her child to "...look forward to the sessions and look forward to having those interactions". Three parents whose children had received direct therapy noted there were times their child would be "a bit stropky" (Rose), disengaged (Liam), or showed distress through crying (Lyla). This was particularly true when starting out in sessions as parents noted their child's comfort levels increased over time, with the clinic becoming one child's "happy place" (Lyla). The child directed nature of ESDM sessions was viewed as particularly beneficial, with Grace sharing that in other services her child had received it had "...felt like my child was a fish being taught to climb a tree. I didn't have a good gut feel as a parent" leading her to stop "some of those therapies". Participation in ESDM services also gave parents an opportunity to reflect on their *child's strengths*, with observations of direct therapy sessions leading to recognition of a child's strong memory (Lyla, Rose), or enjoyment for socialisation (Liam).

Relationship building was viewed as an important process. Parents described therapists they worked with as "...very, very accommodating" (Grace), "amazing" (Lyla), and "awesome" (Rose). Pre-existing relationships appeared to impact parents' decisions when choosing between services. Aaden described being "...referred to another thing at [a different clinic] ... We chose this one because with this one... we know you guys". Therapist qualities such as being understanding, reassuring, and patient were all valued, as was effective communication. A lack of therapist consistency was a concern for Rose, who found it difficult to "...build a relationship with a therapist and then the therapist would change... it would be like starting over again", adding she found for her child that "...consistency is key". Lyla felt having opportunities to meet and get to know other therapists in the clinic had helped her "...build really strong connections with all the therapists... Now we don't mind

when it changes to a different therapist”. The importance of positive relationships extended to the interactions between therapists and children. Grace shared that her child “...looked forward to it [direct therapy], like she’s going on a play date with her very big friend”. Parents felt a positive relationship between their child and the therapist supported their child’s learning (Aaden), goal attainment (Liam), and ability to feel safe and comfortable with new people (Grace).

Parent priorities for *goal setting* included increasing their child’s communication skills (Aaden), their independence (Aaden, Grace), and their happiness (Aaden, Grace, Rose). Parents recognised that despite having therapists work towards set goals with their child, their children did “... things in their own time” (Grace), and progress towards goals felt like “...crawl[ing] forward, every little milestone” (Aaden). Grace experienced conflicting feelings regarding goals, stating “we did enjoy the goals because we stretched her, but when we set the goals and say, in three months... she wouldn’t do that, I would feel very disappointed” adding that “Emotionally it was a bit tough”. Parent suggestions were to add goals related to happiness and well-being (Aaden, Grace, Rose), as well as providing ideas for ways parents could work towards goals within activities at home (Liam).

One of the factors parents contended with while accessing ESDM services was *managing stressful events*. For both Aaden and Rose, who were receiving income tested benefits, unstable housing was a factor which seriously impacted their ability to participate in support services. Rose stated “...another barrier for people who are on a low income, sometimes we can’t pay the rent, we’ve got to go live in a motel”. In addition to challenges with housing, Aaden also spoke about having other children with health challenges “It’s a bit hard for us because it’s not just [our autistic child], ... our other son [has] skin problems, eczema. He wakes up in the middle of the night and will cry”. *Impacts of Covid* were felt by all five parents. Whether it was delays in receiving services (Liam), being unable to leave an

overcrowded home (Aaden), lack of access to the clinic (Lyla), increased child anxiety (Grace), or having to exit ESDM services early (Rose), the Covid-19 pandemic had significant impacts: “There was success. It’s just Covid got in the way... That was a really challenging time” (Rose).

Theme 3: Reflections along the way: “I’m quite knowledgeable about autism now”

While participating in ESDM services parents noted their *child’s growing strengths*. Increases in skills such as non-verbal communication (Grace and Rose), engagement (Lyla), and imitation (Liam) as well as children finding new enjoyable activities (Aaden) were all reported. Rose noticed significant increases in both of her children’s communication, for her son in his spoken language: “My son was not talking when he entered this programme and by the time he exited, he was talking so that is major to me”, and for her daughter in non-verbal communication: “She walked away with pointing, which is amazing... for a nonspeaking autistic person that is huge”. Liam suggested information on supporting skill acquisition while maintaining current skills would have been helpful.

Parents described several *areas of learning* and a breadth of *knowledge gained* during their participation in ESDM services. For parents who participated in parent coaching, it was noted that this was helpful in gaining strategies (Aaden) and tools (Grace) to use with their children. Learning strategies to teach imitation (Liam), understanding the importance of routine (Lyla), and practicing strategies at home between sessions (Grace) were all techniques parents utilised throughout their time in ESDM services. Though Rose had not received parent coaching, observing her children’s direct therapy provided her “... a different approach” to how she could “play with autistic children...”. Challenges to practicing ESDM strategies at home included not being able to locate the same objects, such as toys, as those used in the clinic (Grace and Rose), being consistent with techniques (Lyla), and the use of technical phrases (Aaden). Additionally, Liam noted expectations for parents to deliver

teaching strategies “...every 30 seconds” felt like he was “...using a chess set and my brain was actually planning most of the time. It’s very exhausting”. One suggestion made by both Liam and Lyla was the creation of a diagram or wall chart with a reminder of strategies and examples to use during play with their children.

An increased understanding of autism was frequently associated with parent *acceptance* of their child’s diagnosis. For Lyla, gaining knowledge of autism helped her to understand her child’s diagnosis wasn’t “bad news”, but simply “...a confirmation of what we’re waiting for, for so long”. All five parents expressed the desire for other parents to have opportunities to access education on autism. Rose continued to actively seek out education beyond her participation in services, finding information on neurodiversity and the experiences and knowledge shared by autistic adults particularly useful. Through increased knowledge of autism, parents found *acceptance* for their child’s diagnosis. Aaden summed this up by stating: “It’s hard at the beginning, but now, acceptance. I think the key word is acceptance. When you accept the challenge, whatever it is. That’s the biggest one, acceptance”.

Parents described a range of *desired additional education* which was not currently covered in the programme, based upon current priorities. This included specific tips and education on toilet training (Aaden and Liam), autism specific information (Lyla and Rose), greater dissemination of knowledge of autism to the community (Aaden, Lyla, Rose), education workshops presented by autistic adults, and information on supporting executive functioning (Rose). Lyla noted that while there appeared to be several services for autistic children, there was a lack of education for parents and extended family members to support “...learning to understand autistic kids”. However, not all parents wanted the same types of information, for example while Rose would have liked some additional education on neurodiversity, Liam was not sure of the utility of this. Finally, parents would have found

recommendations on where to buy toys similar to those used at the clinic (Rose and Grace), and information on other available services for their child (Liam and Grace) helpful.

Theme 4: One journey ends, another begins: “What do we do after they turn six?”

Parents were at differing stages of their ESDM journey with their child. Of the five parents spoken with, two had children who had aged out of ESDM services (Grace, Rose), one had recently completed their participation in a research project (Liam), and two were coming to the end of their funded sessions (Lyla and Aaden). Parents were looking to what may come next for their child, including what *additional supports and services* were available. While Aaden spoke of accessing a “helpful” local playgroup, his experience of early childhood education had been that he and his child were “just a number”. Rose had positive experiences with a local organisation which offered weekly activities, such as swimming, “specifically for autistic children”. For many parents, the search for support had started all over again, with Grace noting “...right now it feels like we’re fumbling”. Lyla felt as though there were too few “services ... available for kids with autism in [New Zealand]”.

Two parents (Aaden and Grace) discussed additional supports they would like to have access to, including mental health support for themselves, social workers, and respite care. Grace stated her concern for her child impacted her own health, while Aaden would have appreciated a ‘wellbeing call’ from “...a psychologist or someone...to say ‘are you okay? Are you alright? Do you need any help?’”. Grace also noted wanting services to be more individualised, stating that when being referred for support with her child’s eating “...you get something that is very, very big and you’re like, actually, I just wanted a tiny piece. I didn’t want all of this, just a tiny piece.” *Social support* was something parents relied on for guidance and understanding. It was helpful for parents to know they weren’t alone in raising an autistic child, with Grace stating that speaking with other parents of autistic children was “...very therapeutic because we would sometimes even just trade our war stories, or just talk

about our children” (Grace). Opportunities to meet with other parents of autistic children also gave their child the opportunity to “socialise with other children” (Grace).

Parent reflections on *what comes next* for their child and family once completing ESDM services included considerations of whether they would be *recommending ESDM* to other parents of autistic children. All parents reflected positively on their experience within the service, with Grace liking the “child-directed” nature, Aaden feeling the service “gives people more hope...”, Lyla choosing to find funding to continue with the service, and Rose mentioning the programme had “changed my children’s lives and my life significantly”. Liam shared that if he could speak to other lower-income parents of an autistic child, he would “Highly recommend it [ESDM services]. You have to do it because it’s effective, because whatever we were doing initially doesn’t work. And those tips actually worked very, very well”. All parents expressed gratitude for having the opportunity to participate in ESDM services, with Rose stating “I just want to give back because you guys really gave to me. You gave me the opportunity to do that trial and I’m so grateful for it”.

Three parents were concerned about the challenges and difficulties anticipated or experienced during their child’s *transition to school*, including the suddenness of moving from ESDM services to the school environment. Though Aaden and Lyla’s children were yet to begin school, Lyla was already aware her “...son can only take [ESDM services] up until he is five or six when he does start primary” and Aaden was already concerned with “...how we can make education a bit more inclusive?”. For two parents whose children had started school (Grace and Rose), the search for support had recommenced. Grace felt the end of her child’s ESDM services were “abrupt for us because it was also quite a bit of a transition”, and “outside of school” she was “not sure where to go for support”. Rose felt the emphasis on her children’s early years left a gap once they began school “They say that early intervention is the most crucial years, but what about after that? Do we just stop?” and that once her children

turned six “we’re left alone... my son had no supports, not through school, not through anything.”

Adaptations

The list of potential adaptations for ESDM services is presented in Table 4.2. Adaptations were developed based on the themes identified through data analysis and suggestions made by parents, community partners, and researchers (first and third author, senior clinic staff member). As per the overarching theme of differing parental needs and priorities, key adaptations included ensuring choice, flexibility, and parent input into the structure of the programme.

Table 4.2*Adaptations by theme and stakeholder group*

Theme Name	Suggested Adaptations		
	Parents	Community partners	Researcher
Differing needs and priorities			<ul style="list-style-type: none"> Choice offered to enable parents to build a programme to suit their needs and priorities.*
1.1 Searching for support	<ul style="list-style-type: none"> Increase advertising of services. Develop online educational videos on the topics of autism/neurodiversity. 	<ul style="list-style-type: none"> Develop a phone application with educational videos for parents of autistic children. 	
1.2 Accessibility factors			
Costs	<ul style="list-style-type: none"> Free services Payment plans for paid services 	<ul style="list-style-type: none"> Designate a staff member to provide information and support with funding applications. 	<ul style="list-style-type: none"> Reimburse travel costs
Initial service information	<ul style="list-style-type: none"> Develop online videos describing the service, include past parent experiences. 		<ul style="list-style-type: none"> Welcome pack expanded to include clinic floorplan, timeline of services, options to build programme.*
Waiting lists	<ul style="list-style-type: none"> Regular (e.g. monthly) parent well-being check-ins. 	<ul style="list-style-type: none"> Use time on waitlist to build rapport. 	<ul style="list-style-type: none"> Reduce time on waiting lists.*
Location	Extend distance therapists can travel to cover the entire region.	<ul style="list-style-type: none"> Emphasise parent selection of a comfortable, safe location for service delivery. 	<ul style="list-style-type: none"> Parent chooses location of service delivery.* Optional parent and child clinic visits prior to starting services.

		<ul style="list-style-type: none"> • Extend distance therapists can travel to beyond the local region. 	
2.1 Session flexibility			
Programme length and times	<ul style="list-style-type: none"> • Extend programme length (e.g. to one year). • Offer weekend sessions. 	<ul style="list-style-type: none"> • Carry over any low cost sessions missed as ‘credits’. • Weekend and evening services. • Option to spread services over 10 or 20 weeks. • Option of weekly or fortnightly sessions. 	<ul style="list-style-type: none"> • Set number of sessions provided.* • Flexible rescheduling
Delivery Format	<ul style="list-style-type: none"> • Modelling of strategies by therapist • Playgroups offered at conclusion of 1:1 services. 		<ul style="list-style-type: none"> • Choice of delivery method (e.g. parent coaching, direct therapy)*
Inclusion of others	<ul style="list-style-type: none"> • Option to include extended Whānau (Family). 		
2.2 My child’s experience		<ul style="list-style-type: none"> • End sessions early if needed (e.g. child is tired). • Provide personalisable social story template about attending sessions. 	<ul style="list-style-type: none"> • Therapist to focus explicitly on relationship with child before implementing teaching.
2.3 Relationship Building	<ul style="list-style-type: none"> • Consistency in therapists. • Provide parents opportunities to meet all therapists. 	<ul style="list-style-type: none"> • Photos and brief biographies of clinic staff as a hand-out. • Offer introductory workshops to parents starting with the 	<ul style="list-style-type: none"> • Therapist focus is building and preserving relationships with family.

		<p>service. Have all therapists present.</p> <ul style="list-style-type: none"> • Emphasise parents are the experts in their child. 	
<p>2.4 Goal Setting</p>	<ul style="list-style-type: none"> • Add child wellbeing, safety, and happiness goals. • Provide wall chart with examples of teaching during play and daily routines. 	<ul style="list-style-type: none"> • Remove goals which prioritise teaching neurotypical skills (e.g. eye contact). • Reduce number of goals targeted to promote success. • Provide basic checklist for parents to monitor their weekly use of strategies. 	
<p>2.5 Managing stressful events</p>			<ul style="list-style-type: none"> • Therapists to be mindful of parent wellbeing, refer on for additional services as needed.*
<p>3.1 My child's growing strengths</p>			<ul style="list-style-type: none"> • Therapist to regularly share child strengths with parents*
<p>3.2 Areas of learning</p>	<ul style="list-style-type: none"> • Remove technical language. • Increase parent education on Autism/neurodiversity, including offering education led by autistic people. • Provide information on skill maintenance. • Develop: <ul style="list-style-type: none"> ○ Videos capturing autistic adult experiences of daily life. ○ ESDM-based online educational courses. 	<ul style="list-style-type: none"> • Offer choices of educational topics. • Have hand-outs available online. • Add strategies for teaching within everyday routines to parent coaching booklet. 	<ul style="list-style-type: none"> • Referrals to appropriate services for information on specific topics (e.g. sleep, nutrition)*

- Templates for building strategies into everyday routines.

4.1 Additional supports and services

- Increase accessibility of clinic resource booklet (e.g. online).*

4.2 What comes next?

- Develop ESDM-based school readiness workshops

*Researcher interpretation of parent data

Discussion

We used a research-community partnership along with semi-structured interviews to explore five lower-income parents experiences, perceptions, and recommendations for an early autism support service. Using template analysis, themes related to a journey through the support service were located. An overarching theme, differing needs and priorities, indicated a need for individualisation and flexibility within the service. Parents reported both benefits and challenges of participating in the service. Challenges included limited service visibility, location, costs, and waiting lists, while benefits included positive child experiences, strong relationships with therapists, and fulfilled educational needs. For parents who had exited the service, their search for further supports for their child, particularly within the school environment, had begun again. Suggestions of parents, community partners, and researchers (the first and third author, senior clinic staff member) informed the development of a list of adaptations designed to improve accessibility of an early autism support service.

Parents encountered several challenges throughout their engagement with the early support service. Barriers, including lengthy waiting lists, location of services, and stressful life events, were similar to those reported by parents in previous research (Jurek et al., 2022; Wallace-Watkin et al., 2023b). Additionally, the provision of the support service at no cost to parents was a significant factor influencing parents' decisions to participate. This aligns with research conducted by Shepherd et al., (2018), in which parent selection of a support service for their autistic child was affected by whether the service was funded by a third party (e.g. a government department), or not.

Parents frequently described their journey through the support service as a circular process. Upon completing their involvement with the early support service, parents spoke of returning to a sense of uncertainty as they resumed their search for support for their child. This sense of uncertainty mirrors the sense of disappointment, loss, and confusion reportedly

experienced by parents participating in research conducted by Bent et al. (2022) upon conclusion of an early support programme. For parents in the present study, the return to uncertainty and need to search for further support may be indicative of broader service challenges. Indeed, within Aotearoa New Zealand where this study was located, autism support services are allocated across several government agencies without clear navigational pathways (Htut et al., 2020).

Parents described several factors which facilitated their participation in the early support service. The helpfulness of positive relationships between parents, children, and the therapist was noted as particularly helpful. This aligns with previous research in which parents describe the importance of empathetic, warm, respectful relationships with service providers (Leadbitter et al., 2020; Wallace-Watkin, et al., 2023a). This study adds further evidence to the importance of positive relationships between parents and service providers. Parents in the current study also described enjoying the child-led nature of the service, aligning with previous research by Stahmer et al. (2011) in which parents expressed a preference for child-led play-based approaches.

Parents valued the knowledge they gained during their participation in the early support service. This increased knowledge was connected to an improved understanding of autism and greater acceptance of their child's autism diagnosis. This is similar to results of the study conducted by Anthony et al., (2020) which indicated autism specific education for parents may increase both acceptance and a sense of parental competency. Collectively parents found value in learning skills and strategies to support their children. Similarly, parents in the study conducted by Seo et al., (2022) reported several benefits to having strategies to support their interactions with their autistic children, including a strengthened parent-child relationship.

An overarching need for increased flexibility and individualisation of support services was located within this study. This finding aligns with those of previous research in which

caregivers, autistic adults, and/or service providers have called for greater flexibility in support services (Han et al., 2021; Pickard, Kilgore, & Ingersoll, 2016; Wallace-Watkin et al., 2023b). In research conducted by Eskow et al., (2019), increased parental choice of providers and input into the types of services provided to an autistic child was associated with increases in family quality of life. Several other suggestions made within this study to improve service access were also similar to those made in prior research. For example, suggestions made by parents and providers in research conducted by Pickard, Kilgore, and Ingersoll (2016) also called for a reduction in complex language, and a focus on clear communication and collaboration between parents and providers. Taken collectively, these similarities indicate the presence of broad improvements which may improve the accessibility of autism support services.

Several of the adaptations suggested in this study were relatively novel. These practical recommendations included increasing advertising of services, creating a phone application with autism specific information, and providing well-being check-ins for parents during the wait for services (see Table 4.2). Compared to previous research, there was also a stronger focus on the child's experience including parents' desire for goals based on child wellbeing and happiness. Finding ways in which to measure goals related to a young child's experience in an early support service would be an important area for future research.

An additional consideration within the Aotearoa New Zealand context is the adaptation of support services to meet the needs of whānau Māori (Māori families). Of the five parents included in this study, one parent, Rose, was Māori. Rose identified that consistency in therapist supported her to build a strong relationship. Further, Rose expressed a desire for greater education in neurodiversity. The need for time to develop genuine relationships with whānau (families) and tamariki (children) has been highlighted in previous research exploring experiences of whānau Māori (Māori families) with young autistic children

(Tupou, Ataera, & Waddington, 2023). Additionally, Te Ao Māori (Māori world views) appear to align with neurodiversity affirming understandings of autism, including viewing autism as a ‘difference’ rather than as a deficit and placing value in a child’s unique way of being (Tupou, Ataera, Wallace-Watkin, & Waddington, 2023). This may, in part, be reflected in Rose’s interest in further education specifically in neurodiversity, however research directly examining possible connections between Te Ao Māori and neurodiversity affirming approaches would be useful. For example, research specifically using a kaupapa Māori (Māori ways of being and understanding) approach may be beneficial for identifying the challenges and unique experiences of whānau Māori (Māori families) when accessing early autism support services for their tamariki (children).

An important consideration when engaging with lower-income families is the presence of external stressors. Two families in this study had experienced periods of time in which their housing situation was insecure. It is important to recognise there are certain barriers lower-income families face which may not be addressed through adaptations to a support service. As parents have reported experiencing stress and a sense of being overwhelmed during participation in early support services (Jurek et al., 2022), it is important for providers to be mindful of the pressures families may be under and refer families for further support as needed.

Implications

Results indicate lower-income families may experience a range of both barriers and facilitators to early autism support services and are able to provide a range of ideas of how to improve such services to better support their needs. This highlights the potential value of service providers seeking family and community feedback and using this feedback to implement necessary change. Flexible approaches to service delivery which allow providers to customise the support provided to families appears to be a priority. Providers may look for

ways in which parent choice can be increased within support services more generally in order to meet individual family needs, from developing customisable educational hand-outs through to providing flexibility in scheduling. Two parents also highlighted the need for greater mental health and wellbeing supports. Adaptations described here may not only improve access and participation in early support services for lower-income families, but for families more generally. In the systematic review conducted by Jurek et al., (2022), parents generally reported experiencing some barriers to support services such as time constraints and location challenges.

Limitations and Future Directions

Results of the present study should be interpreted with consideration of several limitations. First, the aim of this study was to understand the experiences of lower-income parents who had participated in a specific early support service available in one Aotearoa New Zealand city. This limited the number of parents who were eligible to participate, and the resultant sample size is small. Whilst the results reflect the experiences of the five parents interviewed, the extent to which these results would represent experiences of other lower-income parents involved in ESDM, or other services, requires further investigation. Additionally, all five parents had accessed the support service for free or at a substantially reduced cost, therefore the results may not be indicative of the experiences of parents participating in full-cost support services. All parents in this study had or were in the process of completing participation in ESDM services. Though parents who had started ESDM services and needed to withdraw early were eligible to participate, none were recruited to the study. Therefore results may not be reflective of the experiences of parents who were unable to access, or who had to withdraw early from, services due to insurmountable barriers. Finally, although the parents interviewed came from a range of cultural and ethnic

backgrounds, all were able to speak fluent English, thus the results may not be reflective of the experiences of parents who are not English speakers.

There are several additional ways in which this research may be extended in the future. First, it could be useful to examine how such an early support service may be adapted to families from different cultural backgrounds. For example, as Māori are the indigenous peoples of Aotearoa New Zealand, exploring the ways in which services may be improved to suit the needs of Māori peoples would be an important next step. Parents reported on the importance of their child having a positive experience within the support service, therefore it may be useful for future research to explore ways in which we may gain an understanding, or measure, of child experience within early support services. Though an autistic person was part of the research-community partnership, it would also be beneficial for future research in this area to include a greater number and wider range of autistic individuals. Finally, it would also be important to apply the adaptations created in this study to ESDM services for lower-income families to evaluate the feasibility and acceptability of this approach.

Summary and Conclusion

This study utilised a research-community partnership along with semi-structured parent interviews to inform the adaptation of an early support service. Parents reported a range of barriers and facilitators to the service, with both parents and providers suggesting ways in which the service may be improved. An important next step would include ensuring the adaptations outlined within this study are acceptable, appropriate, and feasible for lower-income families.

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Declaration of conflicting interests

C.W.W. has delivered community therapy at the clinic attended by the participating families. This includes providing a single therapy session to one of the participants in this study. H.W. is the clinic lead of this same service. J.S. declares no conflict of interest with respects to this research, authorship, and/or publication of this article.

Ethical Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent

Informed consent was obtained for all individual participants included in the study.

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Community Involvement

One of the community partners was an autistic person, and both the first and third author have autistic family members.

CHAPTER 5

Study 3: Adapting an Early Autism Support Service to the Needs of One Lower Financially Resourced Aotearoa New Zealand Family

Chapter Note

This chapter has been submitted for publication in a peer reviewed journal. Dr. Hannah Waddington, Dr. Jessica Tupou, and Mrs Lauren van Noorden provided input into design, assistance with interpretation of results, and editing. Jessica Tupou also provided cultural advisement throughout the case study. Professor Jeff Sigafoos assisted with editing. Aside from this input, this study was designed, conducted, and written by me. The original submitted article is included here in its entirety and only minor grammatical changes have been made. For example, American English spelling has been changed to New Zealand English. Full citation details for this article are as follows: Wallace-Watkin, C., Tupou, J., van Noorden, L., & Waddington, H. (2023). Adapting an early autism support service to the needs of one lower financially resourced Aotearoa New Zealand family. [Manuscript submitted for publication]. School of Education, Victoria University of Wellington.

Abstract

Though research suggests that the provision of early support to young autistic children may be beneficial, access to such services is often inequitable. Lower financially resourced families as well as families from underrepresented ethnic or cultural groups access support services for their young autistic children at a reduced rate. This suggests there are factors which may be precluding these families from accessing and/or participating in such supports. Potentially, adaptations to support services to improve accessibility would be useful. This case study explores the experiences of one lower financially resourced whānau Māori (Māori family) when accessing and participating in an adapted autism support service in Aotearoa New Zealand. This case highlights the need for flexible, culturally responsive practices which

may be individualised to suit the needs of each whānau/family. The importance of clear communication and maintaining structure are emphasised, and implications for practice are discussed.

1 Theoretical and Research Basis for Support Programme

Autism, a form of neurodivergence, is characterised by differences in information processing, social interactions, and preferences for routine (Pellicano & den Houting, 2022). At present, early recognition and diagnosis of autism combined with the expedient delivery of high-quality support services (also referred to as interventions) are recognised as best practice (Whitehouse et al., 2020; Zwaigenbaum et al., 2015). Parents are often encouraged to locate early support services⁵ (also referred to as early intervention) for their young autistic child (Edwards et al., 2017). In Aotearoa New Zealand, such services are typically designed for children between the ages of 0-5 years (Ministry of Education, 2022). Research suggests the potential benefits of early support services may include increases in language, motor skills, and/or daily living skills (Daniolou et al., 2022; Sandbank et al., 2021; Tiede & Walton, 2019).

Naturalistic Developmental Behavioural Supports (NDBSs, also referred to as NDBI⁶) are one form of early support service with a growing evidence base. Generally, NDBSs focus on the delivery of supports within natural contexts and settings, at a child's developmental level, while utilising behaviour-based teaching strategies (Schreibman et al., 2015). In a meta-analysis of 27 group-design studies that evaluated a range of NDBSs, Tiede and Walton (2019) concluded that autistic children who participate in such services may experience

⁵ Early support services are also referred to as early intervention. These services include, but are not limited to, speech language therapy, occupational therapy, and play-based therapy.

⁶ NDBI stands for Naturalistic Developmental Behavioural Intervention. As this manuscript aligns with terminology preferences of the Aotearoa New Zealand autistic community (Monk, 2022), the word “supports” is used rather than “intervention”.

significant improvements in expressive language, cognitive development, and social engagement. While NDBSs may be delivered directly to a child by a trained therapist, several NDBS programmes have been developed to be delivered by parents, for example Joint Attention, Symbolic Play, Engagement and Regulation (JASPER; Kasari, Kaiser et al., 2014), Parent Early Start Denver Model (P-ESDM; Rogers et al., 2012), and Project ImPACT (Ingersoll & Wainer, 2013). Parent-mediated NDBSs may have beneficial effects on factors such as child communication, parent-child engagement, and/or parent fidelity of strategy use (Gevarter et al., 2022; Popovic et al., 2020; Shire et al., 2021). However, parent and child outcomes are mixed both within and across studies, (Ousley, 2022; van Noorden et al., 2022; Waddington et al., 2019). Further research may help elucidate the reasons behind such differences.

While the results of many NDBS studies are promising, research indicates current access to early autism support services is inequitable. Specifically, a family's level of financial resourcing may impact upon access to and/or participation in such services (Nguyen et al., 2016; Pickard & Ingersoll, 2016). One potential reason for this difference may be the large number of barriers faced by lower financially resourced families when trying to access autism support services (Stahmer et al., 2019; Wallace-Watkin, Sigafos, & Waddington, 2023a). Recent research conducted in Aotearoa New Zealand suggests that lower financially resourced families not only experience a greater number of barriers to autism support services, but that those barriers are experienced to a significantly greater degree when compared to higher income families (Wallace-Watkin, Sigafos, Woods, & Waddington, 2023).

The adaptation of an autism support service to the needs of a particular group may reduce barriers and promote equitable access. Several studies have examined the impact of adapting pre-existing autism support services, particularly those which are parent-mediated,

to the needs of lower financially resourced and/or culturally diverse families with an autistic child (e.g., Carr & Lord, 2016; Sengupta et al., 2020). Typically, adaptations retain the core elements of the support service while adding changes such as increased flexibility of scheduling, individualisation of materials and delivery, removal of waiting lists, and/or reduction of costs (Blake et al., 2017; Carr & Lord, 2016; Divan et al., 2015; Kasari, Lawton, et al., 2014; Pickard et al., 2019; Rogers et al., 2022; Sengupta et al., 2020). Although the outcome measures used across studies differ, positive impacts of adapted support services have included increased treatment adherence, reduced parental stress, and/or increased acceptability of the service (Kasari, Lawton et al., 2014; Pickard et al., 2019; Rahman et al., 2016; Sengupta et al., 2020). However, very few studies have collected qualitative data relevant to parent experiences with an adapted support service (Blake et al., 2017; Carr & Lord, 2016).

When adapting a support service for use in Aotearoa New Zealand, it is important to consider the needs of Māori (the indigenous peoples of Aotearoa New Zealand). A recent scoping literature review (Tupou et al., 2021) identified the need for more culturally responsive services to meet the needs of whānau Māori (Māori families) with autistic children in Aotearoa New Zealand. Additionally, Māori are more likely to experience health and income-related inequities (Hobbs et al., 2019), which may serve as barriers to accessing support services. Māori children, for example, are more likely to reside in lower-income households than children from European backgrounds (Statistics New Zealand, 2022). While this does not, of course, mean that all Māori families will be lower financially resourced, it is important to consider the multiple barriers that may be faced by whānau Maori (Māori families) in accessing and participating in autism support services.

The aim of this case study was to gain an in-depth understanding of the perceptions and experiences of one lower financially resourced family who participated in an adapted

version of an NDBS-based early autism support programme. To be considered as lower financially resourced the family needed to be receiving, or be eligible for, an income tested benefit and/or a Community Services Card⁷ (CSC). We also sought to understand how helpful the family found the programme adaptations to be, and whether they found the programme to be acceptable. As the participating family were Māori and used Te Reo Māori (The Māori language) within their home, certain keywords in this study have been written in Te Reo Māori. English translations are provided in brackets.

1a. Case Study Methodology

Case studies are a methodology used frequently within qualitative research and provide researchers with the means to flexibly use a diverse range of observational measures and approaches to collect rich and in-depth data (Sclafani, 2017). Case studies allow researchers to examine a range of phenomena holistically and contextually (Stake, 1995; Yin, 2003). When well-formulated, case studies are not only versatile but are methodologically rigorous, providing a means by which to view a phenomenon through various lenses simultaneously (Baxter & Jack, 2008). There are a wide range of approaches to case study which vary based upon epistemological ideas, structure, flexibility, and the principles and strategies used in both data collection and analysis (Yazan, 2015).

Of primary importance within case studies is both the defining of the case as well as the establishment of clear boundaries. Ensuring case definitions and boundaries are clearly identified ensures coherence, manageability, and relevance (Baxter & Jack, 2008). The process of defining a case and identifying boundaries includes setting clear criteria for inclusion and exclusion as well as determining the specifics of the case (Baxter & Jack, 2008). In the context of the present case study, the focus was on understanding the

⁷ The Community Services Card is an Aotearoa New Zealand initiative which supports lower income families to access lower cost healthcare (Ministry of Health, 2022a).

experiences of one lower income family within an adapted autism support programme. As the whānau (family) recruited to the case study were Māori and spoke Te Reo Māori (The Māori language), additional adaptations to the programme were made, such as using basic Māori kupu (Māori words) as well as starting and ending sessions with karakia (Māori blessing). A descriptive approach to case study (Yazan, 2015) was taken with the aim of gathering rich data regarding the experiences, perceptions, and helpfulness of the programme for the participating whānau (family). To retain the important cultural context of the specific case, certain keywords used throughout this study have been written in Te Reo Māori. English translations are provided in brackets.

Case study methodologies are also grounded within a range of theoretical approaches. For example, both Yin (2003) and Stake (1995), prominent researchers within the field of case study, take a constructivist approach. Constructivism posits that truth is both relative and subjective, with individuals taking an active role in constructing meaning and their own understanding of the world around them (Olssen, 1995). While Yin (2003) and Stake (1995) both acknowledge the subjective nature of reality as well as the importance of context in case study research, there are key differences in their methodological approaches. While Yin (2003) recognises the importance of context, his methodological approach leans towards the prioritisation of objective data collection. Researchers following his approach need to have clear protocols for data collection and analysis, utilise triangulation of multiple sources of evidence, and ensure the validity and reliability of findings (Yin, 2003). In contrast, researchers following Stake's (1995) approach pay more attention to the social and cultural dimensions of knowledge construction by placing emphasis on understanding phenomena within the social context.

The current case study contains elements of social constructivism, with recognition and consideration of the social and cultural context in which the study was conducted. Deep

consideration was given to the influence of sociocultural factors throughout the case study process. The theoretical positioning of this case study therefore aligns most closely with the consideration of social and cultural dimensions described by Stake (1995).

A range of case study types have been developed over time, including explanatory, exploratory, descriptive, multiple, intrinsic, instrumental, and collective (Baxter & Jack, 2008). For example, while intrinsic case studies focus predominantly on the case itself, instrumental case studies tend to focus on an issue (Yazan, 2015). Additionally, while Yin (2003) argues for a tight and structured design for case study, Stake (1995) argues for a more flexible design in which the areas of focus may be clarified and redefined.

The current case study is an intrinsic case study, which provides a flexible approach particularly helpful in understanding a unique situation or phenomenon (Stake, 1995). Flexibility was a key consideration in this study for ensuring the burden of study participation was kept as minimal as possible, given the barriers to support service access and participation lower financially resourced families are likely to already encounter (Wallace-Watkin, Sigafos, Woods, & Waddington, 2023).

While intrinsic case studies have limited transferability (Stake, 1995) they have been widely utilised in the preliminary evaluation of support programmes (Johnson & Christensen, 2016). The current study sought to better understand the case (i.e., the experiences of one lower income whānau Māori within an adapted autism support programme) in and of itself. The case was not selected to represent an abstract construct, or to examine a generic phenomenon, nor was the case chosen to represent or generalise to other situations, nor to develop a theory (Baxter & Jack, 2008). As such, the current study is best conceptualised as a single case study (Yin, 2003), exploring a single whānau (family's) experience of an adapted autism support programme. The study did not seek to focus on exploring the differences and

similarities in several whānau/families' experiences of a programme and so a multiple or collective case study was not appropriate.

Consideration of the types of data collected, and the way in which the data collection occurs, is important across all approaches to case study. Researchers using case study tend to draw data from multiple sources to capture the complexities of a case in its entirety (Yazan, 2015). Data sources may be both qualitative and quantitative, including documentation, archival records, interviews, direct observations, and participant observations (Yin, 2003). Triangulation of the data, including the collection of data from various sources (Yin, 2003), is frequently used to ensure a holistic picture of the case is gained.

While Stake's (1995) approach to case study uses qualitative data sources exclusively, the current case study included a mixture of both exploratory and evaluative measures. Data collection included the use of a demographic survey, a pre- and post-programme measure of acceptability (TARF-R; Reimers et al., 1992), a record of attendance to programme sessions, a semi-structured interview to gain an in-depth understanding of the whānau(family's) experiences in the adapted support program, and a survey to measure the helpfulness of the adaptations used throughout the programme. Inclusion of both quantitative and qualitative measures was intended to support a greater understanding of the whānau (family's) experience of the acceptability and helpfulness of the adapted programme.

The analysis of data within case study also varies depending upon the approach taken. For example, in the approach taken by Yin (2003), the focus is on the steps and techniques the researcher takes to reach the 'truth' of a case. In contrast, the approach to analysis taken by Stake (1995) involves making sense of the data, considering the researcher's 'first impressions', 'final compilations', and direct interpretations. A further example is the data analysis approach taken by Merriam (1998), in which the researcher makes sense of the data by consolidating, reducing, and interpreting what they have seen, heard, and read using

ethnographic analysis, narrative analysis, phenomenological analysis, content analysis, and analytic induction.

The approach to data analysis taken in the present case study was a process of sense making and direct interpretation of the data by the first author. In alignment with the constructivist paradigm, the researcher's positionality and subjectivity was embraced as an inherent part of the data analysis process with a reflexive journal kept throughout. To ensure a rich and in-depth understanding of the current case was gained, both exploratory and evaluative measures were used. The approach taken aligns most closely with the approaches to case study recommended by Stake (1995) and Merriam (1998).

The various approaches to case study also differ in the strategies used to ensure the validity of data and the methods used to enhance internal and external validity and reliability. For example, Yin's (2003) approach includes the triangulation of multiple sources of data, maintaining chains of evidence, member checking to enhance construct validity, and clear case protocols for ensuring reliability. Stake (1995) also suggests using various methods of triangulation (e.g., data source, investigator, and methodological triangulation) to ensure data validation. In regard to both validity and reliability, Merriam (1998) recommends the use of triangulation, member checking, long-term observation, participatory research, and disclosure of researcher bias as strategies for enhancing internal validity.

In the current case study, various methods were used to enhance validity, reliability, and rigour. Throughout the data analysis process, an audit trail was kept which included detailed documentation of theme development and a daily record of the analysis process. Additionally, a reflexive journal was kept as a record of the thought processes and decision making of the first author. The keeping of an audit trail and reflexive journal aligns with recommendations made by Merriam (1998) to enhance reliability. Member checking was also used as the whānau (family) were invited to review the interview transcript, a copy of the

themes developed from the transcript, as well as the final written case study report for accuracy and resonance. Data triangulation also occurred through the use, and collective review, of both interview and questionnaire data. The inclusion of thick descriptive quotes in the reporting of the results also aligns with recommendations by Merriam (1998) as a method to enhance external validity. Collectively, these processes enhance the rigour of the present case study.

2 Case Introduction

Ethical approval was obtained from Northern B Health and Disability Ethics Committee [2023 EXP 15593]. Participation in the study was voluntary. An information and consent form (see Appendix M) was provided to the whānau (family) via email. Informed consent was obtained prior to, and confirmed at the start of, the initial meeting with the whānau (family). All identifiable information was removed during the interview transcription process, and the participants were assigned a pseudonym.

The participating whānau (family) members included Marama, a Māori female aged in her 50's, and her mokopuna (grandchild) Rawiri, a 3-year-old Māori boy. The focus of this case study was on Marama and her perceptions and experiences of the programme. Therefore, only basic demographic information regarding Rawiri was collected (i.e., no child outcome measures were used). The whānau (family) were bilingual, using both Te Reo Māori and English within the home. Though they were unable to participate in the programme, Rawiri's Uncle and Koro (Grandfather) also resided in the same household as Marama and Rawiri. Rawiri had been referred to the Aotearoa New Zealand public child health and development service for an autism diagnostic assessment. While awaiting this assessment, Marama had sought support from several services, including her local marae (a Māori community space that belongs to a specific iwi/tribe) and from an autism specific university clinic through which the current case study was advertised. Marama held a current

community services card (CSC) and lived in a suburban area of a main city. Based on the results of the Social Attention and Communication Surveillance – Pre School (SACS-PR) conducted at the university clinic, Rawiri had a high likelihood of being autistic.

3 Support Needs

Marama described having approached several autism-specific and/or developmental support services in the three months leading up to the case study. Each of these services had lengthy waiting lists or had not responded to her emailed correspondence. Marama had obtained support from a social worker through her local marae who, at the beginning of this case study, was assisting Marama to locate autism-specific supports for Rawiri. This included accompanying Marama and Rawiri to their initial meeting at the university clinic for this case study. Marama's main concern for Rawiri was that he would 'fall through the cracks' and not receive appropriate supports, particularly within educational settings such as kindergarten and primary school.

Marama's primary goals reflected a desire for ongoing support and education for both herself and Rawiri. Upon entry to this case study, Marama identified several key areas in which she hoped to increase her current level of understanding. Primarily, Marama wanted information and education which would increase her knowledge of autism and *takiwātanga* - a Māori term for autism meaning 'my/his/her own time and space' (Te Pou o te Whakaaro Nui, 2019, p. 5). Marama hoped that through this greater understanding she would also learn how to support moments of increased social engagement with Rawiri. Additionally, Marama wanted to gain a greater understanding of the reasons behind some of Rawiri's interests including his enjoyment of loud sounds, climbing, and his exploration of objects through placing them in his mouth.

4 History

At the time of this case study, Rawiri had been in the care of his grandmother, Marama, for approximately four months. Rawiri was receiving early childhood education through a local kindergarten which he attended three days per week for up to six hours per day. Rawiri was mainly non-speaking and communicated predominantly through vocalisations, gestures, and facial expressions. Halfway through the case study Rawiri began participating in speech language therapy once per week for half an hour per session through the university clinic. Marama described Rawiri as a generally happy and relaxed child who enjoyed connecting with other people in his own ways. Marama reported there were times Rawiri bit or kicked her, and she was concerned that he climbed in unsafe places (e.g., on the back of a couch in front of a second-story window). These actions were interpreted by Marama as Rawiri attempting to gain her attention, as the actions often increased when Marama was otherwise engaged (e.g., taking a phone call, in a conversation with an adult). Due to ethical considerations related to aspects of the family's circumstances, a more detailed family and child history was not collected.

5 Assessment

The research team considered it important that the research process did not become burdensome for the participating whānau (family). For this reason, the number of assessments used prior to, during, and after the programme were kept minimal. Assessments are described below chronologically.

5a. Preassessment

After Marama had provided informed consent, she completed an online eligibility and demographic survey. Marama then attended an initial meeting at the university clinic alongside Rawiri and the whānau (family's) social worker. This visit began with a trained clinician conducting a Social Attention and Communication Surveillance – Pre School

(SACS-PR) screening. The SACS-Revised (SACS-R) is a well-validated screening tool used to identify characteristics of autism in young children between the ages of 11 to 30 months (Barbaro & Dissanayake, 2010, 2013; Mozolic-Staunton et al., 2020). The SACS-PR was designed to accompany the SACS-R to extend the use of this tool to children aged between 31 to 60 months (Barbaro et al., 2022). The SACS-PR consists of a checklist of 22 social attention and communication markers, with eight of these items considered to be key. For a child to be deemed to be at a high likelihood for autism, three of the eight key items must be scored as ‘atypical’ (Barbaro et al., 2022). Following this screening, Marama then met with the therapist (first author) to ask questions and begin to build the programme of support for herself and Rawiri.

At the start of the first home visit, Marama also completed an adapted version of the Treatment Acceptability Rating Form - Revised (TARF-R; Reimers et al., 1992). The TARF-R was used to assess Marama’s perceptions of the acceptability of the programme. The TARF-R consists of 20 items, however, two items (numbers 10 and 18 of the original version) related to the “severity” of a child’s difficulties were removed as they did not align with the strengths-based approach taken within the adapted programme. Of the 18 remaining items, 17 related directly to the acceptability of the support programme. These items were divided across six subscales relating to (a) reasonableness, (b) willingness, (c) affordability, (d) side effects, (e) effectiveness, and (f) disruption/time. Subscale scores were summed to provide a total acceptability score. A total acceptability score is calculated by adding the scores across subscales.

5b. Assessment During support

A record of attendance was kept by the therapist (first author) which included details of who attended each session, the topic discussed, and reasons for cancellations where applicable. A check-in survey, based upon a survey developed and used by Tupou et al.

(2022) was completed by Marama during programme sessions in weeks four and six (see Appendix N). This survey was composed of a set of statements related to parent and child experiences of accessing a session alongside a five-point Likert-type scale with ratings from strongly disagree through to strongly agree.

5c. Post Assessment

Both qualitative and quantitative measures were administered one week after the programme had concluded.

Qualitative Measures

Marama participated in a semi-structured interview designed to gain insight into her and her whānau (family's) experiences during the programme. An interview guideline was developed by the first author specifically for this study and included questions related to (a) overall experience of the programme, (b) the fit of the programme with whānau (family) needs, (c) benefits and challenges of the programme, (d) helpfulness of adaptations made, and (e) suggestions for further improvements to the programme (see Appendix O). This interview was conducted by the clinician who had undertaken the SACS-PR screening with the whānau (family). The interview was recorded to a digital voice recorder and transcribed verbatim. The first author then removed any identifying information as well as filler words (e.g., umm). A full transcript was provided via email to Marama for verification, with no suggested changes or additions made.

Interview data were analysed following the four steps of content analysis described by Bengtsson (2016) including decontextualisation, recontextualisation, categorisation, and compilation. The decontextualisation stage consisted of the first author ensuring she was familiar with the transcript through repeated reading. Coding was undertaken by breaking the data into smaller 'meaning units' (sentences or paragraphs which relate back to the study aim)- which were coded. Through this process, a codebook including initial broad code

names and definitions was generated. In the second stage, recontextualisation, the first author returned to the original transcript to read and re-read meaning units, ensuring each were relevant to the study aim. Units not relevant to the study aim (i.e., comments regarding refreshments) were removed. For the categorisation stage, the first author used paper and pen to brainstorm potential top-level themes based on the codes identified in the decontextualisation phase. Resultant themes were entered into NVIVO, defined, and applied across the data set. In the final stage, compilation, results were written and explored in relation to the extant literature.

Quantitative measures

At the same appointment in which Marama participated in the semi-structured interview, she also completed two paper-based surveys. These included (a) an adaptations survey developed specifically for this study consisting of a list of the changes made to the programme which could be rated on a five-point Likert-type scale from very unhelpful to very helpful (see Table 5.1 for the list of adaptations), and (b) the post-programme version of the TARF-R as described above.

Table 5.1*List of adaptations*

Adaptation Description
1. The programme was free
2. Petrol vouchers were provided for every university clinic visit
3. There was no waiting list for the programme
4. The family had the choice of location for the sessions (e.g. home, clinic, community space)
5. The family could choose the delivery method (e.g. direct therapy, parent coaching, teacher coaching, a mixture)
6. The topics and content were individualised to the family
7. The topic of neurodiversity was discussed
8. The family were informed of other support services they could apply to receive prior to the conclusion of the programme
9. Printed, laminated, and digital versions of the programme content were individualised and provided
10. Visuals of strategies were provided
11. Family had the choice of the day and time of sessions
12. The programme focused on parent empowerment
13. The topic of how to take care of your own wellbeing as a parent/caregiver was included
14. The programme did not use goals based on behaviours and skills of ‘typically developing’ children.

Note. Each item was scored using a 5-point Likert-type scale from very unhelpful to very helpful.

6 Case Conceptualisation

Marama expressed an eagerness for herself and Rawiri to begin participating in an autism support service immediately, however the university clinic had a 6-month waiting list and she was yet to receive communications back from other agencies she had contacted. As Marama expressed an interest in participating in research, details of the case study programme and details regarding consent were provided to her, and the initial meeting was scheduled. As described above, this meeting included the collaborative development of Marama's support programme. Additionally, this process identified Marama's key goals related to education and support (outlined under 3 Support Needs). Marama also mentioned it would be useful for the therapist to work one-on-one with Rawiri, which would allow Marama to observe, learn, and ask questions in the moment. Te Ao Māori (Māori worldview) concepts and understandings of autism were also a priority. Priority was given within the programme to whakawhanaungatanga (building relationships) which included the therapist making herself available to communicate over the phone with Marama between sessions to answer questions. Additionally, the programme was delivered in a strengths-based way to preserve, respect, and enhance each whānau (family) member's mana⁸.

7 Summary of Support and Assessment of Progress

7a. Description of the support service

This support service was based primarily on the Early Start Denver Model (ESDM), which is an evidence-based, comprehensive support programme designed for children between the ages of 12 and 60 months who are, or who may be, autistic (Rogers & Dawson, 2010). The programme is play-based and focuses on following the child's lead in play. Typically, a child is assessed through the ESDM curriculum checklist with child goals

⁸ There are several definitions of mana including authority, prestige, and influence (Biggs, 2013).

developed based on the result (Rogers & Dawson, 2010). Given the brevity of the programme provided in this case study and the whānau (family's) clear goal of wanting to increase engagement with Rawiri, a curriculum assessment was not conducted. Additionally, given the focus on parent education and building relationships, only the foundational relationship focused strategies of play-partnering from the ESDM were used (see Rogers & Dawson, 2010).

Adaptations made to improve the accessibility of the ESDM-based programme (see Table 5.1) were based on the input and experiences of five lower financially resourced parents of six autistic children (i.e., one parent had two autistic children) who had previously participated in ESDM services through the university clinic. Additionally, feedback and suggestions on adaptations were provided by five community stakeholders, including an autistic person and team members of the university clinic (see Chapter 4). A list of the resultant adaptations can be viewed in Table 5.1.

7b. Programme overview

The adapted ESDM-based programme was delivered by the first author who had completed advanced training in ESDM, however, was not certified in this approach. The first author is a PhD student of Māori descent with theoretical knowledge of Te Ao Māori (Māori worldviews), is the parent of an autistic child, has experience working with autistic children in both educational and therapeutic settings, and in the co-delivery of an autism-specific parent education programme to whānau/families. She was supervised weekly throughout programme delivery by two experienced certified ESDM therapists.

The programme was designed to consist of six sessions delivered once weekly over six weeks. Options were provided for caregivers to select both the delivery approach (i.e., direct delivery to the child, parent coaching/education, teacher coaching, mixed), length of each session, and location (i.e., within the family home, within the university clinic, or a

community space) of sessions. The session format selected by Marama consisted of six 90 min sessions split into 45 min of direct child therapy and 45 min of caregiver education and reflection. An overview of session types, lengths, locations, and discussion topics are provided in Table 5.2.

Table 5.2*Overview of support service sessions*

Week	Session Type	Session Length	Location	Discussion Topic
1	Direct Therapy and Parent Education	90 min	Family home	Autism/Takiwātanga and neurodiversity
2	Direct Therapy* and Parent Education	90 min	Family home	Being a helpful play partner
3	Direct Therapy and Parent Education	90 min	Family home	Following your child's lead
3	Bonus session: Direct Therapy Cancelled due to therapist illness	-	-	-
4	Direct Therapy and Parent Education	90 min	University clinic	All behaviour is communication
5	Parent Education	45 min	Family Home	Hauora(wellbeing) for parents/caregivers
5	Bonus session: Direct Therapy and brief parent reflection	60 min	University clinic	Not applicable
6	Direct Therapy and Parent Education	90 min	Family home	Programme wrap-up
6	Bonus session: Direct Therapy Cancelled due to whānau commitments	-	-	-
7	Follow-up	60 min	University clinic	Conversation with an autistic person.

Note: *Direct therapy was not observed by Marama
Session was cancelled

To provide flexibility and allow for ongoing individualisation of the programme, discussion topics for the following week were chosen collaboratively by Marama and the therapist at the end of each session. A bonus session was provided at the university clinic in week 5 to align with Marama's desire for greater diversity of programme delivery location. Two additional bonus sessions (i.e., 45 min of direct therapy only at the university clinic) were planned for week three and week six, however these were cancelled due to therapist illness and a conflicting appointment for Marama and Rawiri.

Direct therapy with Rawiri consisted of relationship focused strategies from the ESDM (i.e. play partnering; Rogers & Dawson, 2010). Play items used were those readily available within the whānau (family) home or university clinic. The therapist (first author) gifted the whānau (family) with two play items in week two of the programme – a wooden fruit and vegetable cutting set and a wooden safari shape sorting truck. These were selected based on therapist observations of Rawiri's interests and were items which allowed for shared play and joint engagement. A brief overview of the weekly discussion topics are outlined below. All topics were outlined in hand-outs provided to Marama, both paper-based within a folder and electronically via email. Laminated visuals of relationship focused strategies were also provided. For a full overview of the structure of sessions, see Table 5.2.

Week One: Whakawhanaungatanga, Building Relationships

In week one the therapist focused on whakawhanaungatanga (building relationships) with Marama and Rawiri. The discussion topic included information on understanding autism, neurodiversity, and takiwātanga, including going through a colour-wheel activity designed to visually represent the concept of autism as a spectrum. The colour wheel was used to support Marama in identifying Rawiri's areas of strengths and support needs.

Weeks Two and Three: Engagement through play

Week two focused on ways Marama could begin to engage in play with Rawiri, including identifying Rawiri's interests, finding his comfort zone for joint play, and managing distractions. As Marama was scheduled to meet with an early intervention teacher within the family home, she was unable to observe the direct therapy. Instead, to allow Marama time to focus on this appointment, the therapist delivered Rawiri's 45 min of direct therapy in a close-by room within the whānau (family) home.

In week three, the discussion topic explored further strategies related to ways Marama could join in with Rawiri's play, including narrating his play, being helpful, responding to communications, and copying Rawiri's play ideas.

Week Four: All Behaviour is Communication

As Marama had mentioned wanting to understand some of Rawiri's actions (e.g., clapping objects together, climbing, biting) in week three, the discussion topic in week four explored the concept of all behaviour being a form of communication, outlining ways in which parents may be 'communication detectives'.

Week 5: Parent Wellbeing

The first session in week five was intended to consist of both direct therapy and a parent education session. As Marama was generally feeling 'run down', it was decided that the session would instead be a 45 min discussion of the topic focused on parent Hauora/Wellbeing. Strategies included tips for Marama to prioritise her own health and wellbeing. A bonus session two days after the home visit focused on 45 min of direct therapy within the university clinic with 15 min at the end for Marama to ask questions. The therapist provided Marama with a booklet during this session outlining support services available in her local area and offered to discuss these further in the final programme session.

Week Six

No new topics were introduced in week 6. Instead, the parent education time consisted of a wrap-up of the programme, discussion of next steps, and time for questions.

7c. Attendance, Helpfulness of Adaptations, and Social Acceptability

Marama and Rawiri attended and participated in 100% of the core programme sessions. To assist attendance, the therapist offered flexibility in rescheduling, changing locations, answering and responding to questions via phone or email between sessions, and on one occasion finishing the session early. Of the additional three ‘bonus sessions’ at the university clinic, two were cancelled due to either therapist illness or a conflicting appointment for Marama and Rawiri. The results from the check-in survey completed in weeks four and six are provided in Table 5.3. The results suggest Marama viewed the programme positively. Marama’s responses indicate that Rawiri was both happy and willing to attend programme sessions. Marama rated all but one adaptation as “very helpful”. The remaining item (Item 7) was rated as “helpful”. The full list of the adaptations included in the adaptation helpfulness survey are provided in Table 5.1.

Table 5.3

Marama's check-in survey responses for timepoint 1 (week 4) and timepoint 2 (week 6).

Question	Timepoint	Response				
		Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. My child is benefitting from this programme	Week 4					X
	Week 6					X
2. My child did not want to take part in today's session	Week 4	X				
	Week 6	X				
3. It has been easy to bring my child to today's session	Week 4					X
	Week 6					X
4. The programme is not right for my family/whānau	Week 4	X				
	Week 6	X				
5. I did not want to bring my child to today's session	Week 4	X				
	Week 6	X				
6. My child was happy to come to today's session	Week 4					X
	Week 6				X	
7. It has been difficult to bring my child to today's session	Week 4	X				
	Week 6	X				
8. I feel positive about my child participating in this programme	Week 4					X
	Week 6					X

9. This programme is a good fit for my family/whānau	Week 4		X
	Week 6		X
10. I feel negative about my child participating in this programme	Week 4	X	
	Week 6	X	

Note. The check-in for week 4 was completed during a session at the university clinic. The check-in for week 6 was completed during a session at home.

The results of the TARF-R social validity questionnaire are presented in Table 5.4. The results suggest that Marama found the adapted programme to be socially acceptable, as indicated by a total acceptability score well above the midpoint (i.e., 60 or higher). Post-delivery of the support programme, Marama gave the lowest rating to the reasonableness domain (although still scored this above the midpoint), and the highest ratings to both effectiveness and absence of side-effects.

Table 5.4*Results of pre- and post-support TARF-R*

Scales/Subscales	Pre-support	Post-support	Maximum possible score
Total acceptability	107	107	119
Reasonableness	18	15	21
Willingness	18	18	21
Side-effects#	21	21	21
Effectiveness	18	21	21
Disruption/time#	18	18	21
Affordability	14	14	14
Understanding*	7	4	7

Note. # Includes items which are reverse scored so that a higher score indicated a more favourable rating. *Not included in Total Acceptability Score.

7d. Whānau (Family) Experiences

Marama participated in a 30-min semi-structured interview the week after the programme had ended. Analysis of the interview transcript resulted in four themes: (a) balance, (b) engagement and connection, (c) knowledge sharing, and (d) structure. Each of these themes are explored below:

Balance

Marama expressed a clear desire for greater balance in specific aspects of the support service such as location of service delivery. While Marama expressed that having the initial session in her home was “perfect”, she also discussed a preference for greater variation in locations; “you know, it would have been good one week at home and one week in the clinic just to find a balance”. Marama was also concerned that her home was “a little bit disorganised”, whereas she felt the university clinic had “less distractions”. This desire for greater balance was also present in Marama’s reflections on observing direct therapy. While Marama felt that “just observing how [the therapist] was engaging with [Rawiri] was really good”, she also would have liked to have had the opportunity for the therapist to observe the ways she played and engaged with Rawiri; “We’re getting introduced to all this child play but if [the therapist] actually see the person and the child engaging with each other, seeing where they’re going and maybe [giving] advice”. Overall, however, Marama described the adapted programme as “very helpful”, adding that she would “...recommend it to anyone else that I come across”.

Engagement and Connection

One of Marama’s key goals for the programme included learning ways to increase moments of engagement with Rawiri. The term ‘engagement’ was frequently mentioned throughout the interview, both in terms of factors which supported engagement and those which distracted from it. Marama noted that an aspect of the programme she really liked was

the way “[the therapist] really engaged well with [Rawiri] in the home. She made that space for him” and reflected that observing the ways the therapist engaged with Rawiri gave her ideas and strategies to “...try and incorporate with [Rawiri]”. Marama noted a link between engagement and forming a connection, stating that she “...saw the engagement going on and [Rawiri] actually looking at [the therapist], [there was] trust” and added that “[Rawiri] gave [the therapist] a hug on her second visit, and it’s just like – wow!”. Marama would have liked to have had the opportunity to share with the therapist the ways she engaged with Rawiri, stating it would be beneficial for the therapist to “see how that engagement’s going with the grandparent or caregiver”. Marama highlighted that “home’s where the heart is”, therefore it was important for the therapist to have an understanding of how the whānau (family) were already “engaging with one another to create wellbeing and a sense of belonging”.

Marama also discussed challenges with engagement, both those she noted while observing the therapist and Rawiri, and her own experiences when engaging with Rawiri. Marama recalled observing during a clinic session that “[Rawiri] had stuff in his hands, and [the therapist’s] trying to engage with him, but he’s like [makes an ahh noise]. That’s actually quite a distraction”. Marama described “trying to engage with [Rawiri] more” and feeling as though there were times that she was unsuccessful which was “frustrating”. Marama was highly motivated to continue finding moments of engagement with Rawiri, noting that “where there’s a will there’s a way.”

Knowledge: Learning and Teaching

Broadly, Marama discussed the knowledge she had gained, knowledge she would have liked to share with others, and areas in which she hoped to learn more. Marama described feeling as though she “was a foreigner” when first coming to the university clinic, explaining she “didn’t know nothing [sic] about [autism]”. Joining the programme had felt for Marama “like... going to school for [learning about] Rawiri”. Marama went on to explain

that she had “actually learnt quite a lot” from the therapist, though she also felt she needed “more education”. According to Marama, the programme had given her “the basics that I need to know”, however she felt as though she still didn’t “really understand [autism]”. Marama described the programme as having given her some “methods or tools” which “were not a lot, but it’s something to start with”. Additional education on “how to change” some of Rawiri’s actions (e.g., kicking, biting) which could potentially lead to Marama or Rawiri getting hurt would have been helpful as Marama expressed feeling “really guilty because I’m telling him to stop it and he just doesn’t get it”. Marama mentioned feeling she “appreciate[d] [Rawiri’s] toys more” at the end of the programme and had learnt to reduce distractions during play by putting toys “in stacks” or “up high”.

Marama also described sharing the knowledge she had gained during the programme with whānau (family), stating “I’ve been showing them [whānau/family] the tools”. Marama felt as though her whānau (family) “enjoy[ed] the knowledge” adding that she had learnt to “incorporate” providing suggestions (e.g., “try it this way”) when observing play interactions between whānau (family) and Rawiri. Marama expressed that the programme was “so different” to services being received through a government agency, adding “[the government agency] have a different whole approach” and that though the government agency focused broadly on education, she had “learned more from [the therapist]”. Marama felt that the other agency needed to “jump on board” as the university clinic were “doing the research”. She explained that the other agency seemed to not “really understand who the university clinic are, or what they are”, and it may be helpful if the clinic were to offer to “upskill what it is that people [from the other agency] are doing”. At a much broader level, Marama believed that “the [government agency], the public health system, needs to try and jump on board” with the work occurring at the university clinic.

Structure

Marama reflected that clearer expectations and greater structure would have been helpful for her. Marama shared that at the start of the programme “I didn’t know what I was getting myself into”. In part, she had wanted “everything to happen there and then”, but as the programme progressed, she had “started getting really tired”. Marama felt that it would have been helpful for the therapist to add greater structure to sessions and “[provide] a guide, a list. Like, this is what [the therapists] prefer to do within the home. Have less distractions, have a clear area where [the therapist and Rawiri] can go to, just knowing what is expected”. Marama expanded upon this by adding that “it’s being prepared for when [the therapist] comes [to the home]”. Marama also indicated a desire for more structure in regard to activities and focus within sessions. For example, she described seeing child-led practices happening “in the Kindy” but noted that the kindergarten had greater “structure” than the programme. Marama explained that she felt there were “too many distractions in the clinic” and that she would have preferred “if we can just focus on one or two things [activities]... for the session”.

Subtheme: “I feel it needs to take another step up”

Marama had observed the programme to be “all about play therapy” and “the child’s leading”, which was “good”, however she felt the programme “needs to take another step up”. Marama further described a desire for more modelling of play skills within the programme, stating that “it’s trying to show [Rawiri] what you want him to be doing instead of hop in, however it goes”. For example, Marama shared her preference for the therapist to “actually show [Rawiri] what the pot’s for, what the food’s for, and put it on the stove so he’s got an idea of pretend play”. Marama suggested that the child-led play could have a “timeframe”, as “being a guider or teacher” for Rawiri included knowing when to say, “okay that’s enough now”. Wanting more adult-led interactions was particularly relevant when it

came to Rawiri banging blocks, as Marama felt it was “just best to stop it”, adding “I’d be intervening on that [banging the blocks] straight away and trying to go somewhere else with him”. Additionally, Marama noted that “with [Rawiri], he makes a lot of sounds and I’ve noticed [the therapist copy] those sounds and it’s like... let’s try and move to the next [activity]” as from her perspective the sounds were “a distraction”. Marama explained that “if [Rawiri] had his way, he’d just be tapping those things [wooden blocks] for hours” and that from her experience this indicated Rawiri was “stimulated”. Marama would have preferred for the therapist to provide “another step” to the play and “try and distract that and try to bring him back down”.

8 Complicating Factors

The increased flexibility inherent in the adapted programme presented some practical difficulties when it came to programme delivery. The therapist aimed to offer flexibility to meet whānau (family) need in terms of location for programme delivery. However, rooms at the university clinic had limited availability for the day/s and time/s which worked best for Marama and Rawiri. This made it difficult to reschedule missed “bonus sessions” within the six weeks of programme delivery. These sessions were additional to the planned programme sessions and therefore no content was missed. However, had these sessions gone ahead it would have added to the number of sessions provided at the university clinic potentially achieving the balance Marama mentioned wanting in the interview.

In the initial assessment meeting with Marama, the therapist had briefly gone over the flexibility and choice built into the adapted support programme. Options of how the programme could be delivered were described including direct delivery to the child, parent education or coaching, and teacher coaching. Though Marama expressed interest in teacher coaching, it was interpreted by the therapist at the end of the initial assessment that a mixture of parent education/coaching and direct therapy was the preferred delivery method. This led

to a misunderstanding between the therapist and Marama as to whether educational support in the form of teacher coaching was being provided. Though the therapist had planned for a second “initial assessment” meeting prior to the programme beginning, this conflicted with the whānau (family’s) desire to begin receiving support immediately. Putting the details of the delivery methods in writing would have given Marama the opportunity to clarify her desire for teacher coaching. Though teacher coaching was not provided during this case study, the therapist did electronically share all programme resources with Rawiri’s early childhood teachers and offered to answer any questions they may have.

9 Access and Barriers to Care

Given the high rate of programme attendance, there did not appear to be insurmountable barriers to programme access. However, Marama expressed at the start of the programme that she would have liked for other whānau (family) members or a family friend to participate in the programme alongside her. During week three of the programme, Marama explained that due to shyness, uncertainty regarding speaking with a professional, and scheduling conflicts, it would not be possible for whānau (family) or friends to participate. This indicates barriers to access still likely remained to including broader whānau (family) in the programme.

10 Follow-up

Throughout the programme, Marama reported wanting to gain further knowledge and understanding of Rawiri by speaking to an autistic adult. An autistic person who had previous experience supporting parents to understand autistic children met with Marama and the therapist in a follow-up session two weeks after the programme had concluded. A wide variety of topics were discussed, including childhood experiences, autistic and non-autistic brain differences, how to break down tasks, an explanation of sensory needs, tips to make travel easier, and the ways independence can look different for each person. Marama

expressed that she found this meeting “very helpful”, and that it had given her a deeper understanding of Rawiri and of autism.

11 Implications

This case study explored the experiences of one lower financially resourced family receiving an adapted autism support programme designed to increase accessibility. Quantitative results indicated that Marama reported that she found the programme to be acceptable, and the adaptations were generally perceived to be very helpful. Therefore, it is possible that other lower financially resourced families may find similar adaptations successful and helpful. Additionally, Marama’s 100% attendance rate for the core programme sessions indicated the programme was accessible for this whānau (family). Qualitative data provided additional context to understand nuances in the whānau (family’s) experience and allowed Marama an opportunity to make suggestions for future changes. Results of this case study also add to evidence that autism support services may be successfully adapted to meet the needs of lower financially resourced families.

Marama’s reflection of her experiences in the support service highlighted the importance of flexibility and variety in both setting and delivery method. It may not be possible for all service providers to offer the same degree of flexibility as was offered in this case study. However, it may be useful for providers to consider the ways in which they could sustainably give families greater choice in how or where a service is delivered. Additionally, though Marama viewed child-led play as “good”, she expressed a clear desire for greater structure and teaching within the programme. This indicates that for some families, child-led play strategies alone may not be sufficient.

This case study emphasises the need for greater understanding of the barriers to autism support faced by whānau Māori (Māori families). As noted by Tupou et al. (2022), there is a lack of culturally appropriate services in Aotearoa New Zealand which meet the

needs of a broad range of whānau Māori (Māori families) with tamariki takiwātanga (autistic children). Though the therapist in this case study had some knowledge of Te Ao Māori (Māori world views) delivery of the programme may have been enhanced by a greater knowledge of specific concepts. For example, the concept of ako (to teach and learn) refers to a relationship of reciprocal learning, where the teacher and student both bring knowledge and learn from one another (Keown et al., 2005). Had this concept been embedded into the programme, it may have aligned with Marama's desire to have opportunities to share her own ways of engaging and playing with Rawiri. There was evidence that Marama appreciated the time taken to build whanaungatanga (relationships), noting the trust that had developed between Rawiri and the therapist. Given whanaungatanga is highly valued within Māori culture (Mana, 2023), it is important that additional time be allocated for providers to build relationships with the whānau (families) who access their services.

12 Recommendations

This case study highlights some of the benefits and challenges in providing adapted autism support services to improve accessibility for lower financially resourced whānau/families. Although Marama generally rated the programme adaptations as 'very helpful', there were challenges posed by the increased flexibility inherent to programme delivery. Due to the number of choices whānau (family) could make throughout the programme, there was less structure which was noted as being a challenge for Marama. In future, finding ways to increase the structure of a programme while maintaining flexibility and choice may be important. For example, preparing a list of educational topics prior to the start of the programme from which families could choose and/or providing a visual overview of programme sessions indicating where choices could be made may be helpful.

Typically, research examining adaptations to autism support programmes has not changed the core elements of the adapted service (Carr & Lord, 2016; Pickard et al., 2019).

Delivery of standard Early Start Denver Model (ESDM) or Parent-ESDM (P-ESDM) is typically provided over 12 weeks (Rogers et al., 2012, 2021), and focuses on the therapist implementing, or coaching parents to use, all 12 ESDM fidelity items (Rogers & Dawson, 2010). This case study focused primarily on play partnering strategies, such as following the child's lead, over a six-week period. Several qualitative P-ESDM studies have found that parents often desire longer periods of coaching with a greater number of topics covered, across 12, 14, and even 20-week programmes (Qu et al., 2022; Seo et al., 2022; van Noorden et al., in press; Waddington, van der Meer, Sigafos, & Whitehouse, 2020). The optimal programme duration, delivery method, and included content for P-ESDM programmes is yet to be established and likely differs across families.

This case study was novel in that it adapted the ESDM programme to be six weeks in length and was designed to meet the immediate needs of the whānau (family) while awaiting further services. Additionally, the therapist elected to prioritise relationship building with whānau (family) while also delivering content directly relevant to current whānau (family) areas of interest. There appears to have been good validity and acceptability of this approach with the family involved. However, given that the whānau (family) desired a longer programme duration and more advanced topics, further research needs to be conducted on adapting ESDM programmes to best meet the needs of a wide range of whānau (families). Potentially, there may also be a need for therapists to provide greater clarity as to what can be provided and/or accomplished when a short (i.e., 6 week) programme is delivered.

There were limitations to this case study. The therapist delivering the programme was trained, but not certified, in ESDM. It is possible that a more experienced therapist may have been better able to build more structure into the programme while still maintaining flexibility to meet whānau (family) needs. Additionally, only the relationship focused strategies from ESDM were utilised. Although some relationship focused strategies (e.g., management of

attention, dyadic engagement, increasing child motivation, and sensitivity and responsivity) have had positive associations with improving child engagement and skill acquisition in previous research (Waddington, van der Meer, Sigafos, & Whitehouse, 2020; Zitter et al., 2021), it is possible that using more elements from the ESDM would have improved the experience of the programme. For example, as Marama's goal was to increase engagement between herself and Rawiri, an ESDM curriculum checklist was not used. However, it may have been helpful to utilise the curriculum checklist to break this goal down and identify complimentary accompanying goals. Similarly, the therapist did not use or coach Marama to use behavioural teaching strategies. It is possible that such strategies may have helped Marama to target her goals more effectively. As the aim of this case study was to identify the helpfulness of adaptations to improve accessibility of the programme, and whānau (family) experiences, no data were collected regarding Rawiri's engagement levels prior to, or at the end of, the programme, nor was adult fidelity to the ESDM measured. Future research would benefit from including relevant child and parent measures.

Overall, this case study suggests that the adaptations made to improve the accessibility of an autism support service for lower financially resourced families were helpful to this particular whānau (family). This programme provided Marama with immediate support that was individualised based on her own knowledge of her grandchild and her whānau (family) needs. This case study contributes to the extant literature examining the ways in which autism support services may be individualised and made more accessible for families.

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Declaration of Conflicting Interests

Carla Wallace-Watkin delivers community therapy at the university affiliated clinic described in this study. Lauren van Noorden and Jessica Tupou are both senior staff members and Hannah Waddington is the clinic lead of this same service.

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CHAPTER 6

GENERAL DISCUSSION

Current literature emphasizes the importance of providing early support services to young autistic children (Ben Itzhak & Zachor, 2011; Brasher & Stapel-Wax, 2020; L. K. Koegel et al., 2014). Early support services, including speech language therapy, occupational therapy, and play-based therapy (Kasilingam et al., 2021), are generally aimed at helping autistic children with their development in areas of potential difficulty. For many autistic children and young people, support services appear to result in improvements in the areas of emotional regulation, motor skills, anxiety, daily living skills, and/or communication (Duncan et al., 2018; Linden et al., 2023; Ruggeri et al., 2020; Shire et al., 2020; Weiss et al., 2018).

Despite the potential benefits of autism support services, there are clear disparities in the rates of access for different families. Research indicates that lower financially resourced families access and/or participate in autism support services at a reduced rate compared to higher financially resourced families (Nguyen et al., 2016; Smith et al., 2020). This is despite evidence which suggests autistic children from lower financially resourced families are at a greater likelihood of having difficulties with mood, behaviour, and/or receptive and expressive communication (Mayes & Calhoun, 2011; Olson et al., 2021). Thus, these reduced rates of access and participation are not likely to be due to reduced needs for lower financially resourced families.

The current thesis aimed to understand the factors which may be impeding access to, and/or participation in, autism support services for lower financially resourced families. First, a qualitative systematic literature review was conducted to gain a broad overview of the potential barriers and facilitators lower financially resourced parents experience to autism support services internationally. Based upon the thematic findings of that literature review, a

survey was designed to allow for a quantitative examination of the total number and extent of barriers and facilitators experienced by Aotearoa New Zealand whānau and families when accessing and/or participating in autism support services for their autistic children (Study 1). Study 2 used a qualitative methodological approach to gain a deeper, more nuanced understanding of lower financially resourced families experiences of barriers and facilitators, and suggested adaptations, to an autism support service. A set of adaptations were developed based upon the semi-structured interviews with parents, suggestions of community partners, and researcher knowledge of the literature. Finally, Study 3 piloted an adapted support programme with a single whānau based on the list of adaptations developed in Study 2. The sequential nature of the three studies allowed for a comprehensive examination of the differing factors influencing support service engagement among lower financially resourced families with young autistic children in Aotearoa New Zealand.

The research questions for each study in this thesis are listed below:

Qualitative Systematic Literature Review Questions

1. What do parents from underserved populations (i.e., lower financially resourced, immigrant, located in lower resourced settings, underrepresented ethnic or racial groups) perceive to be the barriers to support services for their autistic child?
2. What do parents from underserved populations (i.e., lower financially resourced, immigrant, located in lower resourced settings, underrepresented ethnic or racial groups) perceive to be facilitators to support services for their autistic child?

Study 1 Research Questions

1. What types of barriers do Aotearoa New Zealand parents report experiencing when accessing and/or participating in support services for their autistic child?
2. What factors do Aotearoa New Zealand parents report as facilitating their access to, and/or participation in, support services for their autistic child?

3. Are there sociodemographic factors (e.g., lower or higher family financial resources, Māori or non-Māori, child age) that relate to the types, number, and/or extent of barriers and/or facilitators to support services reported by Aotearoa New Zealand parents of an autistic child?

Study 2 Research Questions

For lower financially resourced families who have received Early Start Denver Model (ESDM) services from a university affiliated clinic:

1. What were the barriers and/or challenges of receiving ESDM service/s?
2. What were the advantages and/or positives to receiving ESDM?
3. What kinds of changes and/or adaptations do parents and/or a research-community partnership suggest enhancing the fit of the ESDM service to this specific population?

Study 3 Research Questions

The following questions pertain to one lower income parent with an autistic child:

1. How does the parent describe their experience of receiving an adapted ESDM-based service?
2. Does the parent find an adapted ESDM-based programme acceptable?
3. How helpful does the parent find the adaptations to the ESDM-based programme?

This chapter consolidates the results of each individual study to provide a comprehensive analysis of the collective findings. It includes the integration of qualitative and quantitative data and provides an overview of lower financially resourced family's experiences accessing support services for their young autistic children. Barriers, facilitators, and insights gained from parents and community partners are explored alongside the subsequent outcomes of the case study piloting the adapted autism support service. Results

are interpreted alongside extant literature, with implications, limitations, and proposed areas for future research explored.

Barriers and Facilitators to Autism Support Services

Although parents may place importance on their young autistic children receiving early support services (Bent et al., 2023), there has previously been very little acknowledgement of the potential barriers to accessing and/or participating in such services. Qualitative research has suggested that lower financially resourced families experience compounding barriers to support services (Stahmer et al., 2019). Despite this, it appears as though some providers make assumptions regarding lower financially resourced families' apparent decreased engagement in autism support services (Tomczuk et al., 2021). For example, it appears that lower financially resourced families may not be given equal opportunities to participate in parent coaching (Straiton et al., 2021). This in part may be due to the view of some clinicians that parents from lower income households are more difficult to engage in parent coaching, are 'checked out', or are a poor fit for the approach (Tomczuk et al., 2021).

Prior to this thesis, there does not appear to have been research quantifying the number and extent of barriers to autism support services experienced by parents from differing sociodemographic backgrounds. The results of Study 1 suggest that the types of barriers parents face may be similar across sociodemographic groups, however lower financially resourced families experience significantly more barriers and experience those barriers to a greater extent. Aotearoa New Zealand presently has high rates of income inequality and child poverty (OECD, 2022). Additionally, individuals from underrepresented racial and ethnic groups, such as Māori and Pacific peoples, are more likely to reside in lower income households (Statistics New Zealand, 2022). Therefore, it appears particularly

important to understand the experiences of lower financially resourced families with autistic children when seeking to access autism support services in Aotearoa New Zealand.

Barriers and Facilitators: Two Sides of the Same Coin

Given the need to examine the potential ways in which barriers may be reduced, both barriers and facilitators were explored in each of the studies in this thesis. Broadly, the analysis of results within and across studies revealed barriers and facilitators which mirrored one another. For example, results from Study 1 suggested that a lack of clarity in service pathways posed a significant barrier to support service access. In comparison, parents across the studies included in the literature review shared that receiving guidance which clarified service pathways was facilitative. Similarly, across studies providers who were warm, empathetic, and able to clearly communicate appeared to facilitate parent access to, and participation in, autism support services. However, the results of the literature review presented in Chapter 2 of this thesis (herein referred to as the Literature Review) suggested that providers who broke parent trust, were dismissive of concerns, or who did not communicate clearly posed barriers to support services.

The following sections will provide an overview and description of the barriers and facilitators to autism support services as reported by Aotearoa New Zealand parents of autistic children across the studies in this thesis. Similarities and differences between the findings of these studies and the broader literature, including the systematic Literature Review in Chapter 2, will be discussed.

Differing Preferences and Needs: Service Flexibility

The qualitative studies in this thesis (Study 2 and 3, Literature Review), identify a need for flexible, individualized services to meet a range of parent preferences and family needs. It was clear that what worked for one family may not work for, or be wanted by, another family. For example, Lyla (Study 2) expressed that receiving support services via

telehealth would have been ‘perfect’, while Rose (Study 2) preferred to receive support services within the university affiliated clinic. Differences in preferences extended to the number of support sessions received per week, the time and days which parents preferred to engage in support services, and the method used (i.e., delivery via group versus direct therapy). These findings also align with a recent study conducted by van Noorden et al. (in press) in which five parents from the same university affiliated clinic shared mixed preferences and suggestions for the tiered version of Parent Early Start Denver Model (P-ESDM) they had received.

Needs may also vary for a parent from session to session. This was apparent in Study 3, with examples including: a desire to split sessions between the family home and the university affiliated clinic, a need for the therapist to work directly with Rawiri to allow for Marama to meet with a new provider, and flexibility to end sessions early where whānau (family) were feeling fatigued. This indicates a need for services which are flexible enough to adapt to the changing needs of a family. However, it is important factor for providers to consider the increased need for clear communication, as highlighted in Study 3, to ensure a balance is found between programme flexibility and structure.

Navigating Service Systems: The Search for Support

Difficulties navigating complex service system pathways were common for parents across the studies in this thesis. The quantitative results of Study 1 indicated that, regardless of family level of financial resourcing, factors related to navigating service system pathways, such as difficulties gaining referrals and lengthy waiting lists, were experienced to a significantly greater degree than most other barriers. Results from Studies 2 and 3 further illuminated the challenges posed by support service systems, including the sense of pressure parents felt to ‘figure out how to help’ (Grace) their children in Study 2. Marama (Study 3) described the difficulties she had encountered when trying to communicate with agencies

who were not responding to her queries for support. Barriers posed by unclear service pathways are not unique to Aotearoa New Zealand. In the Literature Review, parents from a range of countries described the challenges of trying to navigate complex service systems. Additionally, in research conducted by A. Brewer (2018), the time and effort needed to coordinate an autistic child's care had led to some parents, particularly mothers, reducing their hours in paid employment. The challenges associated with navigating service systems within Aotearoa New Zealand may be exacerbated by the scattered nature of autism support services across several different government agencies (Htut et al., 2020).

Collectively, the results from both Study 1 and Study 2 highlight potential strategies for addressing the challenges associated with unclear service system pathways. In Study 2, Rose recommended that an increase in advertising of autism support services would be helpful. This aligns with research conducted by Pickard and Ingersoll (2016) which indicated that service use is in part influenced by parents' levels of service knowledge. The calculation of percentage overlap between differing barrier and facilitator pairings in Study 1 provided insight into the factors which frequently occurred simultaneously. Results indicated that the barrier of lengthy waiting lists (an aspect of navigating service pathways) co-occurred most frequently with both ease of communication with providers and parental ability to advocate for their child. The directionality of these relationships - for example whether parents were attempting to overcome lengthy waiting lists by communicating with providers and advocating for their child - was unclear. Though it is not possible to determine from Study 1 whether parents were utilising facilitative factors to overcome barriers, research conducted by Smith-Young et al. (2022) indicates this may be the case. The 15 parents in Smith-Young et al.'s (2022) study were asked, in semi-structured interviews, about their advocacy experiences relevant to their autistic children. Parents reported a need to 'fight' for services

for their children, and to maintain a ‘watchful’ eye to make sure their child’s service needs were being met (Smith-Young et al., 2022).

Waiting Lists

Lengthy waiting lists, a factor related to navigation of service pathways, were identified as a significant barrier to support services across the studies in this thesis. Quantitative evidence from Study 1 (Chapter 3) indicated that lengthy waiting lists were experienced to a significantly greater extent across all parents than the majority of other barriers to support services (i.e. all except barrier statements B27 and B28; see Appendix E Table S10). The barriers posed by lengthy waiting lists were reiterated within the Literature Review, as well as Studies 2 and 3. For example, Aaden (Study 2) expressed that when he had tried to find support for his child, he had been told there were waiting times of “...six months, eight months, one year? I need help now” (p. 116). These results add further support to previous research findings suggesting that wait lists pose a barrier to autism support services (Bent et al., 2023; Birkin et al., 2008; Lim et al., 2021; Sun et al., 2013). Where waiting lists cannot be reduced, finding ways to support parents while they are awaiting services for their autistic child, such as the regular wellbeing calls suggested by Aaden (Study 2), would be a logical next step. It would be important, however, to be clear that this form of support does not act as a substitute to the family receiving an evidence-based autism support service (Rivard et al., 2017).

The Cyclical Nature of the Search for Support

It is important to consider the potential for reoccurrence of the barriers described by parents each time a new or additional support service was sought for their autistic child. Several parents in Study 2 described that upon completing participation in an early autism support service, their search for what would ‘come next’ started over again (Liam, Rose, Grace; Study 2). Additionally, Rose (Study 2) expressed that the emphasis on early autism

support had left her feeling uncertain of next steps once her children aged out of the service. These sentiments are similar to those shared by parents in a study conducted by Bent et al., (2023) who felt ‘abandoned’ upon completion of an early autism support programme, and ‘really confused’ about next steps. A number of the recommendations parents made in Study 2 and 3 would likely be relevant to reducing barriers, and increasing facilitators, *across* services.

Knowledge, Information, and Education

Access to, and/or accumulation of, knowledge, information, and education influenced parent experiences of their child’s autism support services. Collectively, the statements related to the subtheme of knowledge and education in Study 1 were rated as the second greatest barrier to support services in Aotearoa New Zealand. This subtheme included uncertainty as to the kinds of support services available and which support services may be most relevant for an individual child (Study 1). A lack of information regarding available support services may in part be due to, as Rose mentioned (Study 2), limited advertising of such services. Additional causes may be limitations in provider knowledge of autism, support services, and/or referral pathways, (Malik-Soni et al., 2022; McCormack et al., 2020). In research conducted by Birkin et al., (2008), parents were less likely to be aware of, and to participate in, an Aotearoa New Zealand support service if they were not members of the agency delivering the programme. This indicates a need for much broader dissemination of support service information.

Timing was also a key factor in the provision of information to parents. In Study 2, parents explained the challenges incurred when receiving information at the same time as receiving their child’s autism diagnosis. Additionally, the information provided was perceived by parents as not helpful given the majority was not autism specific. Parents noted that the provision of the information, typically at the same time a child received a diagnosis,

was ill-timed as parents were overwhelmed. Several studies within the Literature Review reported that parents appreciated providers who were able to follow-up with a family regarding any questions they may have. If this kind of service were to be introduced amongst diagnostic providers, a follow-up call to a family could be a more opportune moment to check whether parents have the information they need to access autism support services for their children.

Having knowledge and information related to autism and/or autism support services appeared to be a facilitative factor for Aotearoa New Zealand parents when accessing and/or participating in services for their children. Within the Literature Review, several studies discussed how parents gained information through online searches and/or speaking with other parents of autistic children (Lee & Meadan, 2021a; Pearson & Meadan, 2018; Stahmer et al., 2019). Parental ability to advocate on behalf of their autistic child also appeared to be connected to levels of knowledge and information (Literature Review). Indeed, in a review of the literature related to parental experiences of advocating for their autistic children, Boshoff et al., (2018) found that parents used self-education in preparation to advocate for their autistic children to receive relevant support/s. Additionally, it appeared that in two of the studies included within Boshoff et al.'s (2018) literature review, families who were lower financially resourced tended "to have less access to resources, information, and support" (Boshoff et al., 2018; p. 156; Jegatheesan et al., 2010; Lalvani, 2012). Results of Study 1 suggest that parents find the ability to advocate on behalf of their child to be the single most helpful factor when accessing and/or participating in autism support services. Therefore, addressing the imbalances in availability of relevant resources, information, and education between lower and higher financially resourced families would be an important step towards easing the present inequity inherent in autism support service access.

Parents in both Studies 2 and 3 indicated a desire for wider dissemination of the knowledge and information they had gained during their participation in an early support service. Interestingly, research suggests that parents themselves may share their knowledge and educate others within the community about autism post their participation in support services (Boshoff et al., 2018). Indeed, Marama in Study 3 discussed sharing the strategies she had learned with her whānau (family). As Marama noted she would have liked for her whānau (family) members to be involved in the support service sessions, sharing her new knowledge may have been one way of including her whānau in the service.

Numerous factors may present barriers to participation in support services for extended whānau (family). In recent research conducted by van Noorden et al., (in press), limited autism-related knowledge appeared to impede some extended family member's participation in an early autism support service. This may highlight the need to ensure sufficient information and resources are shared with a participating family member to aide their ability to share their new knowledge. An additional consideration in Marama's situation was the indication that her whānau (family) were uncertain about meeting with a professional. In a recent scoping review of the literature related to Māori experiences of autism, Tupou et al. (2021) found that distrust of the service system was a potential barrier to autism diagnostic and support services for Māori in Aotearoa New Zealand. Such distrust is understandable given whānau Māori report experiencing health care services which lack culturally relevant care, leave them feeling unheard, and which do not appropriately address their needs (Inquiry into Mental Health and Addiction, 2019). Ensuring providers work collaboratively with whānau Māori (Māori families) while providing support services which are aligned with whānau (family) needs and preferences is important (Tupou, Ataera, & Waddington, 2023). Ensuring time is taken to develop and build strong relationships appears

to be an important factor for providers working alongside whānau Māori (Tupou, Ataera, & Waddington, 2023).

Additional Education Needs

Ideas and suggestions for additional educational topics were shared by parents in both Studies 2 and 3. Suggestions included a need for additional education on topics such as toilet training, neurodiversity, executive functioning, and/or understanding behaviours which may cause harm or injury to the child or others. Parent requests for specific topics which would align with their child or family's specific needs is not uncommon (Jurek et al., 2022). In a recent study by van Noorden et al. (in press), parents described a need for greater education on topics such as breaking down goals, child anxiety, and sensory challenges. Though the ESDM is a relatively comprehensive support (Rogers & Dawson, 2010), these findings indicate a need for additional content to meet the needs of a range of families.

Parents in Study 2 identified a need for greater dissemination of information and education within the wider community, while Marama (Study 3) indicated the potential helpfulness of information sharing between the university affiliated clinic and Aotearoa New Zealand government agencies. It appears strategies targeted at increasing community knowledge of autism, such as informational videos or online training, may be effective in improving community knowledge of autism and/or in reducing stigma associated with stigma (Gillespie-Lynch et al., 2015; Ha et al., 2022; Nah et al., 2023). An additional consideration mentioned by a parent in Study 2 (Rose) and by Marama (Study 3) was the value of having the opportunity to learn from autistic adults. While Rose actively sought out educational information delivered by autistic people, Marama noted the opportunity to meet with an autistic person had been 'very helpful'. As there appears to be very little in the extant literature related to the ways in which autistic adults may support parent knowledge and understanding of an autistic child, this would be an important area for future research.

Learning Specific Strategies: Parent-Mediated Support

Parents in Study 2 along with Marama in Study 3 discussed the benefits and challenges of learning strategies to support their autistic children. Generally, parents found learning new strategies or ‘tools’ (Grace, Study 2) had been helpful. Marama in particular discussed learning through observing the ways the therapist engaged with Rawiri. This finding aligns with research conducted by Seo et al. (2022), in which a parent similarly reported finding value in observing the ways a therapist engaged with their autistic child. Parents also, however, reported experiencing challenges in implementing strategies and techniques themselves. These included a lack of clarity regarding strategies due to the use of technical terms (Aiden), and difficulty with using strategies consistently (Lylah). Finally, Liam noted that he felt pressured by the need to implement strategies frequently within a short period of time, adding “it’s very exhausting” (p. 123). Findings of a recent literature review conducted by Jurek et al. (2022) indicated that some parents experienced a sense of overwhelm during their time within parent-mediated supports. This indicates providers must remain mindful of potential parent experiences of services and considerate of parent health and wellbeing.

Financial Considerations

Several factors related to the costs of accessing and/or participating in autism support services impacted the lower financially resourced families who participated in the studies within this thesis. Within the extant literature, financial barriers to services included not only the actual cost of a support service, but also co-occurring costs such as transport and/or parking (Hong & Singh, 2019; Masri et al., 2023; Pickard & Ingersoll, 2016; van Noorden et al., in press). Additional financial considerations for lower financially resourced families may include challenges related to food and housing insecurity (Anderson et al., 2023). Both Rose, a single parent of two autistic children, and Aaden from Study 2 reported experiencing

challenges related to co-occurring costs and insecure housing. Both parents were receiving income tested benefits. In Aotearoa New Zealand, individuals supported by income tested benefits appear to be more likely to live in a state of material hardship (Rea et al., 2019). Additionally, Aaden had reported needing to 'sacrifice' employment in order to care for his autistic child. Whilst research conducted by Cidav et al. (2012) examining parental employment amongst parents of autistic children indicated mothers of autistic children are less likely to be employed. Aaden's experience suggest that a child's support needs may also affect a parent's ability to participate in the paid workforce.

As with other barrier/facilitator pairings, factors related to the easing of financial pressure appeared to be helpful for parents when accessing and/or participating in autism support services. In Study 1, statements related to removing financial barriers to services by, for example, providing low cost or free services, were rated the second equal greatest facilitator to support services. Parents in Studies 2 and 3 also expressed gratitude for being able to access a support service either for free or at a substantially reduced rate. However, cost upon completion of a free service, in order to continue participating, appeared to pose a barrier for families in Study 2. Lylah (Study 2) had managed to locate funding which allowed her child to continue receiving paid services, other parents such as Aaden (Study 2) were considering the prospect of exiting the service before they were ready due to being unable to afford to continue. Prior research within Aotearoa New Zealand has suggested that parent choice to begin or continue in a support service for their autistic child may be influenced by the costs of a service (Shepherd et al., 2018). Collectively, the results of the studies in this thesis would seem to provide further evidence of the barriers service-related costs can impose, along with identifying the helpfulness of free or cost-effective services.

Geographic Location

Though location-related barriers were present in several studies within the Literature Review in Chapter 2, factors related to location were not found to be experienced to the same extent as most other types of barriers included in Study 1. This finding may in part be because this particular barrier was mentioned most frequently in the Literature Review by parents who were from lower resourced countries (Dababnah & Bulson, 2015; Lee & Meadan, 2021a). Additionally, previous research suggests that families in rural communities experience several barriers to gaining support services for their autistic children (Antezana et al., 2017). As a limited percentage of parents in Study 1 were from rural communities (11.6%), the results may not be representative of this population. It is also important to note that while location-based barriers did not appear to be experienced to as great an extent as other barriers by Aotearoa New Zealand parents in Study 1, 78% of all respondents, and 85% of lower financially resourced respondents indicated they had experienced at least one type of location-related barrier. Additionally, parents in Study 2 discussed several location-related challenges to accessing an early autism support service including the length of travel times, the cost of transport, and not having a therapist based locally. These findings also align with the results of the Literature Review. Taken collectively, it appears as though some Aotearoa New Zealand parents experience location-related barriers to autism support services, however other types of barriers are experienced to a greater extent. This may in part be due to the fact that Aotearoa New Zealand is a relatively small country in geographic terms, with approximately 16.3% of the population residing in rural areas (Environmental Health Intelligence New Zealand, 2023). Therefore, it may be that there are comparatively fewer areas, and therefore members of the population, which are isolated due to remoteness or inaccessibility.

The Role of Providers

Providers play a pivotal role in the experiences parents have when accessing and/or participating in autism support services for their child. The Literature Review identified that parents, particularly those who were lower financially resourced or from underrepresented racial or ethnic backgrounds, often identified ways in which providers could facilitate or create barriers to support services. Similarly, providers who were dismissive of parent concerns, were unclear with communication, and who lacked warmth, created barriers to autism support services. Results of Study 1 suggested that just over 80% of parents had experienced at least one barrier related to service providers. Rose (Study 2) noted an additional concern related to a lack of consistency in therapists. Rose communicated that she would build “a relationship with a therapist, and then the therapist would change, and then it would be like starting over again” (p. 120). This sentiment aligns with those expressed by parents in the research conducted by Bent et al., (2023), including one parent who stated that they were ‘devastated’ when their initial support service therapist left, and “...then we got a new one and she seemed really switched on, and then she stayed a really short time, so that was stressful” (p. 1301). However, Lyla (Study 2) found opportunities to meet and build relationships with other therapists at the university affiliated clinic she was attending had been helpful when her child’s therapist was away. This suggests that providing parents with chances to meet with other clinic staff may assist in reducing the barriers posed by changes in staffing.

Several personal characteristics of providers were associated with facilitating access and participation in autism support services. The Literature Review suggested that provider characteristics such as warmth, cultural awareness, respect, clear communication, and ability to advocate on behalf of parents, facilitated parent access to autism support services. Further highlighting the important role providers have in parent experiences were the results of Study

1 which indicated that factors related to providers were significantly more helpful in facilitating parents to access services compared to the majority of other facilitator subthemes. Parents in Study 2 noted additional therapist characteristics which had supported their access to a support service including patience, reassurance, and flexibility. Research suggests that relationships with providers are likely key to a parent's level of 'buy-in' to, and experience with, a support service (Freuler et al., 2014). The results of the studies within this thesis may assist providers in understanding the ways in which they can best support parents accessing or participating in autism support services. For example, ensuring providers have the training and knowledge needed to assist parents in navigating support service systems would likely be beneficial.

Therapist and Child Relationship

In addition to valuing their relationships with providers, parents also felt the relationship between their child and the provider was important. Grace (Study 2) shared that her child's experience in a support service was a key factor in whether she chose for her child to continue participating. Parents in both Studies 2 and 3 indicated that a warm, positive relationship between their child and their child's therapist facilitated their child's learning and feelings of safety around others. Marama (Study 3) noted that she enjoyed observing the engagement and relationship Rawiri had with the therapist, and that foundational aspect of this relationship was 'trust'. These findings are similar to those of Bent et al. (2023), which included Australian parents from a range of sociodemographic backgrounds. In the Ben et al. study, parents attributed therapist characteristics such as respect, acceptance, and warmth, as contributing to their child having an enjoyable experience within the support programme. These findings suggest that the relationship between child and therapist is likely important to a range of parents, regardless of family level of financial resourcing.

Child-led play and respect for a child's strengths and interests were particularly important to parents in Study 2. Indeed, Grace (Study 2) shared that she had removed her child from a service in which she had "...felt like my child was a fish being taught to climb a tree. I didn't have a good gut feel as a parent" (p. 120). It is common for parents to want their children to enjoy their time in an autism support service (Bent et al., 2023; van Noorden et al., in press). Study 1 results suggest that therapist/provider recognition of a child's strengths, as well as sharing those strengths with parents, may be a facilitative factor for some parents. However, almost half of parents surveyed (46.15%) indicated they had not experienced a provider who discussed their child's strengths with them or had not found this helpful. This may be indicative of the continued influence medicalised, or deficit views of autism have on the provision of support services (Dinishak, 2016). Collectively, results across studies indicate that a focus on positive therapist relationships with both children and parents may be a powerful facilitative factor to accessing and/or participating in Aotearoa New Zealand autism support services.

Cultural and Linguistic Considerations

Parents in the studies included with the Literature Review, particularly those from underrepresented racial and ethnic backgrounds, highlighted cultural and linguistic barriers to support services. Cultural beliefs, including that autism was a 'curse', a result of poor parenting, and/or was something that could be 'grown out of' all negatively impacted upon parent's decision to seek out autism support services (Birkin et al., 2008; Fox et al., 2017; Guler et al., 2018; Sakai et al., 2019; Stahmer et al., 2019). Despite the clear reference to cultural and linguistic barriers within the Literature Review, the results of Study 1 indicated factors related to such barriers were experienced to a significantly lesser extent by Aotearoa New Zealand parents than all other barrier subthemes. While the proportion of Māori parents who participated in the Study 1 survey was similar to that of the general population (Statistics

New Zealand, 2020a), parents from other underrepresented racial and ethnic groups, such as Pasifika families, were not as well represented. Given that families from underrepresented racial and ethnic groups are at a higher likelihood for also be lower financially resourced (Statistics New Zealand, 2022), it is imperative that future research explicitly focusing on cultural barriers to support services in Aotearoa New Zealand is conducted.

Linguistic barriers were also broadly discussed within the studies included in the Literature Review (Chapter 2), however were less frequently mentioned in Studies 1, 2, or 3. Given that participants in Studies 1 and 3 were required to have a good understanding of English to participate in the survey or support service, and no parent requested a Te Reo Māori translator for Study 2, the results across studies are unlikely to be fully representative of the experiences of Aotearoa New Zealand families for whom English is not their preferred language. One mention of language was made by Aaden (Study 2) related to challenges with the academic terminology used within support service handouts and discussions. This led to an adaptation for Study 3 in which academic language was removed. Additionally, as the family who participated in Study 3 spoke Te Reo Māori, basic kupu Māori (Māori words) were included in programme delivery and handouts. Marama did not share her perceptions of this adaptation, so it is unclear whether she personally found this helpful. Based on results of the Literature Review, it appears as though translation services may be of benefit for those families who require them.

Social Support

Social support appeared to be an important factor influencing parent access and participation in autism support services for their child. Over 83% of Aotearoa New Zealand parents in Study 1 had experienced a barrier related to a lack of social support, such as a family member disagreeing with the support service or parents struggling to locate childcare. Marama (Study 3) and Lyla (Study 2) both expressed a desire for their families to be involved

in support services. As this had not been possible for Marama's whānau (family), she instead had spent time sharing the strategies she had learnt with whānau (family) members outside of session times. Grace (Study 2) mentioned the benefit she had found in meeting other parents of autistic children, finding it a 'very therapeutic' experience. This finding aligns with previous research in which parents have noted the helpfulness of peer and/or familial support to accessing and/or participating in a support service (Fox et al., 2017; Hong & Singh, 2019; Lee & Meadan, 2021a; Stahmer et al., 2019; van Noorden et al., in press). Parents also noted the helpfulness of including other key people in their child's life, for example a child's preschool teacher (Grace), in a support service. This may indicate that wider inclusion in support services of individuals important to the child and family may be helpful.

Adapting Early Autism Support Services

Use of Research-Community Partnerships

There is limited research examining the process of adapting an early autism support service using research-community partnership. Though several studies have explored outcomes related to adapted services for lower financially resourced families with an autistic child (Blake et al., 2017; Carr & Lord, 2016; Rogers et al., 2022; Sengupta et al., 2020), few have elaborated on the process by which adaptations were selected. For example, though Rogers et al. (2022) included parents in their research-community partnership, no details were given detailing the level of input parents had, nor whether they had previously participated in P-ESDM.

Collaborative approaches to research are particularly important when the focus is on a vulnerable population (Pritchett et al., 2022), including those who are lower financially resourced (Demi & Warren, 1995). Research practices which focus on inclusion, such as research community partnerships, encompass the community for whom the research proposes to benefit (Cargo & Mercer, 2008; Jull et al., 2017). An additional consideration for

researchers within the field of autism is the importance of including autistic individuals in the research process (Chown et al., 2017; Fletcher-Watson et al., 2019). Differing levels of community involvement were involved in Studies 1, 2, and 3. Study 1 was predominantly researcher led, with feedback from key stakeholders, including one autistic person, sought for the development of the survey. Study 2 involved greater collaboration with key stakeholders, including one autistic person, through the use of a research-community partnership. This approach is founded on ensuring equal consideration is given to both researcher and community input (Key et al., 2019). Whilst community partners were not a part of Study 3, they had provided the insights and suggestions used to adapt the support service provided.

Collectively, the approaches taken in Studies 1, 2, and 3 would fall within the middle of the hierarchy depicted by den Houting et al. (2021; based upon Arnstein, 1969), in which community partners are informed, consulted, or invited to engage in research processes. This level of collaboration may be viewed as conducting research ‘for’ the autistic community. Greater engagement ‘with’ the community through, for example, the co-production of a research project would ensure greater inclusivity of autistic individuals (den Houting et al., 2021). Future research examining the ways in which pre-existing support services may be adapted to ensure an improved fit between the service and a specific context and/or population would likely benefit from greater involvement of autistic people throughout the process.

The experiences and insight of parents of autistic children are also an important consideration when adapting an early autism support service. Collectively, parents across the studies in this thesis identified barriers that they viewed as impeding their access to autism support services, the factors which had supported their engagement within those services, and the ways in which such services may be improved. Research exploring parent experiences of autism services, particularly those which are parent-mediated, has increased in recent years

(Bent et al., 2023; Seo et al., 2022; van Noorden et al., in press; Waddington, van der Meer, Sigafoos, & Bowden, 2020). It appears, however, that there is limited research in which parent's reported experiences have led to changes or adaptations to a support service. Though the pilot of the adapted service in Study 3 is a start to addressing this gap in the literature, a useful next step may be to implement an adapted programme on a larger scale, to a greater number of parents.

General Adaptations

Parents and community partners in Study 2 had numerous recommendations for how the early autism support they had received (i.e., the ESDM programme) could be adapted to improve accessibility and/or participation for lower financially resourced families. These recommendations generally aligned with previous research examining parents' perspectives of an early autism support service, including offering services online, reducing complex language, focusing on parent-provider relationship, and/or providing additional education on specific topics relevant to the family (Pickard, Wainer, Bailey, & Ingersoll, 2016; Singh & Bunyak, 2019; van Noorden et al., in press). Comparatively novel recommendations included creating a mobile phone application to provide families with autism-specific information, providing well-being checks for parents while they were on autism support service waiting lists, and suggestions to remove neurotypical-based goals (e.g., requiring eye contact) while increasing goals based on child wellbeing and happiness (e.g., a focus on positive child experiences during service sessions).

Adaptations and Neurodiversity

As discussed in the introduction to this thesis, a shift towards neurodiversity affirming practices has led to changes in the autism research landscape. The neurodiversity movement proposes that differences in an individual's thought patterns and ways of processing information are an inherent part of who that individual is (den Houting, 2019). Therefore,

respecting each autistic person's ways of being and perceiving the world is an integral part of this movement (Dallman et al., 2022; den Houting, 2019). However, it is important to note that aligning with neurodiversity-affirming approaches does not mean there is no need for autism support services (Pellicano & den Houting, 2022). Rather, it means reframing the approaches taken in providing such supports. For example, rather than focusing on the ways in which an autistic child could be 'changed' or taught to behave differently, the focus instead is on the ways in which the environment around the child may be altered to better meet the child's needs (Gillespie-Lynch et al., 2017; Pellicano & den Houting, 2022).

Several of the adaptations to an early support service suggested by parents and community partners in Study 2, which were then implemented in Study 3, aligned with the approaches recommended, and perspectives taken, within the neurodiversity movement. There were numerous suggestions for tailoring support sessions, including ending sessions early where a child was tired or unsettled, prioritizing relationships, ensuring the therapist shares their observations of a child's strengths, and recommendations to remove goals which prioritized 'neurotypical' social skills (e.g., eye contact). Parents in Study 2 also appeared to appreciate the child-led nature of the early autism support service they had received. The importance of a respectful, child-led approach to supports was so important to Grace (Study 2) that she had removed her child from services she felt did not respect her child's strengths and interests. Additionally, parents desired a greater focus on goals related to their child's happiness and wellbeing (e.g., promoting autonomy and independence, a focus on child experience of sessions). This aligns with research conducted by Waddington, Minnell et al., (2023) in which autistic adults, parents of autistic children, and clinical professionals rated goals which related to a child's quality of life the highest priority.

There were several challenges to adapting a pre-existing early autism support service to bring greater alignment between the service and the neurodiversity affirming approaches

recommended. Previous research which has examined adapting a pre-existing autism support service to improve access and participation by lower financially resourced families have retained the core elements of the programme (Carr & Lord, 2016; Rogers et al., 2022; Sengupta et al., 2020). However, elements of the support service families had received in Study 2 (ESDM) were not in full alignment with neurodiversity affirming approaches. For example, several goals of the ESDM focus on neurotypical ways of being, such as making eye contact, or encouraging ‘appropriate’ ways of playing with objects (e.g., stacking blocks, rolling cars) or greeting others, and visual supports are withheld until a child is clearly not making progress (Rogers & Dawson, 2010). Due to the brevity of the support provided in Study 3, the decision was made to focus on the relationship-building aspects of the ESDM. In future, research co-designed with autistic individuals examining ways in which NDBSs, such as the ESDM, may be brought into greater alignment with neurodiversity affirming practices would be beneficial.

The focus on relationship-based strategies in Study 3 appeared to have an impact on Marama’s experiences of the programme. Marama’s desire for the programme to take ‘...another step up’ may have been met had the support lasted longer and more directive teaching strategies were used. Recent research conducted by M. K. Jones et al. (2023) found that directive strategies alone (e.g., providing child communication opportunities followed by prompts) led to significantly greater communication outcomes than responsive strategies only (e.g., following the child’s lead and modelling language). Responsive strategies were, however, associated with a greater number and longer length of child supported engagement (i.e., engagement with a mutual focus where the child does not exhibit directed gaze or communication to the adult). Although there are some methodological challenges within the study conducted by M. K. Jones et al. (2023), for example in the ways in which directive and responsive strategies were divided and defined, it may be that the use of responsive,

relationship-based strategies from the ESDM in Study 3 aligned with Marama's goal for increased engagement with Rawiri. However, given it appears as though directive strategies may be useful for increasing communication (M. K. Jones et al., 2023), it is imperative that future research examine ways in which directive strategies may be defined, and the extent to which such strategies align with neurodiversity affirming approaches.

It is also important to consider the ways in which conflicts between parent preferences and neurodiversity affirming approaches may be managed. For example, Marama would have preferred for the therapist to show Rawiri specific ways of playing with a set of wooden foods, pots, and a toy oven; "Instead of hop in, however it goes, it's just actually showing him what the pot's for, what the food's for, and put it on the stove..." (p. 163). However, neurodiversity proponents disagree with teaching an autistic child 'appropriate' ways of playing and instead encourage joining in with what a child is showing interest in (Burch, 2022). Additionally, the survey conducted by Waddington, Minnell, et al. (2023) indicated that early support goals focusing on 'neurotypical' play were not only rated as a low priority but were often deemed to be inappropriate particularly by autistic adults. It would be important for research to explore how providers to may navigate differences between parent preferences and neurodiversity affirming approaches.

Additional concerns some autistic adults have regarding NDBSs are that parents or practitioners may interrupt a child's play too frequently, take over control of activities, insinuate there is a 'right' way to learn and/or may not realise the importance of respecting a child's right to say 'no'. (Autistic Self Advocacy Network, 2021; Schuck et al., 2022). A key element of neurodiversity affirming approaches appears to be the provision of learning opportunities to children that do not seek to teach the child to comply with neurotypical ways of being (Pellicano & den Houting, 2022; Schuck et al., 2022). As evaluation of neurodiversity affirming supports is in its naissance, little is known about ways to balance

and respect parent suggestions and requests while ensuring the delivery of a support is neurodiversity affirming. This is a very important area for future research, which could involve interviews and collaboration with both parents and autistic adults.

Aotearoa New Zealand Context: Māori and Neurodiversity

In adapting an autism support service to the Aotearoa New Zealand context, it is important to consider the needs of Māori (the indigenous peoples of New Zealand). An important aspect of Aotearoa New Zealand's history is the formation of a partnership between Māori and the British Crown through the 1840 signing of te Tiriti o Waitangi (the Treaty of Waitangi; K. M. Brewer & Andrews, 2016). Applicable to the delivery of autism support services in Aotearoa New Zealand is Article 3 of te Tiriti, which promised Māori the same "protection and the same rights as British subjects" (K. M. Brewer & Andrews, 2016; p. 89). This may be interpreted as a right for Māori to have equitable access to support services. Ways of achieving greater equitability for Māori may include the option to receive a support service in Te Reo Māori (Māori language) which takes into consideration Te Ao Māori (Māori worldview; K. M. Brewer & Andrews, 2016). Presently, there appears to be a dearth of Māori-centred support services available (Tupou et al., 2021). There may be several factors which contribute to this. Indeed, within this thesis, funding for Study 1 was insufficient to provide a Te Reo Māori version of the survey. It is likely that broader access to funding to support the delivery of Māori-centred supports is needed.

As Māori perspectives regarding autism have begun to be explored, a link between Te Ao Māori (Māori worldviews) and the neurodiversity movement has emerged (Tupou, Ataera, Wallace-Watkin, & Waddington, 2023). Interestingly, Rose, a Māori parent who participated in Study 2, expressed a strong preference for neurodiversity affirming approaches and education. In Study 3, though Marama expressed wanting more directive teaching, the goals she set focused on her own use of strategies and ways she could adapt to

engage with Rawiri. The Te Reo Māori term coined for autism, *takiwātanga*, meaning ‘in one’s own time/space’, acknowledges autism as a difference rather than a deficit (Te Pou o te Whakaaro Nui, 2019). It may be that aligning services to be more neurodiversity affirming (see Chapter 1 for an overview of neurodiversity) will also assist in helping services fit with some Te Ao Māori perspectives. Further research specific to whether this is the case would be beneficial.

Contributions to the Research Literature

There are several ways in which the research contained within this thesis extend upon and contribute to autism support service literature. Prior to the Literature Review in Chapter 2, there had not been a broad review of the research associated with barriers and facilitators to autism support services experienced by underserved families internationally. This allowed for an examination of barriers and facilitators which were common across differing underserved groups, as well as those which were context specific. Study 1 was the first quantitative exploration of barriers and facilitators to autism support services which included measures of both the number of barriers/facilitators experienced by parents, and also the extent of those barriers/facilitators. Additionally, it was also the first to examine the quantitative differences in experienced barriers and to explore sociodemographic factors as predictors of barriers. While this study suggests that lower financially resourced families experience significantly more barriers, and experience those barriers to a greater extent, than higher financially resourced families, the mean number of barriers experienced across all families (17.54) was still reasonably high. Reducing barriers for lower financially resourced families may reduce barriers for all families.

Studies 2 and 3 both contribute to and extend upon the existing literature examining the usefulness of research-community partnerships in adapting an autism support programme. Study 3 specifically was the first to pilot an adapted autism support service informed by

lower financially resourced parent's experiences and community partners, with the Aotearoa New Zealand context in mind. Study 3 also added to the limited research regarding the experiences of whānau Māori (Māori families) when receiving autism support services for their tamariki (children) or mokopuna (grandchildren). The results highlight the importance of relationships and the provision of clear communication. Similarly, in a case study conducted by Tupou et al. (2022) in which one whānau Māori (Māori family) received an autism support programme, the parent described the relationship with the therapist as 'key' to a positive experience within the programme.

The inclusion of differing methodological approaches across Studies 1, 2, and 3 also allowed for broader contributions to the extant literature. While qualitative research is considered to be context dependent, and therefore lacking generalizability (Denny & Weckesser, 2019), quantitative research may allow for greater generalizability but often lacks nuance (Choy, 2014). Through using both qualitative and quantitative methods, an exploration of parent experiences within a specific programme were explored in greater depth (Study 2 and 3), while Study 1 provided statistical evidence supporting the need for a specific focus on lower financially resourced families.

Implications

The results of the research conducted within this thesis suggest there may be a need for clearer support service pathways. In Aotearoa New Zealand, District Health Boards (DHBs) are funded to employ autism coordinators, with a key focus of this role involving coordination of autism diagnostic and support services for families (Thabrew & Eggleston, 2018). However, it appears as though the capacity of autism coordinators may differ across DHBs. For example, while some DHBs employ full or part time autism coordinators, others add autism coordinator tasks to pre-existing roles. Additionally, few coordinators were involved in navigating post diagnostic support (Thabrew & Eggleston, 2018). In a survey of

516 Aotearoa New Zealand parents conducted by Eggleston et al. (2021), those who had access to an autism coordinator post diagnosis expressed greater satisfaction with autism support services. However, over half of families surveyed (58.7%) had not seen an autism coordinator (Eggleston et al., 2021). This implies a need for greater consistency in referrals to autism coordinators, as well as a greater focus on post diagnostic support.

In addition to the support needed to navigate service systems, some parents reported experiencing lengthy waiting lists upon locating a support service. Study 1 suggests that barriers posed by lengthy waiting lists are not unique to lower financially resourced families, but rather are experienced by parents across sociodemographic factors. It is important that ways to reduce waiting lists are located to improve autism support service access for all families. This may include, for example, increased government funding to autism support services which would allow for the hiring of additional staff, wellbeing phone calls to parents on waiting lists as suggested by Aaden in Study 2, or the creation and testing of brief waiting list programmes. Based on the results of a study by Rivard et al. (2017), it does appear that parent wait list programmes may be helpful, however cannot replace the provision of a full support programme.

Providers play a significant role in the experiences parents have while accessing and/or participating in support services. The results of the studies in this thesis indicate parents appreciate providers who are warm, empathetic, and able to advocate on behalf of families. Given parents in Study 1 indicated advocating on behalf of their child was helpful, ensuring providers have the training needed to provide advocacy services, as well as to support parental advocacy, may be beneficial. Having the ability to provide education on a range of topics potentially relevant to families with an autistic child would also be helpful (Study 2 and 3; Jurek et al., 2022). Additionally, it is important for providers to understand that access to support services is not currently equitable. This may help to reduce the

assumptions made by some providers regarding parent's apparent levels of engagement in autism support services (see, for example Tomczuk et al., 2021). Rather than deciding that a certain service or method of delivery is not a 'good fit' for lower financially resourced families (Tomczuk et al., 2021), it may be more helpful for providers to consider ways of adapting services to reduce the barriers faced by such families. Offering individualized, low cost, culturally responsive, flexible services are some ways in which providers may begin to bring equity to autism support services. At a broader level, it is also important for providers to have access to sufficient funding to be able to make the changes needed to implement adaptations.

Lower financially resourced parents need to be supported to advocate for the autism support services which they feel would be beneficial for their autistic children. However, given parents of autistic children experience high levels of stress (Lievore et al., 2023), it is important to consider ways of reducing the need for parents to advocate. This may, for example, include factors such as reducing wait times, in order to alleviate this burden. The provision of clear autism-related information and education appears to be helpful to parents when accessing and/or participating in support services for their autistic children. Ensuring such information is directly related to autism and support services would be helpful. Importantly, the collective results of this research provide strong evidence that parents know the ways in which they may be best supported. Encouraging parents to share recommendations, barriers, and/or facilitators during service participation may be a helpful way of ensuring a support service is meeting a family's needs.

The results of this research have several implications for educational practice. The challenges associated with transitioning out of early support programmes and into the Aotearoa school system were mentioned by both parents in Study 2 whose children had aged out of the early support service. Though there appears to be a gap in the supports provided to

autistic children during educational transitions, there is very little within the research literature regarding this topic indicating a need for greater research in this area. Furthermore, the results of Study 1 imply lower financially resourced families face considerably more barriers to autism support services. Research which expands an understanding of whether these barriers extend to school or early childhood education attendance and participation would be useful. The current shift towards neurodiversity informed practices has called attention to, and created some debate about, the kinds of teaching strategies used within early support services (Dallman et al., 2022; Schuck et al., 2022). Finding ways of integrating the principles of neurodiversity into teaching and learning approaches while ensuring all children have access to evidence-based educational opportunities will be imperative.

Finally, results of Study 1 indicate that families from a range of sociodemographic background experience barriers to support services. Though Study 1 suggests that higher financially resourced families experience barriers to a lesser extent than those who are lower financially resourced, the types of barriers families faced were similar. This included challenges with lengthy waiting lists and unclear service pathways. Thus, it is likely that adaptations made to support services to reduce barriers for lower financially resourced families will improve service accessibility for all families.

Limitations

Limitations specific to individual studies have been discussed in the relevant chapters. In addition to those already discussed, there were several limitations across the three studies. First, there is potential that the results of each study are not representative of those families who are *very* low resourced. The use of internet-based recruitment across studies may have posed barriers for those families who did not have reliable internet access. Within Aotearoa New Zealand, households with an income of between \$10,001 to \$20,000NZD were less likely to have access to the internet (Digital Government, 2022). Additionally, given the

parents in Study 2 were required to have participated in the services offered by the university affiliated clinic, results may not be representative of lower financially resourced families who experienced insurmountable barriers to accessing the support service, or those who had withdrawn from the service early.

Results of Studies 2 and 3 may not be indicative of the experiences of lower financially resourced families who choose not to, or are unable to, participate in research. Each of the parents in Study 2 had initially gained access to the support services offered by a university affiliated service due to their willingness to participate in research. Additionally, the whānau (family) in Study 3 only had immediate access to the support service due to being willing to participate in research. Though participation in research was not mentioned to be a barrier within the results of Study 1, it would be beneficial to include a specific question related to this factor in future survey-based barrier research.

Results of Study 1 indicated there were no significant differences in the number or extent of barriers and/or facilitators experienced by whānau Māori (Māori families) relative to other ethnic or racial groups. However, research specific to Māori families with an autistic child suggests that barriers posed by a distrust in medical professionals, living rurally, and having limited financial resourced may be more likely for whānau Māori (Tupou et al., 2021). These differences may in part be due to the fact the survey used in Study 1 was not available in Te Reo Māori. Linguistic challenges to participating in the survey may also in part explain the low response rate from Pasifika parents of autistic children.

While Study 1 examined barriers and facilitators experienced by Aotearoa New Zealand parents from differing socioeconomic backgrounds, Studies 2 and 3 focussed only on lower financially resourced families/whānau. As such it is not possible to ascertain whether parents who are higher financially resourced would describe similar experiences with the support service focused on in Study 2 or whether adaptations parents suggest differ

depending upon the parent's sociodemographic background. These factors also apply to Study 3, as it is unknown how parents from a range of sociodemographic backgrounds may have viewed the adapted program. It may be that adaptations made to improve service access and participation for lower financially resourced parents in fact improve accessibility for all parents. Additionally, as this research was conducted in Aotearoa New Zealand, it is not known to what extent parent reported barriers extend to other countries. Based on the Literature Review (Chapter 2), it may be inferred that similar barriers do exist for parents generally, however Study 1 suggests that the extent of specific barriers, such as those related to location, likely differ between countries.

Future Research

Several recommendations regarding areas for potential future research have been discussed throughout this thesis. In addition to those already mentioned, there are several areas in which further research would be beneficial. For example, further research utilizing surveys which are available in a greater range of languages may be useful. Research specifically looking at the ways in which an existing support service may be adapted to align with neurodiversity affirming approaches, which is led by, or co-designed with, autistic individuals is essential. Similarly, there is a need for more research regarding the ways in which child and family outcomes could be measured in respectful, neurodiversity affirming ways. Additionally, finding methods which allow children to provide feedback regarding their experiences of a support service would also be useful (Schuck et al., 2022). While recent research has indicated the kinds of goals for early support services which are a priority for autistic individuals, parents of autistic children, and providers (Waddington, Minnell, et al., 2023), little is known regarding the types of strategies which may be appropriate to utilize in a neurodiversity affirming early autism support service. This is also an area which would be useful to explore through a research-community partnership including autistic adults.

Given the novelty of the quantitative research conducted in Study 1, further refinement and use of the survey would provide additional evidence of the barriers and/or facilitators parents experience to autism support services. Conducting a study similar to Study 1 with autistic adults to explore the barriers and facilitators experienced when accessing and/or participating in adult support services would provide greater information regarding how best to support autistic individuals across the lifespan. Additionally, research using a survey similar to that used in Study 1 internationally would be important in determining the differences and similarities in barriers and facilitators parents experience across countries and contexts. Including a measure of parent stress and/or wellbeing alongside the survey would also provide additional information regarding possible connections between the number and extent of experienced barriers and/or facilitators and parental levels of stress or wellbeing. Finally, extending the survey to parents of children who are showing social communication differences but who are not yet diagnosed may be useful in determining whether, and to what extent, a lack of diagnosis poses a barrier to support services. It would also be valuable to find ways to explore whether parents are utilizing facilitators to overcome the barriers they face.

As Study 3 was a pilot study, it would be useful for further research examining the usefulness of adapting an early support service to involve a greater number of parents. As noted by Pellecchia et al. (2018), it is difficult to ascertain the specific strategies which may improve the accessibility of, or facilitate engagement in, support services as such strategies tend to be used collectively. The same was true of the adaptations used in Study 3 with Marama, with all adaptations implemented throughout the programme. Replication of Study 3 with a broader range of families may allow for the analysis of which factors may be most helpful, and for whom. Additionally, research conducted with a greater number of families may highlight the ways in which a service needs to be individualized for families across a

range of sociodemographic backgrounds. This kind of study may also include offering families greater choice as to the adaptations they would like implemented within the programme they receive. Using research-community partnerships in this kind of research would be one way of ensuring the voices of those who would be utilizing such services continue to be heard and embedded into the adapted support.

Conclusion

Early autism support services appear to be of benefit for young autistic children and their families. Presently, however, family access and participation in such services appears to be marked by inequity. A review of the literature suggested that lower financially resourced families experienced numerous compounding barriers to early autism supports for their children. Study 1 provided quantitative evidence that lower financially resourced families do indeed experience a significantly greater number of barriers, and experience those barriers to a greater extent, than families from higher financially resourced backgrounds. While families also experienced a range of facilitators to services, there were no significant differences in the number or extent of helpfulness of these factors based on family level of financial resourcing.

In Study 2, five lower financially resourced families reflected on their experiences of a specific early autism support service. Along with suggestions from community partners, parent experiences and recommendations were used to develop adaptations to improve accessibility to, and participation in, the support service. Study 3 involved the implementation of the adapted support service with one lower financially resourced family, with results suggesting the adapted service was acceptable and the adaptations were helpful.

This research highlights the challenges and facilitative factors lower financially resourced families experience when accessing or participating in support services for their young autistic children. The preliminary evidence provided in Study 3 suggests that pre-existing support services may be successfully adapted to improve their fit to specific

populations and/or settings. Several unique contributions to the research literature were identified, including the novelty of Study 1 in providing quantitative evidence for the greater number of barriers experienced by lower financially resourced families. Limitations of the research were identified including the lack of translated surveys, particularly to Te Reo Māori, in Study 1, and the absence of comparison groups for Studies 2 and 3. Several areas for future research, particularly those examining factors related to the neurodiversity movement, were highlighted. Collectively, the research within this thesis highlights the vast range of barriers and facilitators parents experience while they seek support for their autistic child. Additionally, results suggest that parents know what factors will facilitate their access and participation in autism support services for their children. Providers and researchers can play a key role in improving the accessibility of support services and giving parents opportunities to be heard.

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APPENDIX A

PUBLISHING AGREEMENTS

Publishing Agreement for Systematic Qualitative Review

JOURNAL CONTRIBUTOR'S PUBLISHING AGREEMENT

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TITLE OF ARTICLE: Parent Reported Barriers and Facilitators to Support Services for Autistic Children in Aotearoa New Zealand

JOURNAL: Autism

ALL AUTHOR(S): Wallace-Watkin, Carla; Sigafos, Jeff; Woods, Lisa; Waddington, Hannah

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APPENDIX B

SUPPLEMENTARY MATERIAL FOR SYSTEMATIC LITERATURE REVIEW

Table S1

Variations to Protocol

Protocol submitted to PROSPERO	Variation to protocol	Rationale
Review team members included (LvN)	Review team member (LvN) removed	This team member was unable to participate in the review process due to time constraints and high workloads.
Terminology originally: Under-represented Intervention	Terminology Changes: Underserved Support services	The terminology was updated to reflect ongoing changes in language guidelines in relation to autism and differing population groups.
We will conduct electronic searches of the following databases for peer-reviewed studies in English: a. PsycINFO b. MEDLINE c. Scopus d. PubMed	We will conduct electronic searches of the following databases for peer-reviewed studies in English: a. PsycINFO b. MEDLINE c. Scopus d. PubMed e. CINAHL	We chose to also search the CINAHL database to ensure we had captured as many of the relevant studies as possible
Search Terms: (Underserve* OR “Under resource*” OR “Under rep*” OR “Low resource*” OR Poor OR Poverty OR “Ethnic minorit*” OR “Low SES” or “Low Socioeconomic Status” OR Medicaid) (Intervention* OR Programme* OR Service*)	Search Terms: (Underserve* OR “Under resource*” OR “Under rep*” OR “Low resource*” OR Poor OR Poverty OR “Ethnic minorit*” OR “Racial minorit*” OR Immigrant OR “Low SES” or “Low Socioeconomic Status” OR Medicaid)	We updated our search terms to include those directly related to our population and area of interest.

	(Intervention* OR Programme* OR Service* OR “Support Service*”)	
<p>Inclusion criteria</p> <p>Criteria 4: The paper was published prior to and including June 2021</p> <p>Criteria 5: The majority of participants in the study are identified as lower resourced (i.e., receiving income-tested government assistance such as Medicaid in the US, or are identified as being from low socioeconomic households or socioeconomically disadvantaged, or reside in a low- to middle-income country) and/or are from ethnic minority backgrounds. In the case that a study compares lower resourced participants to those who are higher resourced, if the data of the lower resourced participants can be isolated it will also be included.</p> <p>Criteria 7: The children referred to in the study are 18 years of age or younger.</p>	<p>Changes to inclusion criteria</p> <p>Criteria 4: The paper was published prior to and including May 2022</p> <p>Criteria 5: The majority of participants in the study are identified as lower resourced (i.e., receiving income-tested government assistance such as Medicaid in the US, or are identified as being from low socioeconomic households or socioeconomically disadvantaged, or reside in an area defined within the study as lower resourced, or reside in a low- to middle-income country) and/or are from ethnic minority backgrounds. In the case that a study compares lower resourced participants to those who are higher resourced, if the data of the lower resourced participants can be isolated it will also be included.</p> <p>Criteria 7: Removed</p>	<p>Criteria 4: To ensure the most up-to-date literature had been located.</p> <p>Criteria 5: Addition of the setting referred to as ‘lower resourced’ to reflect terminology within studies.</p> <p>Criteria 7: To ensure we did not miss important relevant information and to ensure the review had a wide enough scope to contribute to the current literature.</p>
... using the JBI Critical Appraisal Checklist for Qualitative Research (Lockwood et al., 2015).	... using the Critical Appraisal Skills Programme qualitative checklist (CASP; 2019)	The CASP tool was a better fit with our data.

Table S2*PRISMA 2020 Checklist*

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	p. 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	p. 1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	p. 5
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	pp. 4-5
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	p. 7
Information sources	6	Specify all databases, registers, websites, organizations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	p. 6
Search strategy	7	Present the full search strategies for all databases, registers, and websites, including any filters and limits used.	p. 6
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	p. 8
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	p. 8
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g., for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	p. 8
	10b	List and define all other variables for which data were sought (e.g., participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	p. 8

Section and Topic	Item #	Checklist item	Location where item is reported
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	p. 9
Effect measures	12	Specify for each outcome the effect measure(s) (e.g., risk ratio, mean difference) used in the synthesis or presentation of results.	Not applicable (qualitative review)
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g., tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	pp. 8-9
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Not applicable (qualitative review)
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	pp. 9-10
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	p. 9
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g., subgroup analysis, meta-regression).	Not applicable (qualitative review)
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	Not applicable (qualitative review)
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Not applicable (qualitative review)
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	p. 8
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	p. 7
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they	Table S3,

Section and Topic	Item #	Checklist item	Location where item is reported
		were excluded.	supplementary material p. 4
Study characteristics	17	Cite each included study and present its characteristics.	pp 10 and 11, Table S5, supplementary materials p. 16
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	p. 11 and Table S6
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g., confidence/credible interval), ideally using structured tables or plots.	pp. 9-19
Results of syntheses	20a	For each synthesis, briefly summarize the characteristics and risk of bias among contributing studies.	p. 10 and Table S6, supplementary material p. 22
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g., confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	No statistical analyses (qualitative review).
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	No investigations of heterogeneity (qualitative review)
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	No results of sensitivity analyses (qualitative review)
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	No calculation of reporting bias (qualitative)

Section and Topic	Item #	Checklist item	Location where item is reported
			review)
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Not possible (qualitative review)
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	pp. 24-27
	23b	Discuss any limitations of the evidence included in the review.	pp. 26-27
	23c	Discuss any limitations of the review processes used.	pp. 26-27
	23d	Discuss implications of the results for practice, policy, and future research.	pp. – 25-26 recommendations
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	p. 5
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	p. 5
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	p. 5 and Table S2
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	p. 28
Competing interests	26	Declare any competing interests of review authors.	p. 28
Availability of data, code, and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Available from first author

Table S3*Excluded Studies*

Reference	Reason for Exclusion
<p>Anderson, C., Lupfer, A., & Shattuck, P.T. Barriers to receipt of services for young adults with autism. <i>Pediatrics</i>, 141(4), S300-S305. https://doi.org/10.1542/peds.2016-4300G</p>	<p>Majority of participants are not from an underserved population/s as defined in this review</p>
<p>Benevides, T., Carretta, H.J., & Mandell, D.S. (2016). Differences in perceived need for medical, therapeutic, and family support services among caregivers of children with autism spectrum disorder. <i>The American Journal of Occupational Therapy</i>, 70(4,1) https://doi.org/10.5014/ajot.2016.70S1-RP102C</p>	<p>The study does not have a qualitative component (i.e., this is a quantitative study)</p>
<p>Blumling, A.A., Brasher, S., Stapel-Wax, J. (2019) Engaging parents of children with autism spectrum disorder to identify rural health disparities and factors related to delayed diagnosis and treatment. <i>International Journal of Child Health and Human Development</i>, 12(4), 379-389.</p>	<p>Majority of participants are not from an underserved population/s as defined in this review</p>
<p>Brewer, A. (2018) "We were on our own": Mothers' experiences navigating the fragmented system of professional care for autism. <i>Social Science & Medicine</i>, 215, 61-68. https://doi.org/10.1016/j.socscimed.2018.08.039</p>	<p>Majority of participants are not from an underserved population/s as defined in this review</p>
<p>Burke, M.M., Rios, K., Garcia, M., Sandman, L., Lopez, B., & Magaña, S. (2019) Examining the perspectives of Latino families of children with autism spectrum disorder towards advocacy.</p>	<p>Does not focus on Support Services (i.e., examines advocacy)</p>

<p>Exceptionality, <i>A Special Education Journal</i>, 27(3), 201-214. https://doi.org/10.1080/09362835.2018.1433041</p>	
<p>*Burkett, K., Morris, E., Manning-Courtney, P., Anthony, J., & Shambley-Ebron, D. (2015). African American families on autism diagnosis and treatment: The influence of culture. <i>Journal of Autism and Developmental Disorders</i>, 45(10), 3244-3254. https://doi.org/10.1007/s10803-015-2482-x</p>	<p>Cannot isolate responses from underserved parents</p>
<p>Camard, S., Chatenoud, C., & Rivard, M., (2022) "We've got to fight; that's the story of our lives": Advocacy experience of immigrant families of children with autism spectrum disorder. <i>Early Years; An International Research Journal</i>, 1-15, Advance online publication. https://doi.org/10.1080/09575146.2022.2047898</p>	<p>Does not focus on barriers or facilitators to support services (i.e., examines general advocacy)</p>
<p>Carson, T.B., Palacio, A.E., Hextall, S., & Guerrero, L.A. (2021). Therapy needs for children with autism in a rural, underserved island community, <i>Journal of Rural Mental Health</i>, 45(2), 129-140. https://doi.org/10.1037/rmh0000177</p>	<p>Majority of participants are not from an underserved population/s as defined in this review</p>
<p>Dababnah, S., Shaia, W.E., Champion, K., & Nichols, H.M. (2018). "We had to keep pushing": Caregivers' perspectives on autism screening and referral practices of Black children in primary care. <i>Intellectual and developmental disabilities</i>, 56(5), 321-336. https://doi.org/10.1352/1934-9556-56.5.321</p>	<p>Does not focus on Support Services (i.e., examines diagnosis)</p>

<p>Elder, J.H., Brasher, S., & Alexander, B. (2016). Identifying the barriers to early diagnosis and treatment in underserved individuals with autism spectrum disorders (ASD) and their families: A qualitative study. <i>Issues in Mental Health Nursing</i>, 37(6), 412–420. https://doi.org/10.3109/01612840.2016.1153174</p>	<p>Cannot isolate responses from underserved parents</p>
<p>Eskow, K.G., & Summers, J. A. (2019). Family perceptions of the impacts of a home and community-based services autism waiver: Making family life possible. <i>Journal of Applied Research in Intellectual Disabilities</i>, 32(1), 159–171. https://doi.org/10.1111/jar.12518</p>	<p>Does not focus on Support Services (i.e., examines waivers)</p>
<p>Fontil, L., & Petrakos, H. H. (2015). Transition to school: The experiences of Canadian and immigrant families of children with autism spectrum disorders. <i>Psychology in the Schools</i>, 52(8), 773–788. https://doi.org/10.1002/pits.21859</p>	<p>Does not focus on Support Services (i.e., examines transition to school/education)</p>
<p>* Gona, J.K., Newton, C. R., Rimba, K. K., Mapenzi, R., Kihara, M., Vijver, F. V., Abubakar, A. (2016). Challenges and coping strategies of parents of children with autism on the Kenyan coast. <i>Rural and Remote Health</i>, 16(2), 3517–3517.</p>	<p>Does not focus on barriers or facilitators to support services (i.e., examines general challenges)</p>
<p>Gordillo, M.L., Chu, A., & Long, K. (2020). Mothers' adjustment to autism: Exploring the roles of autism knowledge and culture. <i>Journal of Pediatric Psychology</i>, 45(8), 877–886. https://doi.org/10.1093/jpepsy/jsaa044</p>	<p>Does not focus on barriers or facilitators to support services (i.e., focus is on diagnosis)</p>
<p>* Habib, S., Prendeville, P., Abdussabur, A. & Kinsella, W. (2017). Pakistani mothers' experiences</p>	<p>Does not focus on barriers or facilitators to support services (i.e.,</p>

<p>of parenting a child with autism spectrum disorder (ASD) in Ireland. <i>Educational & Child Psychology</i>, 34(2). 67-79</p>	<p>examines general experiences and education)</p>
<p>Jegatheesan, B., Fowler, S., & Miller, P. J. (2010). From symptom recognition to services: how South Asian Muslim immigrant families navigate autism. <i>Disability & Society</i>, 25(7), 797–811. https://doi.org/10.1080/09687599.2010.520894</p>	<p>Does not focus on barriers or facilitators to support services (i.e., majority of study examines diagnosis, medical services, support groups)</p>
<p>Kang-Yi, C.D., Grinker, R. R., Beidas, R., Agha, A., Russell, R., Shah, S. B., Shea, K., & Mandell, D. S. (2018). Influence of community-level cultural beliefs about autism on families' and professionals' care for children. <i>Transcultural Psychiatry</i>, 55(5), 623–647. https://doi.org/10.1177/1363461518779831</p>	<p>Does not include Parents</p>
<p>Longtin, S.E., & Principe, G.M. (2016). The relationship between poverty level and urban African American parents' awareness of evidence-based interventions for children with autism spectrum disorders: Preliminary data. <i>Focus on Autism and Other Developmental Disabilities</i>, 31(2), 83–91. https://doi.org/10.1177/1088357614522293</p>	<p>The study does not have a qualitative component (i.e., this is a quantitative study)</p>
<p>Lopez, K., Magaña, S., Morales, M., & Iland, E. (2019). Parents Taking Action: Reducing disparities through a culturally informed intervention for Latinx parents of children with autism. <i>Journal of Ethnic & Cultural Diversity in Social Work</i>, 28(1),</p>	<p>The study does not have a qualitative component (i.e., this is a quantitative study)</p>

<p>31–49. https://doi.org/10.1080/15313204.2019.1570890</p>	
<p>Luelmo, P., & Kasari, C., & Fiesta Educativa, Inc. (2021). Randomized pilot study of a special education advocacy programme for Latinx/minority parents of children with autism spectrum disorder. <i>Autism: The International Journal of Research and Practice</i>, 25(6), 1809–1815. https://doi.org/10.1177/1362361321998561</p>	<p>The study does not have a qualitative component (i.e., this is a quantitative study)</p>
<p>Makombe, C., Shabalala, N., Viljoen, M., Seris, N., de Vries, P. J., & Franz, L. (2019). Sustainable implementation of early intervention for autism spectrum disorder through caregiver coaching: South African perspectives on barriers and facilitators. <i>Pediatric medicine</i> (2), 39. https://doi.org/10.21037/pm.2019.07.08</p>	<p>Cannot isolate responses from parents</p>
<p>Mbamba, C.R., Yeboaa, P. A., & Ndemole, I. K. (2022). Autistic children in the care of single mothers: Opportunities and barriers to safeguarding the welfare of special needs children. <i>Vulnerable Children and Youth Studies</i>, 1–12. Advance online publication. https://doi.org/10.1080/17450128.2022.2080895</p>	<p>Does not focus on Support Services (i.e., examines welfare/wellbeing)</p>
<p>Medina, J.A.V., Rios, K., Aleman-Tovar, J., & Burke, M. M. (2022). Exploring patterns between school perceptions, child behavior, and maternal well-being among Latina mothers of children with autism spectrum disorder (ASD). <i>International Journal of Developmental Disabilities</i>, 68(2), 122–</p>	<p>Does not focus on Support Services (i.e., focuses on education)</p>

<p>130. https://doi.org/10.1080/20473869.2019.1706332</p>	
<p>Millau, M., Rivard, M., & Mello, C. (2018). Immigrant families' perception of the causes, first manifestations, and treatment of autism spectrum disorder. <i>Journal of Child and Family Studies</i>, 27(11), 3468–3481. https://doi.org/10.1007/s10826-018-1180-7</p>	<p>Does not focus on barriers or facilitators to support services (i.e., examines treatment priorities)</p>
<p>Miller, K.H.K, Mathew, M., Nonnemacher, S. L., & Shea, L. L. (2018). Programme experiences of adults with autism, their families, and providers: Findings from a focus group study. <i>Autism: The International Journal of Research and Practice</i>, 22(3), 345–356.</p>	<p>Cannot isolate responses from parents</p>
<p>* Miller-Gairy, S., & Mofya, S. (2015). Elements of culture and tradition that shape the perceptions and expectations of Somali refugee mothers about autism spectrum disorder. <i>International Journal of Child and Adolescent Health</i>, 8(4), 425–438.</p>	<p>Does not focus on Support Services (i.e., focuses mainly on diagnostic and school-based experiences)</p>
<p>* Morgan, E.H. & Stahmer, A. C. (2020). Narratives of single, black mothers using cultural capital to access autism interventions in schools. <i>British Journal of Sociology of Education</i>, 42(1), 48–65. https://doi.org/10.1080/01425692.2020.1861927</p>	<p>Does not focus on Support Services (i.e., focus is on cultural capital and advocacy)</p>

<p>Platos, M. & Pisula, E. (2019). Service use, unmet needs, and barriers to services among adolescents and young adults with autism spectrum disorder in Poland. <i>BMC Health Services Research</i>, 19(1), 587–587. https://doi.org/10.1186/s12913-019-4432-3</p>	<p>The study does not have a qualitative component (i.e., this is a quantitative study)</p>
<p>Ratto, A.B., Anthony, B.J., Pugliese, C., Mendez, R., Safer-Lichtenstein, J., Dudley, K. M., Kahn, N. F., Kenworthy, L., Biel, M., Martucci, J. L., & Anthony, L. G. (2017). Lessons learned: Engaging culturally diverse families in neurodevelopmental disorders intervention research. <i>Autism: The International Journal of Research and Practice</i>, 21(5), 622–634. https://doi.org/10.1177/1362361316650394</p>	<p>Children had differing diagnoses (i.e., not all children were diagnosed with autism)</p>
<p>Rios, K., Aleman-Tovar, J., & Burke, M. M. (2020). Special education experiences and stress among Latina mothers of children with autism spectrum disorder (ASD). <i>Research in Autism Spectrum Disorders</i>, 73, 101534–. https://doi.org/10.1016/j.rasd.2020.101534</p>	<p>Does not focus on Support Services (i.e., examines education)</p>
<p>* Rivard, M., Millau, M., Magnan, C., Mello, C., & Boulé, M. (2019). Snakes and ladders: Barriers and facilitators experienced by immigrant families when accessing an autism spectrum disorder diagnosis. <i>Journal of Developmental and Physical Disabilities</i>, 31(4), 519–539. https://doi.org/10.1007/s10882-018-9653-6</p>	<p>Does not focus on Support Services (i.e., examines diagnosis)</p>

<p>Rosales, R., Leon, A., Serna, R. W., Maslin, M., Arevalo, A., & Curtin, C. (2021). A first look at applied behavior analysis service delivery to Latino American families raising a child with autism spectrum disorder. <i>Behavior Analysis in Practice</i>, 14(4), 974–983. https://doi.org/10.1007/s40617-021-00572-w</p>	<p>The study does not have a qualitative component (i.e., this is a quantitative study)</p>
<p>Schwartz, J.K., Agrawal, M., Treminio, I., Espinosa, S., Rodriguez, M., & Richard, L. (2020). Caregivers' perspectives on health-care transition in autism. <i>Advances in Autism</i>, 6(2), 153–164. https://doi.org/10.1108/AIA-07-2019-0022</p>	<p>Does not focus on Support Services (i.e., examines health care)</p>
<p>*Lovelace, T.A., Robertson, R.E., & Tamayo, S. (2018). Experiences of African American Mothers of sons with autism spectrum disorder: Lessons for improving service delivery. <i>Education and Training in Autism and Developmental Disabilities</i>, 53(1), 3–16.</p>	<p>Unable to isolate results specific to support services.</p>
<p>Thomas, K. C., Ellis, A.R., McLaurin, C., Daniels, J., & Morrissey, J.P. (2007). Access to care for autism-related services. <i>Journal of Autism and Developmental Disorders</i>, 37(10), 1902–1912. https://doi.org/10.1007/s10803-006-0323-7</p>	<p>The study does not have a qualitative component (i.e., this is a quantitative study)</p>
<p>Wagner, S., Rubin, I. L., & Singh, J. S. (2021). Underserved and undermeasured: A mixed-method analysis of family-centered care and care coordination for low-income minority families of children with autism spectrum disorder. <i>Journal of</i></p>	<p>Does not focus on Support Services (i.e., examines approaches - family centered care and care coordination)</p>

Racial and Ethnic Health Disparities, 9(4), 1474–1487. https://doi.org/10.1007/s40615-021-01086-5	
* You, H.K., & Rosenkoetter, S. E. (2014). Listening to Korean immigrant mothers: meanings of raising a child with a disability. <i>Multiple Voices for Ethnically Diverse Exceptional Learners</i> , 14(1), 30–41.	Children had differing diagnoses (i.e., not all children were diagnosed with autism)

Note. * Indicates studies located within ancestral searches

Table S4*Summary of Study Characteristics*

Authors	Study Aim	Qualitative data collection and Analytic approach	Geographic Location	Parent Characteristics (Race or Ethnicity)	Child characteristics (Age in years)	Focus Population	Relevant Question Topics
Birkin et al., (2008)	To determine the cultural barriers which may have been influencing access to and participation in the EarlyBird programme.	Semi-structured interviews. Analysed using thematic analysis.	New Zealand	8 parents (2 Māori, 4 Pasifika, 2 Korean)	Number and gender of children not reported. (6 years of age or younger).	Racial or ethnic underrepresented group/s (Stated in study to be focused on ethnic groups)	Barriers and Facilitators
Blanche et al., (2015)	To examine the potential influence of cultural factors on the perceptions of parenting and experiences with services for Latino parents with an autistic child.	Semi-structured interviews. Analysed using thematic analysis.	U.S.A.	12 mothers, 3 fathers (15 Latino)	13 children, 12 boys, 1 girl. (Mean age 5.4 years, range 3-8 years).	Racial or ethnic underrepresented group/s (Stated in study to be focused on ethnic groups)	Barriers and Facilitators
Chlebowski et al., (2018)	To explore parent perceptions of the AIM-HI service.	Phone-based interviews. Analysed using grounded theory.	U.S.A.	29 parents, 93% female. (29 Latinx)	29 children, 90% male. (Mean age 9.8 years, range 5-13 years).	Lower financially resourced, Racial or ethnic underrepresented group/s	Barriers

Dababnah & Bulson, (2015)	To further extend knowledge of the experiences of families with autistic children in the West Bank including availability of support services.	Semi-structured individual interviews (n = 11) and group interviews (n = 4). Analysed using grounded theory.	West Bank	20 mothers, 4 fathers (24 Palestinian Arab).	24 children, 67% male. (Mean age 10 years, range 4-17 years).	Lower resourced setting	Barriers and Facilitators
Fox et al., (2017)	To address a gap in existing research literature, and to gain a greater understanding, of the needs, experiences, and barriers to diagnosis and care for United Kingdom based Somali migrant families with an autistic child.	Semi-structured individual interviews. Analysed using inductive thematic analysis.	England	12 female, 3 male (15 Somali)	17 children, 5 female, 12 male (Average age 7 years, range 4-13 years)	Immigrant population	Barriers and Facilitators
Guler et al., (2018)	To explore contextual factors which may influence service access and/or participation in support services for South African parents of autistic children.	In-depth interviews (n= 6) and focus groups (n= 4). Analysed using thematic analysis.	South Africa	20 mothers, 5 fathers, 3 grandmothers. (12 mixed ethnic heritage, 12 Black African, 2 white, 2 Asian/Indian).	22 children, 20 male, 2 female. (7 years of age or younger).	Lower resourced setting	Barriers and Facilitators
Hong & Singh, (2019)	To identify and investigate potential challenges and/or limitations faced by sole female caregivers when accessing services for their autistic child through Medicaid insurance.	In-depth individual interviews. Analysed using grounded theory.	U.S.A.	16 mothers, 5 grandmothers (21 Black)	Number and gender of children not reported.	Lower financially resourced, Racial or ethnic underrepresented group/s	Barriers

Khanlou et al., (2017)	To identify the barriers to services and social support faced by immigrant families with an autistic child in Canada.	Semi-structured telephone interviews. Analysed using thematic analysis.	Canada	21 mothers (Not identified, places of origin included Asia, 14; Europe, 5; Latin America, 2	27 children, 16 male, 11 female. (Mean 3.7 years, range 2-12 years)	Immigrant population	Barriers and Facilitators
Lee & Meadan, (2021a)	To explore the perceptions and experiences, particularly of barriers and needs, of Mongolian parents when accessing services for their autistic child/ren	Four in-person and one online focus groups of 5-7 caregivers. Analysed using constant comparative method (Strauss & Corbin, 2015).	Mongolia	23 mothers, 5 fathers, 1 grandparent, 1 extended family member (30 Mongolian).	30 children, gender not reported. (Mean age not reported, 25 0-8 years; 4 8-17 years, 1 18 or above).	Lower resourced setting, Racial or ethnic underrepresented group/s	Barriers and Facilitators
Luelmo et al., (2020)	To explore the experiences, both barriers and facilitators, of undocumented Mexican mothers when accessing diagnosis and services for their autistic child	One-on-one in person semi structured interviews. Analysed using thematic analysis.	U.S.A	6 mothers (6 Mexican)	6 male children. (Age not reported)	Immigrant population	Barriers and Facilitators
Nilses et al., (2019)	To gain an understanding of immigrant parents' experiences of gaining a diagnosis and a community support service for their autistic child.	One-on-one semi structured interviews. Analysed using phenomenological hermeneutic method.	Sweden	7 females, 4 males (not identified, areas of origin included East Africa, 3; North Africa, 1; Middle east, 5; Eastern Europe, 2)	11 children, gender not reported. (Average age 4.55 years, range 3-5 years).	Immigrant population	Barriers

Pearson & Meadan (2018)	To explore those factors which facilitate or impede access to support services for African American parents with an autistic child.	Individual semi-structured interviews. Analysed using constant comparative method.	U.S.A.	11 mothers (11 African American)	13 children, 9 boys, 4 girls. (Mean age 7.92 years, range 4-11 years).	Racial or ethnic underrepresented group/s	Barriers and Facilitators
Pickard & Ingersoll (2016)	To gain an understanding of the factors which may influence the disparities in service access for families with an autistic child.	Online questionnaire. Analysed using grounded theory.	U.S.A.	84 parents (87.5% White, 5.2% African American, 5.2% Hispanic, 1% Asian/Pacific Islander, 1% Biracial/other.	Total number and gender of child not reported. (Range 2-17 years of age).	Lower financially resourced	Barriers
Pickard, Kilgore, & Ingersoll, 2016	Utilizing a research-community partnership to explore factors which may impede and/or improve access to a support service (Project ImPACT)	3 Focus groups. Analysed using rapid evaluation and assessment method followed by thematic analysis.	U.S.A.	16 parents, 87.5% female. (62.5% African American, 18.8% Biracial/other, 12.5% White, 6.3% Middle Eastern)	Total number of children not reported 77.8% male. (Mean age 4.5 years, range 18 months – 6 years).	Lower financially resourced, Racial or ethnic underrepresented group/s	Barriers and Facilitators

Pickard et al., (2019)	A mixed methods study with the aim of comparing parent perceptions of a support service to a proposed adapted version (Project ImPACT), and how specific factors (household income, programme type) may influence these perceptions. Qualitative data was gathered to compliment quantitative analysis and to gather parent identified strengths and limitations of both the original and adapted programme.	2 open-ended questions within a larger online survey. Analysed using Miles and Huberman's (1994) qualitative analysis approach.	U.S.A.	103 parents, 87.4% female. (64.08% White, 14.58% African American, 8.73% Hispanic/Latino, 3.89% Middle Eastern, 3.89% Asian/Pacific Islander, 4.83% Biracial/other)	Total number and gender not reported - at least one autistic child per parent. (Mean 4.14 years, range 18 months to 8 years)	Lower financially resourced	Barriers and Facilitators
Sakai et al., (2019)	To identify, through the perceptions of parents and providers, barriers and facilitators to diagnosis and support services for Chinese immigrant autistic children.	In person one-on-one semi-structured interview. Analysed using a modified grounded theory framework.	U.S.A.	2 fathers, 14 mothers (16 Chinese).	Total number and gender not reported (Mean age 5.9 years, range 2 years to 15 years 11 months).	Immigrant population	Barriers

Shanmugarajh et al., (2022)	To both describe and explore the experiences of Sri Lankan-Canadian parents when navigating their child's autism diagnosis and support services (specifically occupational therapy).	Semi-structured interviews. Analysed using content analysis.	Canada	8 mothers (8 Sri Lankan Tamil)	8 children, 7 male, 1 female (Range 16-23 years)	Immigrant population	Barriers and Facilitators
Stahmer et al. (2019)	To gain an understanding of the barriers and facilitators to support services experienced by lower financially resourced families with autistic children.	Focus groups (n = 19) and individual structured interviews (n = 15). Analysed using thematic analysis.	U.S.A.	50 mothers, 6 fathers, 2 legal guardians. (14 Asian, 18 African American, 26 Hispanic/Latino).	Total number and gender not reported. (Mean 66.9 months, range 2-8 years of age.)	Lower financially resourced, Racial or ethnic underrepresented group/s	Barriers and Facilitators

Table S5*Results of Critical Appraisal Skills Programme (CASP) Qualitative Studies Checklist*

Author	Appraisal Criteria								
	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9
Birkin et al., 2008	Y	Y	Y	Y	Y	N	C	Y	Y
Blanche et al., 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y
Chlebowski et al., 2018	Y	Y	Y	Y	Y	N	Y	Y	Y
Dababnah & Bulson, 2016	Y	Y	Y	Y	Y	N	Y	Y	Y
Fox et al., 2017	Y	Y	Y	Y	Y	C	Y	Y	Y
Guler et al., 2018	Y	Y	Y	Y	Y	N	Y	Y	Y
Hong & Singh, 2019	Y	Y	Y	C	Y	N	Y	Y	Y
Khanlou et al., 2017	Y	Y	Y	Y	Y	N	Y	Y	Y
Lee & Meaden, 2021a	Y	Y	Y	Y	Y	N	Y	Y	Y
Luelmo et al., 2020	Y	Y	Y	Y	Y	Y	Y	Y	Y
Nilses et al., 2019	Y	Y	Y	Y	Y	N	Y	Y	Y
Pearson & Meadan, 2018	Y	Y	Y	Y	Y	Y	Y	Y	Y
Pickard, Kilgore, & Ingersoll, 2016	Y	Y	Y	Y	Y	N	Y	Y	Y

Pickard & Ingersoll, 2016	Y	Y	Y	Y	Y	N	Y	Y	Y
Pickard et al., 2019	Y	Y	Y	Y	Y	N	C	Y	Y
Sakai et al., 2019	Y	Y	Y	Y	Y	N	Y	Y	Y
Shanmugarajh et al., 2022	Y	Y	Y	Y	Y	N	Y	Y	Y
Stahmer et al., 2019	Y	Y	Y	Y	Y	N	Y	Y	Y

Note. Y = criteria met, N= criteria not met, C = Can't tell if criteria is met or not

Table S6*Theme Names, Definitions, and Supporting Evidence*

Theme/Subtheme Name	Definition	Evidence from Text
Theme 1: Support service accessibility		
1a. Knowledge and education	Where a parent states or infers that their and/or a provider's limited knowledge of autism and/or support services posed a barrier to accessing and/or participating in services. Additionally, any factors related to knowledge or education (e.g., targeted education, dissemination of information, learning to advocate) which parents reported facilitated access and/or participation in support services.	We surf through the internet as much as we can. We get all the information from the internet. (Lee and Meadan, 2021a; p. 3593) No one seems to know what services we should be getting. Pediatricians say to call psychiatrist. Psychiatrist says we don't need anything. I wish we had a set person that I could ask questions to about ASD and that could advise us at to which services we could and should be receiving. (Pickard & Ingersoll, 2016; p. 111).
1b. Service Pathways	Structural challenges and/or delays parents reported encountering when attempting to access and/or participate in support services (e.g., long waiting lists, lack of clarity of the system pathway, denial of access). Additionally, any	The system is very fragmented. The school does not speak about social services. No combined packages. (Khanlou et al., 2017; p. 246)

	factor which parents report facilitated their navigation of service systems.	Everyone says the earlier you start services the better off you are, and that intervention is everything, especially in the first 5 years, yet that's about how long you have to wait before you ever see any real services manifest. (Pickard & Ingersoll, 2016; p. 111).
1c. Financial Pressure	Parents state or indicate that the direct and/or associated costs of support service/s acts as a barrier to the family receiving and/or participating in support services. Alternatively, parent reported factors which reduced or removed financial barriers to support services.	<p>When he turned three years of age his services ended which means I am responsible to pay out of pocket for his therapies. It is very expensive. It is aggravating that insurance companies don't help. (Pickard & Ingersoll, 2016; p. 111)</p> <p>When he turned three years of age his services ended which means I am responsible to pay out of pocket for his therapies. It is very expensive. It is aggravating that insurance companies don't help. (Pickard & Ingersoll, 2016; p. 111)</p>
1d. Geographic Location	Barriers to access and/or participation in support services associated with the family's geographic	Well, I can say the area I live [and] the locations of some of the places that offer the services are...not

	<p>location. This includes unavailability of services locally, transportation issues, and unique barriers by location (e.g., West Bank). Alternatively, any factor which reduces or removes geographic challenges</p>	<p>in my local area, so I have to drive a great distance to get the services. So that's the biggest challenge. There's nothing in my area within a twenty-mile radius, so I have to drive to get there. (Hong and Singh, 2019; p. 371)</p> <p>We need enough professionals for all Mongolian children. There isn't anyone who is capable of teaching and treating our children even if we offer money. I have tried for many years, but there isn't any improvement. I just lose my money and time, so I thought I am the only one who can work with my child (Lee and Meadan, 2021a; p. 3591)</p>
1e. Providers	<p>Barriers to support services which are created or, if the opportunity was present, were not otherwise circumvented by a provider (e.g., Doctor, Service provider, Diagnostician). Alternatively, provider characteristics and/or actions which facilitated parent access and/or participation in support services.</p>	<p>"I think that human quality, knowing that [the therapist] understands, give us the confidence to feel comfortable in asking [questions], knowing that he [therapist] as a professional also is sympathetic to what you are going through, that would help a lot. (Chlebowski et al; 2018; p. 558).</p>

		In the beginning, I contacted them, or called them, quite often ... rather often. More than usual. I asked quite a lot of questions. But now these contacts aren't as frequent. If I feel I need their help, they schedule an interpreter, and we meet with them. (Nilses et al 2019; p. 3403)
Theme 2: Diversity of Support Services		
2a. Cultural and Linguistic Considerations	Barriers to support services which arise due to cultural and linguistic challenges. This may include a mismatch between the support service and cultural understandings of ASD and/or linguistic diversity. Alternatively, any factors which addressed, recognized, or in some way incorporated cultural considerations and facilitated access and/or participation in support services.	They don't really [accept autism]. In our culture, it's more like, 'Give her a little spanking; it'll go away.' (Blanche et al., 2015, p. 4) I would have loved to have seen some people from a Somali background who are doing this, who are making family members understand a little bit more about autism, especially the ones that have a language barrier, which I think, 70 to 60 % of them do have that problem." (Fox et al., 2017; p. 311)
2b. Service Flexibility	Features of a particular support service/s which parents infer, or state has facilitated access and/or	Even if it can be traditional ... you know ... an example ... this seat. There are plastic chairs that

	<p>participation in that support service. Alternatively, any inflexibility within a service/s which posed a barrier to access and/or participation in that service.</p>	<p>we find in the shop. They might be very expensive, but there is a way of having a small wood and make it as a seat, and then teach him how to sit on that. So that when he goes to the next place and he finds a seat, he will know how to use it. How to sit and eat. I think it's ... we need to focus on something that is helpful to local South African people (Guler et al., 2018; p. 1011)</p> <p>Like with the feeding. I don't know if I can call it an American way or something ... they think every child must have a table and two chairs ... and a fork ... which is most of us ... we don't even have that ... (Guler et al., 2018; p. 1011)</p>
<p>Theme 3: Community</p>		
<p>3a. Stigma</p>	<p>Parental experiences of stigma and/or judgement which pose barriers to seeking out support services. Alternatively, any factors which supported parents to overcome stigma which facilitated participation and/or access to support services</p>	<p>I'm not the kind of person who hides my child and I'm not afraid; I'm not ashamed that my son has autism... I am not, but there are people out there who are ashamed. People hide; people say, 'Don't tell other people that my son has autism'... I don't care what other people think. I've got my normal</p>

		<p>children, and my son has autism. I don't care what people think. (Fox et al., 2017; p. 309)</p> <p>Other parents approach us saying that, 'you know, we paid for this for my child. We would like our child to not be in the same class with this kind of child [with disabilities]. (Lee & Meadan, 2021a; p. 3592)</p>
3b. Social Support	<p>Barriers to support services which arise due to limited or a lack of social support for the parent/s. This includes within families, extended family, friends, and community members. Alternatively, where social support has facilitated access and/or participation in support services.</p>	<p>As an immigrant I had no family, I had a few friends, but we moved a lot. However, I made a couple of friends in a parent group, and I am still friends with them.... One of the most important things is to speak to others in the same situation. (Khanlou et al., 2017; p. 249)</p> <p>Also, in my case in the beginning I did not have support from anybody and it kind of shut me down from even wanting to get help from my daughter. (Stahmer et al., 2019; p. 760)</p>

Table S7*Studies Coded at Each Theme and Subtheme*

Author/s	Theme 1	1a	1b	1c	1d	1e	Theme 2	2a	2b	Theme 3	3a	3b
Birkin et al., (2008)	X	X				X	X	X	X			
Blanche et al., (2015)	X	X	X		X	X	X	X		X	X	X
Chlebowski et al., (2018)	X	X				X						
Dababnah & Bulson, (2015)	X	X	X	X	X	X	X		X	X	X	
Fox et al., (2017)	X	X	X			X	X	X		X	X	X
Guler et al., (2018)	X	X			X	X	X	X	X	X	X	X
Hong & Singh, (2019)	X	X	X	X	X	X	X		X	X		X
Khanlou et al., (2017)	X	X	X	X	X	X	X	X	X	X	X	X
Lee & Meadan, (2021a)	X	X	X	X	X	X	X	X	X	X	X	X
Luelmo et al., (2020)	X	X	X	X	X	X	X	X		X		X
Nilses et al., (2019)	X	X	X	X		X	X	X	X	X	X	X
Pearson & Meadan (2018)	X	X		X	X	X	X		X	X		X
Pickard & Ingersoll (2016)	X	X		X	X	X	X		X			
Pickard, Kilgore, & Ingersoll, (2016)	X	X	X	X	X	X	X		X	X	X	X
Pickard et al., (2019)	X				X	X	X		X	X		
Sakai et al., (2019)	X	X	X			X	X	X	X	X		X

Shanmugarajh et al., (2022)	X	X	X		X	X	X	X	X	X		X
Stahmer et al. (2019)	X	X	X	X	X	X	X	X	X	X	X	X

Note. 'X' indicates the study contributed to this theme/subtheme.

APPENDIX C

STUDY 1 PARENT SURVEY

Overview

In this study, we will be looking to see if different life situations, circumstances and/or factors impact the types of barriers and helpers to Professional Support Services for a child (18 years of age or younger) on the autism spectrum in New Zealand.

What are Professional support services?

Professional support services may also be referred to as intervention or therapy. Examples may include, but are not limited to, speech and language therapy, occupational therapy, ABA-based therapy, psychologist support, physical therapy, play therapy, drama therapy, art therapy, music therapy, social skills support, Cognitive behavioural therapy (CBT), parent education/training programmes, routine/play-based therapy, behaviour support.

Survey Outline:

The survey is made up of:

1. A set of questions to check eligibility.
2. Demographic questions which are important to our research
3. A list of 35 potential barriers and the opportunity to add your own.
4. A list of 35 potential helpers and the opportunity to add your own.
5. Two (2) optional questions for further information you may wish to provide.

The survey should take no more than 20 minutes to complete.

Your child: While we understand that there are many caregivers in Aotearoa New Zealand who care for more than one child on the autism spectrum, we would appreciate if you could please fill in this survey with any one child in mind. You are most welcome to fill in further surveys for each of your children on the autism spectrum if you wish.

Anonymity: This survey is completely anonymous. All information you provide will remain confidential. Please do not include any information which could identify you or your child (e.g. names, address, phone numbers).

If you have not visited the study website, you may do so at:

nzasdsupportresearch.wordpress.com.

Consent: Please note: your consent to participate in this study is implied through your voluntary participation in this survey

Closure Date: Please mail the completed survey by December 10th, 2021. Ngā mihi.

Eligibility Questions

Q1-Do you currently live in New Zealand?

Yes

No

Q2 Is the child you are completing this survey for 18 years of age or younger?

Yes

No

Q3 Has your child been diagnosed as on the autism spectrum?

Yes

No

Q4 Are you one of the child's primary caregivers?

Yes

No

If you answered no to any of the above questions:

Ngā mihi nui, thank you so much for your interest in this study. At this time we are specifically looking for feedback from New Zealand primary caregivers to a child 18 years or younger on the autism spectrum. Unfortunately, the answers provided do not meet our current criteria for participation. We appreciate and thank you for your time.

If you answered yes to all of the above questions:

Please continue

Demographic Questions
Parent/Caregiver Questions

1. What is your relationship to your child?

- | | |
|-------------------------------------|--|
| <input type="checkbox"/> Mother | <input type="checkbox"/> Grandmother |
| <input type="checkbox"/> Father | <input type="checkbox"/> Grandfather |
| <input type="checkbox"/> Stepmother | <input type="checkbox"/> Other (Please state): _____ |
| <input type="checkbox"/> Stepfather | |

2. Who currently lives within your household? My child's:

- | | |
|-------------------------------------|--------------------------------------|
| <input type="checkbox"/> Mother | <input type="checkbox"/> Grandmother |
| <input type="checkbox"/> Father | <input type="checkbox"/> Grandfather |
| <input type="checkbox"/> Stepmother | <input type="checkbox"/> Sibling/s |
| <input type="checkbox"/> Stepfather | (Please state how many): _____ |
| | <input type="checkbox"/> Others: |
| | (Please state): _____ |

3. Are you the person who would usually access, co-ordinate, and/or participate in support services for your child on the autism spectrum?

- Yes
 No

4. Which ethnic group(s) do you belong to? Please select all which apply to you:

- | | |
|---|--|
| <input type="checkbox"/> New Zealand European | <input type="checkbox"/> Niuen |
| <input type="checkbox"/> Māori | <input type="checkbox"/> Chinese |
| <input type="checkbox"/> Samoan | <input type="checkbox"/> Indian |
| <input type="checkbox"/> Cook Islands Māori | <input type="checkbox"/> Other e.g. Dutch, Japanese, Tokelauan |
| <input type="checkbox"/> Tongan | (Please state): _____ |

5. How would you describe the area that you live in?

- Urban/Suburban
 Rural

6. People in Aotearoa New Zealand have different levels of access to formal education.

What is the highest level of education you have completed?

- | | |
|--|--|
| <input type="checkbox"/> Primary/Intermediate School | <input type="checkbox"/> Bachelor's/Undergraduate Degree |
| <input type="checkbox"/> College/High School | <input type="checkbox"/> Postgraduate Degree |
| <input type="checkbox"/> Trade/technical/vocational training | <input type="checkbox"/> Other |

(Please describe): _____

7. What is the highest level of education completed by anybody living in your household?

- | | |
|--|--|
| <input type="checkbox"/> Primary/Intermediate School | <input type="checkbox"/> Bachelor's/Undergraduate Degree |
| <input type="checkbox"/> College/High School | <input type="checkbox"/> Postgraduate Degree |
| <input type="checkbox"/> Trade/technical/vocational training | <input type="checkbox"/> Other |

(Please describe): _____

8. We would like to find out how a family's level of financial resourcing may affect barriers and helpers to support services for their child on the autism spectrum.

I currently receive or have a:

- Community Services Card
- An income tested benefit.
- Both an income tested benefit and the Community Services Card
- Neither an income tested benefit OR the Community Services Card
- I prefer not to say

Child-related Questions

1. How old is your child?

Years _____

Months _____

2. How old was your child when they were diagnosed as on the autism spectrum?

If you cannot recall or prefer not to say, please move to the next question.

Years _____

Months _____

Children with autism spectrum sometimes have other diagnoses as well. Does your child have any of the following clinical diagnoses in addition to autism?

Please select all which apply to your child:

- | | |
|--------------------------------------|---|
| <input type="checkbox"/> ADHD or ADD | <input type="checkbox"/> Intellectual disability |
| <input type="checkbox"/> GDD | <input type="checkbox"/> Other; Please state: _____ |
| <input type="checkbox"/> Anxiety | <input type="checkbox"/> No other diagnoses |
| <input type="checkbox"/> Depression | <input type="checkbox"/> I prefer not to say |

How would you describe your child's gender?

- Male
- Female
- Non-binary
- I prefer not to say

Which ethnic group(s) does your child belong to?

Please select all which apply to your child

- | | |
|---|--|
| <input type="checkbox"/> New Zealand European | <input type="checkbox"/> Niuen |
| <input type="checkbox"/> Māori | <input type="checkbox"/> Chinese |
| <input type="checkbox"/> Samoan | <input type="checkbox"/> Indian |
| <input type="checkbox"/> Cook Islands Māori | <input type="checkbox"/> Other e.g. Dutch, Japanese, Tokelauan |
| <input type="checkbox"/> Tongan | (Please state): _____ |

How much spoken language does your child have?

- | | |
|---|---|
| <input type="checkbox"/> No spoken language | <input type="checkbox"/> Phrase level speech (3–4-word sentences e.g. “I go car”, “Grandma at shop”). |
| <input type="checkbox"/> Single words | <input type="checkbox"/> Fluent speech (full sentences e.g. “I went to the zoo and saw a bear”) |
| | <input type="checkbox"/> I prefer not to say |

Barriers to Professional support services

We would like to know your experience of barriers to any of the support services you have accessed, wanted to access, or participated in for your child on the autism spectrum in the past 12 months.

To answer, please select one of five responses:

Not Applicable: This is not applicable to me/my child

Not at all a barrier: This is something you have not experienced or, if you have, it was not a barrier

Somewhat a barrier: This was a challenge which was relatively easily solved

A barrier: This was a definite challenge which was not easily solved

Very much a barrier: This was very much a challenge. It could not be solved and/or I could not access or participate in the support service because of this.

Potential Barriers to any professional support service you have accessed, wanted to access, or participated in over the past 12 months.

	Not applicable	Not at all a Barrier	Somewhat a Barrier	A Barrier	Very much a barrier
The support service(s) were only offered in English	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The support service(s) cost too much	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The time of sessions did not suit my work schedule or a family member's work schedule	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The support service(s) conflicted with my cultural beliefs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The support service(s) were not responsive to my/my child's cultural needs/values	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt my parenting would be/was judged	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I could not find a clinician or provider who was able/willing to help me access support service(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I could not find information on how to access support service(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not have a good relationship with the provider	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The provider did not appear to understand my child's/family's needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Potential Barriers to any professional support service you have accessed, wanted to access, or participated in over the past 12 months.

	Not applicable	Not at all a Barrier	Somewhat a Barrier	A Barrier	Very much a barrier
The provider did not respond to my phone calls/emails/texts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The provider requested too much personal information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There was nobody providing the support service(s) in my local area	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had difficulty gaining a referral for the support service(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It was difficult to communicate with the provider during the support service session(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The available appointment times were not suitable.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child was not the right age for the support service(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Waiting lists for the support service(s) were too long	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was unable to access childcare during the support service(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child and/or a family member's illness made attending the support service(s) difficult	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Potential Barriers to <u>any</u> professional support service you have accessed, wanted to access, or participated in over the past 12 months.					
	Not applicable	Not at all a Barrier	Somewhat a Barrier	A Barrier	Very much a barrier
Stressful personal event(s) made attending the support service(s) difficult	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A family member disagreed with the support service(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child refused to attend the support service(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had obligations to extended family/friends which needed to be prioritised	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had no access to transport	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There was no affordable/accessible parking at the support service(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm not sure which support service(s) are best for my child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm not sure what kinds of support service(s) are available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The support service(s) sessions were too long	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The support service(s) was not individualised to my child and/or my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Potential Barriers to any professional support service you have accessed, wanted to access, or participated in over the past 12 months.

	Not applicable	Not at all a Barrier	Somewhat a Barrier	A Barrier	Very much a barrier
The support service did not align with my parenting approach	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking part in the support service added/would add stress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was given too much homework from the support service sessions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The strategies taught in the support service(s) were too confusing or difficult to learn	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There were not enough opportunities for me to provide input into the support service(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The support service(s) was of low quality	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The support service(s) was delivered in my home.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The support service(s) was delivered in a clinic or community setting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Optional Question: Are there any Barriers you experienced which have not been listed?
Please continue to the next question if you have not experienced any additional barriers

	Somewhat a barrier	A Barrier	Very much a barrier
Other barrier 1 (Please share below) <hr/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other barrier 2 (Please share below) <hr/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Optional Question: Is there anything else which you would like to share with us about barriers to professional support services for your child on the autism spectrum?

Helpers to professional support services

Please think about all of the services that you have accessed or wanted to access for your child over the last 12 months and rate the extent to which the following factors were helpful.

To answer, please select one of five responses:

Not helpful: Mark this box if you have experienced the helper stated but it was not helpful.

Somewhat helpful: This was only a little helpful, it did not make a large difference.

Helpful: This was helpful to the support service(s) for my child

Very Helpful: This made a big difference and/or was vital to the support service(s) for my child/family

I did not experience this: You have not experienced the helper stated.

Potential helper to any professional support service you have accessed, wanted to access, or participated in over the past 12 months

	I did not experience this	Not Helpful	Somewhat Helpful	Helpful	Very Helpful
The support service(s) was offered in more than one language	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The support service(s) was affordable or free	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I and/or a family member were able to work from home or take time off work so my child could access the support service(s).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My and/or my child's culture was acknowledged in the support service.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The support service(s) approaches were responsive to my/my child's cultural beliefs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The support service(s) was a good fit with my parenting approach	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had help/support in accessing the support service(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was able to easily find information about how to access a support service(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had a good relationship with the provider	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The provider understood my child's and/or family's needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Potential helper to any professional support service you have accessed, wanted to access, or participated in over the past 12 months

	I did not experience this	Not Helpful	Somewhat Helpful	Helpful	Very Helpful
It was easy to communicate with the provider during support service sessions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The provider responded to my calls/texts/emails	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The provider did not ask for too much personal information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There were a range of support services in my local area	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A professional quickly referred me to a support service(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The support service(s) had a range of times to choose from when scheduling an appointment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child was seen soon after referral	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had access to reliable childcare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child enjoyed the support service(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child's strengths were highlighted and shared with me by the provider	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Potential helper to any professional support service you have accessed, wanted to access, or participated in over the past 12 months

	I did not experience this	Not Helpful	Somewhat Helpful	Helpful	Very Helpful
The support service helped me to better understand my child and their needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other adult family members (e.g. other parent, grandparent, aunt, or uncle) were included in the support service(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child's siblings were included in the support service(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It was easy to reschedule appointments when needed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had access to transport to get to and from sessions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There was plenty of affordable/accessible parking at the support service(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I knew how to find information about available support service(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was able to advocate for my child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accessing the support service(s) was a simple process	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was able to easily find information on support service(s) which would suit my child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Potential helper to any professional support service you have accessed, wanted to access, or participated in over the past 12 months

	I did not experience this	Not Helpful	Somewhat Helpful	Helpful	Very Helpful
I was able to easily find information on local provider(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The support service(s) was individualised to my child and family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The support service(s) taught me helpful strategies to work with my child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The length of support service sessions was flexible and adapted to my family's needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My input and feedback were used in the support service(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was provided with information on "next steps" for my child when the support service(s) ended	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The support service(s) was delivered in my home.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The support service(s) was delivered in a clinic or community setting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q34 Are there any Helpers you experienced which have not been listed?

Please continue to the next question if you have not experienced any additional helpers

	Somewhat Helpful	Helpful	Very Helpful
Other helper 1 (Please State)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other helper 2 (Please State) (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Optional Question: Is there anything else which you would like to share with us about helpers to professional support services for your child on the autism spectrum?

Optional Question: If you would like to share with us the support services your child is currently receiving, please list them here. If possible, please also state an estimate of the number of hours your child receives services for per week.

Ngā mihi nui – Thank you so much for responding to this survey. We know how valuable your time is and appreciate your participation!

If you have any questions regarding this study, or the survey, don't hesitate to contact myself, Carla Wallace-Watkin at Carla.wallacewatkin@vuw.ac.nz, or my supervisor Hannah Waddington at Hannah.waddington@vuw.ac.nz. The study website will be updated with results once data has been reviewed and analysed. You may access the website and the results at nzasdsupportresearch.wordpress.com

APPENDIX D

STUDY 1 PARTICIPANT INFORMATION AND CONSENT FORM



Barriers and Facilitators to Intervention for New Zealand Families with a Child on the Autism Spectrum

INFORMATION FOR PARTICIPANTS

You are invited to take part in this research. Please read this information before deciding whether or not to take part. If you decide to participate, thank you. If you decide not to participate, thank you for considering this request.

Who am I?

My name is Carla Wallace-Watkin and I am a PhD student at Victoria University of Wellington. This research project is work towards my PhD thesis.

What is the aim of the project?

This project aims to examine the types of barriers and helpers New Zealand parents experience when accessing and/or participating in intervention for their child with autism spectrum disorder (ASD). It will also explore how different factors (e.g. your child's age, family level of financial resourcing) might impact the types and/or amounts of barriers and helpers parents report.

Your participation will support this research by helping us to understand what parents find helpful and/or challenging when accessing and participating in intervention for their child with ASD. Information gathered will also be used to adapt an early intervention to the New Zealand setting, particularly for families who experience financial challenges. This research has been approved by the Victoria University of Wellington Human Ethics Committee #29469.

How can you help?

You have been invited to participate because you are a New Zealand parent or caregiver to a child aged 18 years or younger who has been diagnosed with autism spectrum disorder (ASD). If you agree to take part, you will complete a survey. The survey will ask you questions about barriers and helpers to intervention. The survey will take you approximately fifteen to twenty (15-20) minutes to complete.

What will happen to the information you give?

This research is anonymous. This means that nobody, including the researchers will be aware of your identity. Consent is implied through voluntary participation. This means that by answering the survey, you are giving consent for us to use your responses in this research. Your answers will remain completely anonymous and unidentifiable. Once you submit the survey, it will be impossible to retract your answer. Please do not include any personal identifiable information in your responses.

What will the project produce?

The information from my research will be used in my PhD thesis and in an academic publication as well as conferences. The information will also be shared with community intervention providers.

If you have any questions or problems, who can you contact?

If you have any questions, either now or in the future, please feel free to contact either me or my supervisor using the below details:

PhD student:

Name: Carla Wallace-Watkin
Email: Carla.wallacewatkin@vuw.ac.nz

Supervisor:

Name: Hannah Waddington
Role: Senior Lecturer, Educational Psychologist & Clinic Lead of the VUW Autism Clinic
School: School of Education
Phone: 04 463 9733
Email: Hannah.waddington@vuw.ac.nz

Human Ethics Committee information

If you have any concerns about the ethical conduct of the research, you may contact the Victoria University of Wellington HEC Convenor: Associate Professor Judith Loveridge. Email hec@vuw.ac.nz or telephone +64-4-463 6028.

APPENDIX E
STUDY 1 SUPPLEMENTARY MATERIAL

Table S8*Demographic Characteristics of Parents by Response Type*

Demographic characteristic	Barriers			Facilitators		
	Mean (SD)	n	%	Mean (SD)	n	%
Relationship to child						
Mother		163	94.2		136	95.1
Father		4	2.3		3	2.1
Other (grandmother; birthing parent)		4	2.3		3	1.4
Preferred not to say		2	1.2		1	0.7
Parent relationship						
Single parent		40	23.1		31	21.7
Two parents		132	76.3		112	78.3
Preferred not to say		1	0.6		-	-
Child's sibling status						
No siblings		48	27.7		43	30.1
At least one sibling	1.3 (1.2)	124	71.7	1.2 (1.2)	100	69.9
Preferred not to say		1	0.6		-	-
Parent ethnicity						
New Zealand European/European		126	72.8		105	73.4
Māori		31	17.9		25	17.5
Other		15	8.7		12	8.4
Preferred not to say		1	0.6		1	0.7
Household location						

Urban/Suburban	152	87.9	128	89.5
Rural	20	11.6	15	10.5
Preferred not to say	1	0.6	-	-
Household highest level of education				
Trade or secondary school qualification	54	31.2	43	30.1
University degree	115	66.5	99	69.2
Preferred not to say	4	2.3	1	0.7
Household level of resourcing				
Lower Income	78	45.6	63	44.1
Higher Income	93	54.4	79	55.2
Preferred not to say	2	1.2	1	0.7

Table S9*Demographic Characteristics for the Children of Parent Participants*

Demographic characteristic	Barriers			Facilitators		
	Mean (SD)	n	%	Mean (SD)	n	%
Child age						
Current (Years.Months)	11.1 (3.7)			11.3 (4)		
At diagnosis (Years.Months)	6.7 (3.7)			6.8 (3.8)		
Additional diagnoses						
No additional diagnoses		29	16.8		21	14.7
One or more additional diagnoses	1.8 (1.5)	144	83.2	1.9 (1.6)	122	85.3
*Types of additional diagnoses						
Anxiety		76	43.9		66	46.2
ADHD/ADD		72	41.6		63	44.1
Global development delay		24	13.9		17	11.9
Depression		20	11.6		16	11.2
Intellectual disability		22	12.7		17	11.9
Dyspraxia		15	8.7		14	9.8
Sensory processing difficulties		11	6.4		10	7.0
Specific learning disability (e.g., dyslexia, dysgraphia)		9	5.2		9	6.3
Auditory processing disorder		6	3.5		5	3.5

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Other	55	31.8	51	35.7
Child gender				
Male	129	74.6	106	74.1
Female	35	20.2	29	20.3
Non-binary	7	4.0	7	4.9
Preferred not to say	2	1.2	1	0.7
Child ethnicity				
New Zealand European/European	113	65.3	94	66.7
Māori	38	22.0	30	21.0
Other	20	11.6	17	11.9
Preferred not to say	2	1.2	2	1.4
Level of language				
Speaking	160	92.5	135	94.4
Non-speaking	11	6.4	7	4.9
Preferred not to say	2	1.2	1	0.7

Note. * Parents were able to select more than one additional diagnosis, therefore the totals sum to more than 173 (100%)

Table S10*Barrier and Facilitator Statements for Each Thematic Grouping*

Theme or subtheme	Statement
Support service accessibility	
Knowledge and education	<p><u>Barriers</u></p> <ol style="list-style-type: none"> 1. I could not find information on how to access support service(s) (B8) 2. I'm not sure which support service(s) are best for my child (B27) 3. I'm not sure what kinds of support service(s) are available (B28) <p><u>Facilitators</u></p> <ol style="list-style-type: none"> 1. I knew how to find information about available support service(s) (F27) 2. The support service helped me to better understand my child and their needs (F21) 3. I was able to easily find information on support service(s) which would suit my child (F30) 4. I was able to easily find information about how to access a support service(s) (F8) 5. I was able to advocate for my child (F28)
Service pathways	<p><u>Barriers</u></p> <ol style="list-style-type: none"> 1. I had difficulty gaining a referral for the support service(s) (B14) 2. I could not find a clinician or provider who was able/willing to help me access support service(s) (B7) 3. My child was not the right age for the support service(s) (B17) 4. Waiting lists for the support service(s) were too long (B18) <p><u>Facilitators</u></p>

Theme or subtheme	Statement
	<ol style="list-style-type: none"> 1. A professional quickly referred me to a support service(s) (F15) 2. I had help/support in accessing the support service(s) (F7) 3. My child was seen soon after referral (F17) 4. Accessing the support service(s) was a simple process (F29) 5. I was provided with information on “next steps” for my child when the support service(s) ended (F36)
Financial pressure	<p><u>Barriers</u></p> <ol style="list-style-type: none"> 1. The support service(s) cost too much (B2) 2. The time of sessions did not suit my work schedule or a family member’s work schedule (B3) <p><u>Facilitators</u></p> <ol style="list-style-type: none"> 1. The support service(s) was affordable or free (F2) 2. I and/or a family member were able to work from home or take time off work so my child could access the support service(s) (F3)
Geographic location	<p><u>Barriers</u></p> <ol style="list-style-type: none"> 1. There was nobody providing the support service(s) in my local area (B13) 2. I had no access to transport (B25) 3. There was no affordable/accessible parking at the support service(s) (B26) 4. The support service(s) was delivered in my home (B37) 5. The support service(s) was delivered in a clinic or community setting (B38) <p><u>Facilitators</u></p>

Theme or subtheme	Statement
	<ol style="list-style-type: none"> 1. There were a range of support services in my local area (F14) 2. I had access to transport to get to and from sessions (F25) 3. There was plenty of affordable/accessible parking at the support service(s) (F26) 4. The support service(s) was delivered in my home (F37) 5. The support service(s) was delivered in a clinic or community setting (F38) 6. I was able to easily find information on local provider(s) (F31)
Providers	<p><u>Barriers</u></p> <ol style="list-style-type: none"> 1. I did not have a good relationship with the provider (B9) 2. The provider did not appear to understand my child's/family's needs (B10) 3. The provider did not respond to my phone calls/emails/texts (B11) 4. The provider requested too much personal information (B12) 5. It was difficult to communicate with the provider during the support service session(s) (B15) <p><u>Facilitators</u></p> <ol style="list-style-type: none"> 1. I had a good relationship with the provider (F9) 2. The provider understood my child's and/or family's needs (F10) 3. The provider responded to my calls/texts/emails (F12) 4. The provider did not ask for too much personal information (F13) 5. It was easy to communicate with the provider during support service sessions (F11)
Diversity of support services	
Cultural and linguistic	<u>Barriers</u>

Theme or subtheme	Statement
considerations	<ol style="list-style-type: none"> 1. The support service(s) were only offered in English (B1) 2. The support service(s) conflicted with my cultural beliefs (B4) 3. The support service(s) were not responsive to my/my child's cultural needs/values (B5) <p><u>Facilitators</u></p> <ol style="list-style-type: none"> 1. The support service(s) was offered in more than one language (F1) 2. The support service(s) approaches were responsive to my/my child's cultural beliefs (F5) 3. My and/or my child's culture was acknowledged in the support service (F4)
Service flexibility	<p><u>Barriers</u></p> <ol style="list-style-type: none"> 1. There were not enough opportunities for me to provide input into the support service(s) (B35) 2. The available appointment times were not suitable (B16) 3. My child refused to attend the support service(s) (B23) 4. The support service(s) sessions were too long (B29) 5. The support service(s) was not individualised to my child and/or my family (B30) 6. The support service did not align with my parenting approach (B31) 7. I was given too much homework from the support service sessions (B33) 8. The strategies taught in the support service(s) were too confusing or difficult to learn (B34) 9. The support service(s) was of low quality (B36) <p><u>Facilitators</u></p> <ol style="list-style-type: none"> 1. The support service(s) had a range of times to choose from when scheduling an appointment (F16)

Theme or subtheme	Statement
	<ol style="list-style-type: none"> 2. It was easy to reschedule appointments when needed (F24) 3. The support service(s) was individualised to my child and family (F32) 4. The support service(s) taught me helpful strategies to work with my child (F33) 5. The length of support service sessions was flexible and adapted to my family's needs (F34) 6. My input and feedback were used in the support service(s) (F35) 7. My child enjoyed the support service(s) (F19) 8. The support service(s) was a good fit with my parenting approach (F6)
Community	
Stigma	<p><u>Barriers</u></p> <ol style="list-style-type: none"> 1. I felt my parenting would be/was judged (B6) <p><u>Facilitators</u></p> <ol style="list-style-type: none"> 1. My child's strengths were highlighted and shared with me by the provider (F20)
Social support	<p><u>Barriers</u></p> <ol style="list-style-type: none"> 1. A family member disagreed with the support service(s) (B22) 2. I had obligations to extended family/friends which needed to be prioritised (B24) 3. Taking part in the support service added/would add stress (B32) 4. Stressful personal event(s) made attending the support service(s) difficult (B21) 5. My child and/or a family member's illness made attending the support service(s) difficult (B20) 6. I was unable to access childcare during the support service(s) (B19)

Theme or subtheme	Statement
	<p data-bbox="633 260 786 288"><u>Facilitators</u></p> <ol data-bbox="685 316 1917 512" style="list-style-type: none"><li data-bbox="685 316 1917 403">1. Other adult family members (e.g. other parent, grandparent, aunt, or uncle) were included in the support service(s) (F22)<li data-bbox="685 424 1917 461">2. My child's siblings were included in the support service(s) (F23)<li data-bbox="685 481 1917 512">3. I had access to reliable childcare (F18)

Table S11*Definitions Provided for Each Possible Response to Barrier and Facilitator Statements*

Possible Response	Numeric Value	Definition Provided
Barriers		
Not applicable	1	This is not applicable to me/my child
Not at all a barrier	1	This is something you have not experienced or, if you have, it was not a barrier
Somewhat a barrier	2	This was a challenge which was relatively easily solved
A barrier	3	This was a definite challenge which was not easily solved
Very much a barrier	4	This was very much a challenge. It could not be solved and/or I could not access or participate in the support service because of this.
Facilitators		
I did not experience this	1	You have not experienced the helper stated.
Not helpful	1	Mark this box if you have experienced the helper stated but it was not helpful.
Somewhat helpful	2	This was only a little helpful, it did not make a large difference.
Helpful	3	This was helpful to the support service(s) for my child
Very helpful	4	This made a big difference and/or was vital to the support service(s) for my child/family

Table S12

Median and p-value Results of Posthoc Pairwise Comparison Tests of Significance Between Barrier and Facilitator Subthemes

Subtheme	Facilitator Median	Knowledge & education	Service pathways	Financial pressure	Geographic location	Providers	Culture	Service flexibility	Stigma	Social support	Barrier Median
Knowledge & education	1.8	-	1	.093	<.001	<.001	<.001	<.001	<.001	<.001	2.3
Service pathways	1.4	.005	-	.072	<.001	<.001	<.001	<.001	<.001	<.001	2.5
Financial pressure	2.0	.070	<.001	-	<.001	<.001	<.001	<.001	.90	<.001	2.0
Geographic location	1.8	1	.010	.034	-	.023	.003	<.001	<.001	.035	1.4
Providers	2.4	<.001	<.001	1	<.001	-	<.001	1	.034	1	1.6
Culture	1.0	<.001	.25	<.001	<.001	<.001	-	<.001	<.001	<.001	1
Service flexibility	1.75	1	.032	.011	1	<.001	<.001	-	.76	1	1.6
Stigma	2.0	1	.019	.019	1	<.001	<.001	1	-	.022	2.0
Social support	1.3	<.001	1	<.001	.001	<.001	1.0	.002	.001	-	1.5

Note. Significance values have been adjusted by Bonferroni correction for multiple tests

Bold values indicate a significant difference

Barriers Facilitators

Table S14*Mean Rating and Number of Parents Selecting Each Additional Barrier*

New Code	M (SD)	n
1. My child was declined support based on the support service/s criteria	3.87 (0.35)	14
2. The provider appeared to have limited knowledge of autism or autism-specific supports	3.83 (0.39)	13
3. The support service I would like my child to receive is not currently offered.	4 (0)	5
4. I do not agree with the approaches taken within the support service/s	4 (0)	3
5. The provider was unwilling to collaborate with other services	3.33 (0.58)	3
6. There was a lack of consistency in and/or between services	3.33 (0.58)	3
7. There was no follow-up from the provider	4 (0)	2
8. My child's difficulties were focused on rather than their strengths	4 (0)	2
9. There were long waiting times for meetings, planning, and/or initiation of services once my child began the support service	3 (0)	1
10. The support service did not have multi-cultural providers	3 (0)	1

Table S16*Rating and Number of Parents Selecting Each Additional Facilitator*

New Facilitator Statement	Rating	n
1. I had Social Support from family, friends, and/or other parents of autistic children	3	1
2. The support service is informed by the views of autistic adults	3	1
3. The provider taught the adults in my child's life (e.g. teachers) helpful strategies	4	1
4. The support service is/was available online	3	1

Table S17

Percentage of Participants Selecting Paired Barrier and Facilitator Statements

Statement #	Percent																																					
	B 1	B 2	B 3	B 4	B 5	B 6	B 7	B 8	B 9	B 10	B 11	B 12	B 13	B 14	B 15	B 16	B 17	B 18	B 19	B 20	B 21	B 22	B 23	B 24	B 25	B 26	B 27	B 28	B 29	B 30	B 31	B 32	B 33	B 34	B 35	B 36	B 37	B 38
F 1	0	3	3	0	1	3	3	3	2	4	2	2	2	2	3	3	3	4	2	2	3	2	2	1	1	1	3	4	1	3	1	3	1	2	2	1	1	2
F 2	1	52	55	9	18	52	51	51	34	50	36	18	43	53	38	40	31	68	22	30	43	22	37	22	7	23	58	62	22	43	39	50	32	30	38	39	8	28
F 3	1	37	35	6	13	34	34	33	22	32	25	10	29	33	19	27	18	44	13	18	27	13	21	12	3	11	36	39	17	26	22	28	20	12	22	25	6	20
F 4	1	23	24	5	13	20	20	21	12	20	15	8	19	21	15	13	15	29	8	13	15	11	16	11	3	8	20	25	7	19	15	20	13	9	17	14	3	10
F 5	1	21	22	5	10	19	17	20	10	19	13	8	19	19	12	13	15	28	8	12	15	10	16	10	3	7	21	24	8	17	14	20	12	11	14	12	2	8
F 6	2	47	47	6	15	42	45	48	25	41	31	13	41	46	27	36	29	62	24	24	36	20	33	17	5	18	53	58	22	37	28	43	27	23	29	27	6	23
F 7	2	31	32	5	10	29	26	27	15	26	20	10	22	29	18	22	17	42	18	20	27	11	20	15	4	11	31	36	15	24	23	30	20	20	20	19	5	15
F 8	1	28	28	5	9	26	20	18	11	22	19	6	20	22	13	22	14	35	14	15	22	9	19	10	3	10	27	27	12	22	17	25	17	14	15	16	4	13
F 9	3	51	50	8	15	47	48	54	27	45	31	15	43	49	29	36	30	67	25	28	40	23	33	21	6	19	56	62	23	41	35	49	29	26	30	30	7	24
F 10	1	48	46	5	11	41	43	48	25	39	31	15	38	45	27	34	29	61	24	24	37	17	31	17	6	17	52	57	21	35	30	44	27	25	29	28	4	22
F 11	2	54	53	8	16	48	51	55	31	48	33	17	45	53	30	37	30	69	26	27	41	20	33	20	6	18	60	65	23	45	35	49	30	26	34	35	7	24
F 12	2	51	52	6	16	47	48	52	29	47	30	17	45	52	30	37	29	68	27	27	38	20	34	21	7	19	59	64	23	44	34	48	30	25	33	31	7	24
F 13	2	40	44	6	11	41	38	43	28	41	24	15	36	41	29	29	26	55	23	24	33	17	27	17	6	17	50	52	20	37	29	39	23	25	29	26	6	21
F 14	1	13	16	2	3	13	9	12	6	10	11	4	11	13	8	12	7	21	10	6	14	4	12	7	2	6	15	17	6	12	11	16	11	10	10	10	3	5
F 15	2	28	31	3	6	24	24	26	13	25	17	10	22	24	15	25	14	40	17	15	24	9	21	14	4	11	33	37	13	24	18	27	18	18	20	19	5	13
F 16	2	32	31	3	11	28	27	28	15	25	21	10	23	30	17	22	17	42	16	17	24	13	20	17	3	8	36	36	16	27	20	29	20	19	22	19	5	15

F 17	1	19	16	2	4	17	16	18	10	14	13	6	17	16	12	11	9	26	10	10	17	7	13	8	3	6	20	23	8	15	13	18	10	13	11	10	1	9
F 18	1	20	21	3	8	22	17	18	12	15	15	6	20	20	12	15	13	26	11	13	17	10	9	9	4	7	20	23	9	16	12	20	13	13	15	13	3	12
F 19	1	34	33	5	10	28	31	31	16	27	22	8	27	34	17	24	20	45	17	18	26	15	22	14	4	11	36	41	15	22	20	34	21	17	19	18	5	13
F 20	2	37	34	4	11	33	35	36	17	31	22	10	27	36	20	27	21	48	19	20	31	13	23	17	6	13	40	44	17	28	23	37	24	18	20	21	5	16
F 21	2	47	46	6	13	41	45	50	24	41	31	12	39	45	27	35	27	61	24	26	38	19	32	18	6	19	52	58	23	34	30	46	28	24	29	28	6	22
F 22	1	27	27	4	8	25	28	29	17	26	21	11	25	31	17	20	15	36	13	18	24	12	21	11	3	13	31	34	11	22	19	27	16	17	22	21	3	17
F 23	1	11	13	3	3	13	11	13	7	10	10	6	14	14	8	8	8	18	8	6	13	5	10	8	3	6	15	16	6	9	9	14	8	10	10	9	1	6
F 24	1	30	27	3	8	29	27	29	15	23	19	9	26	29	19	19	18	39	14	16	24	12	22	15	4	10	34	35	13	24	22	31	20	20	21	21	3	15
F 25	1	39	38	6	13	36	36	38	22	35	27	13	31	39	24	31	22	52	22	21	31	17	27	15	5	19	42	46	17	31	27	36	25	23	28	27	6	20
F 26	1	38	37	6	12	34	35	39	22	34	26	10	31	36	22	27	17	48	17	15	25	11	24	13	4	12	44	48	10	28	23	35	20	19	25	26	4	17
F 27	1	27	27	3	6	24	22	22	15	21	19	7	22	24	13	22	13	37	15	10	19	10	17	11	3	7	29	30	13	22	18	25	18	14	16	15	5	11
F 28	2	54	52	6	16	48	50	55	30	48	35	17	45	52	31	40	32	69	26	29	43	22	36	21	7	20	59	64	23	42	33	51	31	27	34	34	8	25
F 29	1	22	22	4	7	19	15	15	12	16	11	7	17	18	10	15	8	27	13	13	18	7	14	8	3	8	21	24	9	16	12	19	13	12	12	13	3	9
F 30	1	20	20	2	5	16	10	13	8	14	11	5	15	14	10	13	9	24	10	10	15	6	13	9	3	6	19	20	8	15	10	17	11	10	10	8	3	8
F 31	1	22	21	4	6	20	13	13	11	15	12	6	13	16	10	15	8	29	10	10	17	6	13	10	3	5	22	22	11	16	13	20	13	11	9	13	4	10
F 32	2	35	34	3	9	34	33	36	15	29	22	11	27	34	19	26	19	49	17	18	31	13	23	17	7	14	38	45	15	24	23	36	21	20	21	22	5	16
F 33	1	39	41	4	12	39	36	41	21	34	28	10	33	41	22	31	24	55	21	20	31	16	27	17	6	13	45	50	20	31	25	38	25	21	28	25	7	20
F 34	2	30	31	4	11	28	27	31	14	24	20	9	24	29	13	20	16	43	15	15	23	11	18	14	4	8	36	39	13	23	19	30	19	18	18	18	4	13
F 35	2	39	36	6	12	34	32	35	17	30	24	12	29	36	19	27	22	50	20	20	31	14	25	16	5	14	39	45	16	27	24	36	23	18	23	23	6	19
F 36	1	27	24	2	6	24	22	22	13	20	15	8	19	22	13	20	14	34	14	11	21	10	14	10	3	8	27	29	12	17	16	25	16	14	13	14	4	13
F 37	2	34	33	6	13	34	30	32	20	31	22	13	30	31	22	22	21	43	20	22	31	15	25	17	3	12	35	39	20	29	25	37	25	22	22	22	5	15

F 38	1	42	41	5	14	36	36	40	24	35	27	13	34	41	28	31	24	52	19	20	31	15	27	15	4	17	44	48	18	32	24	36	25	20	29	27	6	18
---------	---	----	----	---	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	----	---	----	----	----	----	----	----	----	----	----	----	----	---	----

Note. Bold values indicate that 60% or more of participants selected both statements.

APPENDIX F

STUDY 2 PARENT INFORMATION SHEET



Adapting the Early Start Denver Model for lower financially resourced Aotearoa New Zealand families with an autistic child: A research-community partnership approach.

INFORMATION SHEET FOR PARTICIPANTS

Tēnā koe, Hello,

You are invited to take part in this research. Please read this information before deciding whether or not to take part. If you decide to participate, thank you. If you decide not to participate, thank you for considering this request.

Ko wai ahau / Who am I?

My name is Carla Wallace-Watkin and I am a Doctoral student in educational psychology at Te Herenga Waka—Victoria University of Wellington. This research project is work towards my PhD thesis.

He aha te whāinga mō tēnei rangahau / What is the aim of the project?

This project aims to find out your experience of receiving ESDM, including how this service fit with your values and beliefs, any strengths and/or challenges which came with accessing or participating in the service, as well as any possible improvements which could be made.

Your participation will support this research by helping us to understand what parents find is working well and what may be challenging when taking part in the ESDM service and provide some insight into the ways in which we could improve the service for families and whānau. This research has been approved by the Te Herenga Waka—Victoria University of Wellington Human Ethics Committee (#0000030539).

Ka pēhea tō āwhina mai / How can you help?

You have been invited to participate because you are a New Zealand parent/caregiver of a child (6 years or younger) who is, or has a high likelihood of being, autistic, you qualify for or have a community services card or an income tested benefit, and you have taken part in the ESDM service.

If you agree to take part, I will interview you in your preferred location (i.e. within your home, online via zoom, over the phone, in a quiet community location). I will ask you questions about your experiences with receiving ESDM. The interview will take no more than 1 hour (60 minutes). I will audio record the interview with your permission and write it up later. There will also be a brief demographic survey which you may fill in prior to the interview or with me during the interview. This brief survey will cover questions such as your child's age and your ethnicity. This is to provide context to the research results and to examine whether there are any differences in preferences and/or challenges between different demographic groups. You can choose to not answer any question or stop the interview at any time, without giving a reason. Any feedback you provide will be confidential and treated with care. We are very interested in learning ways we can improve our services. Your feedback, either positive or negative, will have no impact on your access to services or existing relationships.

After the interview, you will have the opportunity to provide feedback on your interview transcript, interview summary, my analysis of the results, and proposed changes to the ESDM service. This process is completely optional, you may choose to receive documents without providing feedback, or to not receive any of the aforementioned documents.

As a thank you for your time and insight you will receive a \$60 gift voucher. If you need to travel to participate in the interview, you will also be compensated for travel costs – up to \$20 for petrol or transport tickets and up to \$10 for parking.

You can withdraw from the study by contacting me at any time before 31 December 2022. If you withdraw, the information you provided will be destroyed or returned to you.

Ka ahatia ngā kōrero ka tukuna mai / What will happen to the information you give?

This research is confidential. This means that the researchers named below will be aware of your identity, but the research data will be combined and your identity will not be revealed in any reports, presentations, or public documentation. However, you should be aware that in small projects your identity might be obvious to others in your community.

Only my supervisors and I will read the notes and/or transcript of the interview. Recordings will be uploaded to the artificial intelligence transcription service otter.ai. The recording and transcript will be deleted from the transcription service as soon as transcripts are complete. The interview transcripts, summaries and any recordings will be kept securely and destroyed on or before 2 August 2026.

He aha ngā hua o te rangahau / What will the project produce?

The information from my research will be used in my PhD thesis and in an academic publication as well as conferences. The information will also be shared with providers from the autism clinic – Te Rāngai Takiwātanga team and community intervention providers.

Ki te whakaae mai koe, he aha ō mōtika hei kaitautoko i tēnei rangahau / If you accept this invitation, what are your rights as a research participant?

You do not have to accept this invitation if you don't want to. If you do decide to participate, you have the right to:

- choose not to answer any question;
- ask for the recorder to be turned off at any time during the interview;
- withdraw from the study before 31 December 2022;
- ask any questions about the study at any time;
- receive a copy of your interview recording;
- receive a copy of your interview transcript;
- read over and comment on a written summary of your interview
- be able to read any reports of this research by emailing the researcher to request a copy.

Mehemea ngā pātai, he raruraru rānei, me whakapā ki a wai / If you have any questions or problems, who can you contact?

If you have any questions, either now or in the future, please feel free to contact either:

PhD student:

Name: Carla Wallace-Watkin

Email: Carla.wallacewatkin@vuw.ac.nz

Supervisor:

Name: Hannah Waddington

Role: Senior Lecturer, Educational

Psychologist & Clinic Lead of the VUW

Autism Clinic

School: School of Education

Phone: 04 463 9733

Email: Hannah.waddington@vuw.ac.nz

He kōrero whakamārama mō HEC / Human Ethics Committee information

If you have any concerns about the ethical conduct of the research you may contact the Te Herenga Waka—Victoria University of Wellington HEC Convenor, Associate Professor Rhonda Shaw, by emailing hec@vuw.ac.nz.

APPENDIX G

PARENT CONSENT FORM



Adapting the Early Start Denver Model for lower financially resourced Aotearoa New Zealand families with an autistic child: A research-community partnership approach.

CONSENT TO INTERVIEW

This consent form will be held for five years.

Researcher: Carla Wallace-Watkin, School of Education, Te Herenga Waka—Victoria University of Wellington.

- I have read the Information Sheet, and the project has been explained to me. My questions have been answered to my satisfaction. I understand that I can ask further questions at any time.
- I agree to take part in an audio recorded interview.

I understand that:

- I may withdraw from this study at any point before 31 December 2022, and any information that I have provided will be returned to me or destroyed.
- The identifiable information I have provided will be destroyed on 31 December 2022
- Any information I provide will be kept confidential to the researcher and their supervisor. Audio recordings only may be uploaded to otter.ai for transcription purposes and will be deleted from this service as soon as the transcription is complete.
- The findings may be used for a PhD dissertation and/or academic publications and/or presented to conferences.
- The interview notes/recordings will be kept confidential to the researcher, the supervisor, and the transcription service.
- My name will not be used in reports and utmost care will be taken not to disclose any information that would identify me.
- I would like a copy of the transcript of my interview: Yes No
- I would like a summary of my interview: Yes No
- I would like a copy of the initial results and understand I am not obligated to provide feedback: Yes No

- I would like a copy of the proposed changes to the ESDM and understand I am not obligated to provide feedback: Yes No
- I would like to receive a copy of the final report and have added my email address below: Yes No

Signature of participant: _____

Name of participant: _____

Date: _____

Contact details: _____

APPENDIX H

PHASES OF STUDY 2 FOR COMMUNITY PARTNERS

Community Provider Phases

Below is an outline of the phases and the tasks associated with each phase. You may choose to participate in one full phase, or as many of the phases you wish.

Phase Number & Title	Tasks	Anticipated Dates Start - End
1. Research Design	<p>Communicate with the researcher (Carla) regarding the design of the study. This includes:</p> <ul style="list-style-type: none"> - Reviewing documents which will be emailed to you outlining the study aims, research questions, a copy of the parent demographic survey and interview guide. - Provide feedback/comments on the above documents via your preferred means (email, online using zoom, a phone call, in person) - An opportunity to review the edited documents and provide further feedback or comment. 	Friday October 21 st – Monday November 7 th 2022
2. Consultation during interviews	<p>Communicate with the researcher (Carla) regarding factors specific to the interview process. This may include:</p> <ul style="list-style-type: none"> - Cultural advice - Interview strategies 	Monday 14th November – Monday 19th December 2022
3. Data analysis process	<p>Review and provide feedback/comments on the following documents which will be emailed to you:</p> <ul style="list-style-type: none"> - De-identified initial researcher reflections and meaning making of the data. - De-identified thematic analysis results 	Tuesday 7th February – Thursday 22nd February
4. Adaptation process	<p>Review an initial list of proposed adaptations to the ESDM service designed to improve accessibility and participation for lower financially resourced families.</p>	Monday 6th March – Tuesday 26th March

	<ul style="list-style-type: none">- Provide feedback, comments, and your own ideas for adaptations to the ESDM based on the document emailed to you outlining the list of proposed adaptations.- An opportunity to review the final list of adaptations and provide further comment or feedback if you wish.	
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APPENDIX I

STUDY 2 COMMUNITY PARTNER INFORMATION SHEET



Adapting the Early Start Denver Model for lower financially resourced Aotearoa New Zealand families with an autistic child: A research-community partnership approach.

INFORMATION SHEET FOR COMMUNITY PARTNERS

Tēnā koe, Hello,

You are invited to take part in this research. Please read this information before deciding whether or not to take part. If you decide to participate, thank you. If you decide not to participate, thank you for considering this request.

Ko wai ahau / Who am I?

My name is Carla Wallace-Watkin, and I am a Doctoral student in educational psychology at Te Herenga Waka—Victoria University of Wellington. This research project is work towards my PhD thesis.

He aha te whāinga mō tēnei rangahau / What is the aim of the project?

This project aims to find out the experiences of lower financially resourced families when accessing and receiving a support service (The Early Start Denver Model, ESDM). This will include looking at how this service fit with family's values and beliefs, any strengths and/or challenges which came with accessing or participating in the service, as well as any possible improvements which could be made. We want to ensure that the ways we approach families are sensitive and considerate of their needs.

Your participation will support this research by providing us with insight based on your professional experiences and feedback as to the most appropriate and sensitive methods of approaching and working with a range of families. This research has been approved by the Te Herenga Waka—Victoria University of Wellington Human Ethics Committee (#0000030539).

Ka pēhea tō āwhina mai / How can you help?

You have been invited to participate because you: (1) provide services to autistic children or their families, (2) have relevant experience with autistic children or their families, (3) you have experience with lower financially resourced families, (4) you have research expertise in the field of autism, and/or (5) you are an autistic adult.

If you agree to take part, you may choose to communicate and provide feedback on this project via your preferred method (i.e. email, online via zoom, over the phone, in person). Participation will involve: (1) discussing the project with me, (2) advising on factors relevant to the project (e.g. cultural considerations, terminology), (3) reading relevant documents, (4) providing feedback on documents, and (5) discussing feedback with me. You will have the opportunity to participate in your chosen phase/s of the project including (1) the design (i.e., providing feedback on potential parent interview questions), (2) the data analysis (i.e. providing feedback on my initial reflections and themes from the parent interviews) and (3) the adaptation process (i.e., discussing the ways we may adapt the ESDM for lower financially resourced families).

You can choose to participate in one phase of the project, or up to all three. You can choose to withdraw from the study at any time without giving a reason. Where possible, any information that I have provided will be returned to me or destroyed. You can withdraw from the study by contacting me at any time before 31 December 2022.

Ka ahatia ngā kōrero ka tukuna mai / What will happen to the information you give?

This research is confidential. This means that the researchers named below will be aware of your identity, but the research data will be combined and your identity will not be revealed in any reports, presentations, or public documentation. You may choose how you wish to be referred to within the written report (i.e. your professional title). However, you should be aware that in small projects your identity might be obvious to others in your community.

Only my supervisors and I will read the notes or emails regarding this project. Relevant information (i.e. your feedback, suggestions, relevant project information) will have all identifiable information, aside from your professional title, removed before being transferred to a word document and the email deleted. These documents will be securely held on a password protected hard drive and destroyed on or before 2 August 2026.

He aha ngā hua o te rangahau / What will the project produce?

The information from my research will be used in my PhD thesis and in an academic publication as well as conferences. The information will also be shared with providers from the autism clinic – Te Rāngai Takiwātanga team and community support service/intervention providers.

Ki te whakaae mai koe, he aha ō mōtika hei kaitautoko i tēnei rangahau / If you accept this invitation, what are your rights as a research participant?

You do not have to accept this invitation if you don't want to. If you do decide to participate, you have the right to:

- choose not to answer any question.
- choose not to participate in any particular project phase.
- withdraw from the study before 31 December 2022.
- ask any questions about the study at any time.
- receive a copy of our email correspondence or meeting notes.
- receive a copy of, read over, and comment on my written summaries of your feedback.
- be able to read any reports of this research by emailing the researcher to request a copy.

Mehemea ngā pātai, he raruraru rānei, me whakapā ki a wai / If you have any questions or problems, who can you contact?

If you have any questions, either now or in the future, please feel free to contact either:

PhD student:

Name: Carla Wallace-Watkin

Email: Carla.wallacewatkin@vuw.ac.nz

Supervisor:

Name: Hannah Waddington

Role: Senior Lecturer, Educational

Psychologist & Clinic Lead of the VUW
Autism Clinic

School: School of Education

Phone: 04 463 9733

Email: Hannah.waddington@vuw.ac.nz

He kōrero whakamārama mō HEC / Human Ethics Committee information

If you have any concerns about the ethical conduct of the research you may contact the Te Herenga Waka—Victoria University of Wellington HEC Convenor, Associate Professor Rhonda Shaw, by emailing hec@vuw.ac.nz.

APPENDIX J

COMMUNITY PARTNERS CONSENT FORM



Adapting the Early Start Denver Model for lower financially resourced Aotearoa New Zealand families with an autistic child: A research-community partnership approach.

CONSENT TO JOIN COMMUNITY PARTNERSHIP

This consent form will be held for five years.

Researcher: Carla Wallace-Watkin, School of Education, Te Herenga Waka—Victoria University of Wellington.

- I have read the Information Sheet, and the project has been explained to me. My questions have been answered to my satisfaction. I understand that I can ask further questions at any time.
- I agree to take part in communicating via email, online call, or in person to provide feedback, advisement, and to share recommendations regarding this project

I understand that:

- I may withdraw from this study at any point before 31 December 2022, and where possible any information that I have provided will be returned to me or destroyed.
- The identifiable information I have provided will be destroyed on 31 December 2022
- Any information I provide will be kept confidential to the researcher and their supervisor.
- The findings may be used for a PhD dissertation and/or academic publications and/or presented to conferences.
- The notes/emails will be kept confidential to the researcher and the supervisor.
- My name will not be used in reports and utmost care will be taken not to disclose any information that would identify me.
- I would like a copy of the email communications: Yes No
- I would like a copy of the summary of my feedback: Yes No
- I would like to receive a copy of the final report and have added my email address below: Yes No

Signature of participant: _____

Name of participant: _____

Date: _____

Contact details: _____

APPENDIX K

STUDY 2 SEMI-STRUCTURED INTERVIEW GUIDE

Adapting the Early Start Denver Model for lower financially resourced Aotearoa New Zealand families with an autistic child: A research-community partnership approach.

INTERVIEW GUIDE

The interviewer will begin the interview with the parent as follows: I am going to ask you some questions about your experiences with ESDM services. Any feedback you provide will be confidential. We're very interested in ways we can improve our services, and your feedback – either positive or negative – will have no impact on your access to services or existing relationships. You don't have to answer any questions that you do not want to, and you can ask for a break or ask to stop whenever you like.

Topic	Questions	Probes
Icebreaker	Why did you choose ESDM for your child/whānau?	This question is designed to act as an icebreaker, no probes will be used.
Experiences with ESDM Service	How would you describe your overall experience/journey with the ESDM service to other parents?	<ul style="list-style-type: none"> • What did you think about the amount of information provided to you prior to starting the ESDM Service? • If relevant – did you have a clear idea of the next steps you could take once you had finished with the service? <ul style="list-style-type: none"> - Other services which could be accessed - Where to go for further information/support
	How does ESDM/ESDM service fit, or not fit, with your family/whānau?	<ul style="list-style-type: none"> • Your everyday life • Being the kind of parent you want to be?

		<ul style="list-style-type: none"> • Your views on children and how children learn? • Your views and understanding of autism? • Your goals or hopes for your child? <ul style="list-style-type: none"> - Further clarification – if you already had goals in mind for your child, did ESDM help you/your family/your child to achieve these? - Did ESDM change your mind about the kinds of goals you had for your child? • Any other services your child/family were receiving at the same time?
Facilitators of ESDM	What did you like about the ESDM, or the service in general?	<p>What were the benefits for your:</p> <ul style="list-style-type: none"> • Child? • Family/whānau?
	Was there anything which made accessing and/or participating in the ESDM service easier?	<ul style="list-style-type: none"> • Did you receive help from family/friends? • Did you have access to reliable transport? • Child's level of enjoyment? • Relationships with staff/therapists? • Affordability of the programme/related costs? • Flexibility of delivery (Being able to reschedule sessions, bring siblings to playgroup etc.) • The delivery format/location/timing • Length or frequency of sessions?
Barriers to ESDM	What were the challenges of ESDM?	<ul style="list-style-type: none"> • For your child? • For you/your whānau

	Was there anything which made accessing or participating in the ESDM service difficult?	<ul style="list-style-type: none"> • Location of the service? • Transport to the service? • Financing the service/ related costs (e.g. petrol, public transport)? • Waiting lists? • Childcare of other children? • Length or frequency of sessions? • Content of the programme (Skills to learn if parent coaching was received)? • Delivery method preferences? • Amount of homework/activities to do at home?
Adapting the ESDM	How do you think the ESDM could be improved?	<p>Would it be helpful to:</p> <ul style="list-style-type: none"> • include other family members (e.g. child's siblings)? • Individualise handouts (e.g. specific to your child's goals, providing your own folder)? • Changes to the content (e.g. more neurodiversity affirming, to cover topics such as toileting, feeding, sleep etc.) • Increase diversity (e.g. in types of materials, through recognising whānau spiritual beliefs/parent wellbeing)? • Increasing flexibility (A set number of sessions regardless of cancellations, session times, rebooking of sessions)?
Close of interview	Finally, is there anything else regarding your experience with the ESDM which hasn't	Closing of interview, no probes needed.

	been mentioned which you would like to share with me?	
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APPENDIX L**STUDY 2 FIRST AUTHOR POSITIONALITY STATEMENT**

Presently, I am a doctoral student in the area of educational psychology. I hold a Bachelor of Arts degree majoring in Psychology and Criminology, and a Master of Educational Psychology. I have also received additional education regarding neurodiversity, anxiety, and advanced introductory training in the Early Start Denver Model (ESDM). I have resided in Aotearoa New Zealand for the entirety of my life and am Pākehā and Māori. I am also the parent of an autistic child. I take a strengths-based approach to both my practice and research, with the hope of empowering parents. I also align with neurodiversity affirming definitions and descriptions of autism. I acknowledge the privileged position I hold as a researcher to be able to access the resources and funding required to complete this project. I strive to be cognisant of my own biases by keeping a password protected de-identified research journal.

APPENDIX M

STUDY 3 PARENT INFORMATION AND CONSENT FORM

Primary Participant Information Sheet



Case Study of an Adapted Autism Support Programme

Formal Study title:

Adapting an Autism Support Programme for a Lower Financially Resourced Family: A Case Study

Organisation: Victoria University of Wellington

Lead Researcher: Carla Wallace-Watkin

Contact phone number: [Redacted for privacy]

Ethics committee ref.:15593

You are invited to take part in this PhD study looking at how we can make a support programme more accessible for lower income families. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time without any impact on any future services you wish to access.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is 8 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

VOLUNTARY PARTICIPATION AND WITHDRAWAL FROM THIS STUDY

Your participation in this study is completely voluntary – you can decide if you would like to participate, and you can withdraw from the study at any time without any disadvantage - you will still be able to access other services from the Victoria University of Wellington Autism Clinic even if you withdraw from the study.

WHAT IS THE PURPOSE OF THIS STUDY?

Research suggests that there may be many barriers for families when trying to access autism support services for their autistic child, and that lower income families often experience a greater number of these barriers. In this case study, we would like to find out your experiences and perceptions of the acceptability and usefulness of an adapted support programme based upon the Early Start Denver Model (ESDM). We have made changes to the way the programme is delivered and will work together to choose the best programme for you and your child. We hope that this research will help us to understand how we can better support lower income families with an autistic child who access the Victoria University of Wellington Autism Clinic services.

HOW IS THE STUDY DESIGNED?

This study is a case study, this means we will be working with one parent/caregiver only. You are welcome to have family and whānau attend the programme, support you in the end of programme interview, and/or support you during the other study assessments. However you will be the primary participant who attends all sessions with your child and participates in surveys and an end of study interview.

WHO CAN TAKE PART IN THE STUDY?

To be able to take part, you need to meet all of the following criteria:

1. I am on an income tested benefit, or am a holder of a community services card (Your own card, not your child's); and
2. I am a parent or caregiver for a child who is currently 5 years of age or younger who has been diagnosed as, or is likely to be autistic; and have not yet started primary school.

What will my participation in the study involve?

We anticipate the study will take place over at least 8-10 weeks. This will include visits with the therapist, (also the lead researcher: Carla), before the programme begins and after it ends. Before we start the programme, we will meet at least once to design your programme and decide where you would like sessions to be held. We will also get to know each other, talk through consent, fill in a survey on the research, and answer any questions you may have.

The programme will run for at least 6-8 weeks. This will be made up of 6 weeks' worth of sessions, with 2 extra weeks to make up any missed or rescheduled sessions. You will choose the kinds of services you would like to receive and where. This might include:

- | |
|--|
| <ul style="list-style-type: none"> • Direct therapy – This is when the therapist works directly with your child for 45 minutes once per week for 6 weeks. The therapist will use ESDM-based strategies while playing with your child. |
| <ul style="list-style-type: none"> • Parent coaching - This is when the therapist works with you and, if you choose, other whānau members, for one to one and a half hours, once per week for six weeks. We will talk about autism, neurodiversity, and how you can use ESDM-based strategies with your child. |
| <ul style="list-style-type: none"> • Teacher coaching – This is when the therapist will meet with your child's teacher to talk through ESDM-based strategies and provide general information, for example about autism, based on what the teacher requests. Based on the teacher's availability this will take place for a maximum of one hour once per week for 6 weeks. |

At the end of the programme, you will have two visits. One visit will be with the therapist (Carla) who will answer any questions you might have and go through two final surveys. There will be one survey asking how you found the changes to the programme and one on how acceptable you found the programme (one about how you found the changes to the programme and one on how acceptable you found the programme).

The second visit will be with a research assistant who will take you through a semi-structured interview. You can meet the research assistant before the day of the interview if you would like. On the day of the interview, the

research assistant will ask you some questions about your experience with the programme. You will choose a location suitable for the interview (for example, a quiet space in your home, at the Autism Clinic) and can choose whether you would like to meet in person or over the phone/online on Zoom. The interview will take no longer than one hour and will be recorded on an audio recorder and/or an Apple iPhone. A transcript of your interview will be made and shared with you. You will be able to check this transcript and make corrections or clarifications. You will also receive a copy of the results of the analysis of your transcript and can provide feedback on this if you would like. Once a write-up of the study has been completed, the final version will also be shared with you.

What are the possible risks of this study?

There are no anticipated serious risks for this study. If any adverse events do arise, for example if the research team are concerned for your or your child's wellbeing, we will speak with you about this and work with you to gain a referral to the appropriate agencies.

WHAT ARE THE POSSIBLE BENEFITS OF THIS STUDY?

We hope this study will have benefits for you and your whānau. This might include gaining a greater understanding of autism and your child, strategies to support your child and ways you can make learning fun. We hope that the skills you gain will be useful to you long after the study ends.

This study will also add to our understanding of how we can help lower income families to access autism support services. We will be able to implement what we learn from this study more widely within the Victoria University of Wellington (VUW) Autism Clinic, and we hope other services and providers might gain ideas of how to support all families to access services.

WHAT ARE THE ALTERNATIVES TO TAKING PART?

You do not need to take part in this study to access either ESDM or ESDM-based therapy for your child, or parent coaching for yourself. You may make contact with our community advisor, Courtney, to discuss other options currently available: autism-clinic@vuw.ac.nz

Will any costs be reimbursed?

There are no costs to you to be involved in this study.

- You will be provided with a koha of \$100 in the form of grocery vouchers for your participation at the end of the study.
- If you choose to travel as part of this study (i.e. to sessions or to assessments), you will be reimbursed with transport vouchers at each session.

What if something goes wrong?

If you were injured in this study, you would be eligible to apply for compensation from ACC just as you would be if you were injured in an accident at work or at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery.

What will happen to my information?

During this study the researchers will record information about you and your study participation. This includes the results of any study assessments, which will consist of two surveys on programme acceptability, one survey on the

helpfulness of the programme, and one interview where you will be asked how you found the programme. You cannot take part in this study if you do not consent to the collection of this information.

Identifiable Information

Identifiable information is any data that could identify you (e.g. your name, date of birth, or address). Only researchers will have access to your identifiable information.

De-identified (Coded) Information

To make sure your personal information is kept confidential, information that identifies you will not be included in any report generated by the researcher and/or any study information sent to Victoria University of Wellington. Instead, you will be identified by a pseudonym (A pretend name)

The following groups may have access to your coded information.

- The research team which consists of the lead researcher's PhD supervisors at Victoria University of Wellington.

The results of the study will be included in the lead researcher's PhD thesis. They may also be published or presented, but not in a form that would reasonably be expected to identify you.

Future Research Using Your Information.

We do not plan to use your coded information in future research.

Security and Storage of Your Information.

Your identifiable information (i.e. your name and contact details) will be held by the lead researcher only on a password protected USB hard drive. This hard drive will be stored in the CI's office within a locked filing cabinet. Your identifiable information will be destroyed once the study has concluded. Study information which does not identify you (e.g. de-identified interview transcript, responses to surveys) will be kept using the same secure hard drive for a period of no more than 10 years. All storage will comply with local and/or international data security guidelines.

Risks.

Although efforts will be made to protect your privacy, absolute confidentiality of your information cannot be guaranteed. Even with coded and anonymised information, there is no guarantee that you cannot be identified. The risk of people accessing and misusing your information (e.g. making it harder for you to get or keep a job or health insurance) is currently very small but may increase in the future as people find new ways of tracing information.

Rights to Access Your Information.

You have the right to request access to your information held by the research team. You also have the right to request that any information you disagree with is corrected.

If you have any questions about the collection and use of information about you, you should ask the lead researcher, Carla.

Rights to Withdraw Your Information.

You may withdraw your consent for the collection and use of your information at any time, by informing the lead researcher.

If you withdraw your consent, your study participation will end, and the study team will stop collecting information from you.

If you agree, information collected up until your withdrawal from the study will continue to be used and included in the study. You may ask for it to be deleted when you withdraw unless you withdraw after the study analyses have been undertaken.

Māori Data Sovereignty

Māori data sovereignty is about protecting information or knowledge that is about (or comes from) Māori people. We recognize the taonga of the data collected for this study. To help protect this taonga:

- We have consulted with Māori staff from the School of Education at Victoria University of Wellington about the collection, ownership, and use of study data.
- We may, with your consent, allow Māori organisations to access de-identified study data, for uses that may benefit Māori. This may, for example, include for research being conducted by your iwi.

What happens after the study or if I change my mind?

If you wish to withdraw from the study at any time, please let the lead researcher, Carla, know by email, phone call, or in person. If you would like the data collected about your participation withdrawn, this can be done up until study analyses begin, anticipated to be the sixth week of the programme. You are most welcome to take part in other services offered through Victoria University of Wellington Autism Clinic, however you will need to pay for these services.

CAN I FIND OUT THE RESULTS OF THE STUDY?

We look forward to sharing the results of the study with you. You will have an opportunity to give feedback on the initial study results before they will be written into a report. We anticipate initial results to be returned within one month of the study ending, and a full report by December 2023.

WHO IS FUNDING THE STUDY?

This study is being funded, in part, by a Victoria University of Wellington PhD scholarship awarded to the lead researcher. Funding to cover the specific costs of this study have been sought from the School of Education, Victoria University of Wellington through a small study grant.

WHO HAS APPROVED THE STUDY?

This study has been approved by an independent group of people called a Health and Disability Ethics Committee (HDEC), who check that studies meet established ethical standards. The Health and Disability Ethics Committee has approved this study.

Who do I contact for more information or if I have concerns?

If you have any questions, concerns, or complaints about the study at any stage, you can contact:

Carla Wallace-Watkin, Lead Researcher

[Phone number redacted for privacy]

Carla.wallacewatkin@vuw.ac.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050

Fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@advocacy.org.nz

Website: <https://www.advocacy.org.nz/>

For Māori cultural support please contact:

Name Jacqui Wardle

Position Kaitohutohu Rangahau Māori

Telephone number [Redacted for privacy]

Email Jacqui.wardle@vuw.ac.nz;

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHIC

Email: hdecs@health.govt.nz

Consent Form

Case Study of an Adapted Autism Support Programme



Please tick to indicate you consent to the following:

I have read the Participant Information Sheet or have had it read to me in a language I understand, and I fully comprehend what it says.

I have been given sufficient time to consider whether or not to participate in this study.

I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.

I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my care.

I consent to the research staff collecting and processing my information.

If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed. Yes No

I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.

I understand the compensation provisions in case of injury during the study.

I know who to contact if I have any questions about the study in general.

I understand my responsibilities as a study participant.

I wish to receive a summary of the results from the study. Yes No

Declaration by participant:

I hereby consent to take part in this study.

Participant's name: _____

Signature: _____

Date: _____

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: _____

Signature: _____

Date: _____

APPENDIX N

STUDY 3 CHECK-IN SURVEY



Adapting an Autism Support Programme

CHECK-IN QUESTIONNAIRE

Based upon survey created by Tupou et al., (2022)

Date: _____

For each of the following statements, please select the option that best represents your view:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. My child is benefiting from this programme.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. My child did not want to take part in today's session.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. It has been easy to bring my child to today's session.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. This programme is not right for my family/whānau.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I did not want to bring my child to today's session.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. My child was happy to take part in today's session.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. It has been difficult to bring my child to today's session.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I feel positive about my child participating in this programme.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. This programme is a good fit for my family/whānau.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I feel negative about my child participating in this programme	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

APPENDIX O

STUDY 3 SEMI-STRUCTURED INTERVIEW GUIDE

Adapting an Autism Support Programme for a Lower Financially Resourced Family: A Case Study

INTERVIEW GUIDE

The interviewer will begin the interview with the parent as follows: I am going to ask you some questions about your experiences with the adapted ESDM programme. Any feedback you provide will be confidential. You don't have to answer any questions that you do not want to, and you can ask for a break or ask to stop whenever you like.

Topic	Questions	Probes
Icebreaker	How would you describe your overall experience with the service/programme to other parents?	This question is designed to act as an icebreaker, no probes are needed.
Perceptions of the adapted service	How well did the service/programme fit, or not fit, with your family/whānau needs?	<ul style="list-style-type: none"> • With your everyday life (routines, commitments)? • With the way you like to parent? • With other service you are receiving? • With your views/understanding of autism?
	What, if anything, did you like about the programme?	What were the benefits for your: <ul style="list-style-type: none"> • Child? • Family/whānau?
	What, if anything, did you find hard or challenging about the programme?	What was difficult for your: <ul style="list-style-type: none"> • Child? • Family/whānau?
Usefulness of Adaptations	[provide list of adaptations] Can you share with me which, if any, of the changes to the programme you found most useful? How were they helpful?	

	Can you share with me which, if any, of the changes to the programme you thought were least useful? What made them less useful?	
Future improvements	In what ways do you think we could improve this programme?	<ul style="list-style-type: none"> • Refer back to anything brought up in previous answer about adaptations which weren't useful. Ask: "You mentioned that Wasn't very useful. Could you share with me anything which might have been more useful?"
Close of interview	Finally, is there anything else regarding your experience with this programme which hasn't been mentioned which you would like to share with me?	Closing of interview, no probes needed.