Adapting a Support Service for Lower Income New Zealand Families with an Autistic Child: A Research-Community Partnership Approach

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Research indicates that lower-income families encounter barriers to early support services for their autistic children. However, limited research has explored parent suggestions to reduce such barriers. Through a research-community partnership, this study used semi-structured interviews to explore lower-income parents' experiences of an early support service their child had participated in. Interviews were analysed using template analysis with themes located including navigating service pathways, child centred, service flexibility, and increased understanding. An overarching theme, differing needs and priorities, highlighted a necessity for greater flexibility within early support services. Collectively, suggestions from parents and research-community partners informed the development of potential adaptations aimed at enhancing support service accessibility. Implications and future research directions are discussed.

Key words: *Autism, Early support, Adaptations*

INTRODUCTION

Parents often express a desire to engage in early support services[1] 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 these potential benefits, 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, Sigafoos, Woods, & Waddington, 2023).

Adapting pre-existing autism services to better suit a particular population and/or context could improve the 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), 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). Including key stakeholders in the research process means the skills and knowledge of both community members and researchers are honoured (Key et al., 2019). Additionally, such partnerships help to ensure that research undertaken with vulnerable populations are in no way harmful (McDonald, 2017). 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-Frazee et al., 2012). Such an approach would ensure adaptations are informed by the very families who would stand to benefit from them.

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 et al., (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 participated in the original programme, nor, it appeared, in creating the proposed adaptations (Pickard et al., 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

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

provided regarding the processes followed. Additionally, data on parent perceptions of the resultant 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 (herein Aotearoa), 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) 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). In the context of autism support services, the results of a recent scoping review of the literature undertaken by Tupou et al. (2021) 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 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

Parent Participants

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 university affiliated research clinic (hereafter referred to as 'the clinic'). ESDM is a comprehensive, naturalistic, developmental, behavioural intervention (NDBI), and includes a 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 provided a variety of ESDM-based services including direct therapy (i.e., trained therapist works directly with a child) and parent coaching. These services took place in the clinic, family home, or via telehealth (parent coaching only). Initial services (10 weeks) were subsidised. At the time of this study, continuing support cost families approximately $845NZD per term, consisting of one therapy session per week for 10 weeks.

Parents were recruited through emails sent via the university affiliated research clinic database. At the time of this study, the clinic database consisted of 224 families/whānau, of whom 149 had received some form of ESDM services. Data on family level of financial resourcing is not recorded on this database. Five parents including two fathers and three mothers of six autistic children participated. One mother (Rose) was a single parent to 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 families with costs of healthcare (Ministry of Health, 2022). 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

Table 1. Parent demographic information

Pseudonym	Age range	Ethnicity	# 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

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 1.

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. See Table S1 in Supplementary Materials for the full interview guide.

Procedure

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. Community partners came from a diverse range of backgrounds which included Māori, Pasifika, and New Zealand European individuals. All had experience working with lower-income families, families with an autistic child, and/or lived experience as an autistic person. All community partners were paid for their time via the funding received for this research. 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. For community partners, the study was organised 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. Community partners were given the autonomy to choose their level of involvement dependent upon their own commitments and desires without question. To avoid placing pressure on these partners, they were not required to provide a reason for non-participation in any phase. 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).

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, with an average interview length of 46 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 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) in the form of $60NZD supermarket vouchers to acknowledge their expertise. After each interview the interviewer wrote reflective interview summaries to capture details of the interview relevant to the transcription or analysis process (e.g., a parent's apparent level of comfort during the interview). Interviews were recorded using two forms of digital voice recording (i.e., a digital voice recorder and the interviewers cell phone/secure cloud Zoom recording) and transcribed using otter.io. 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.

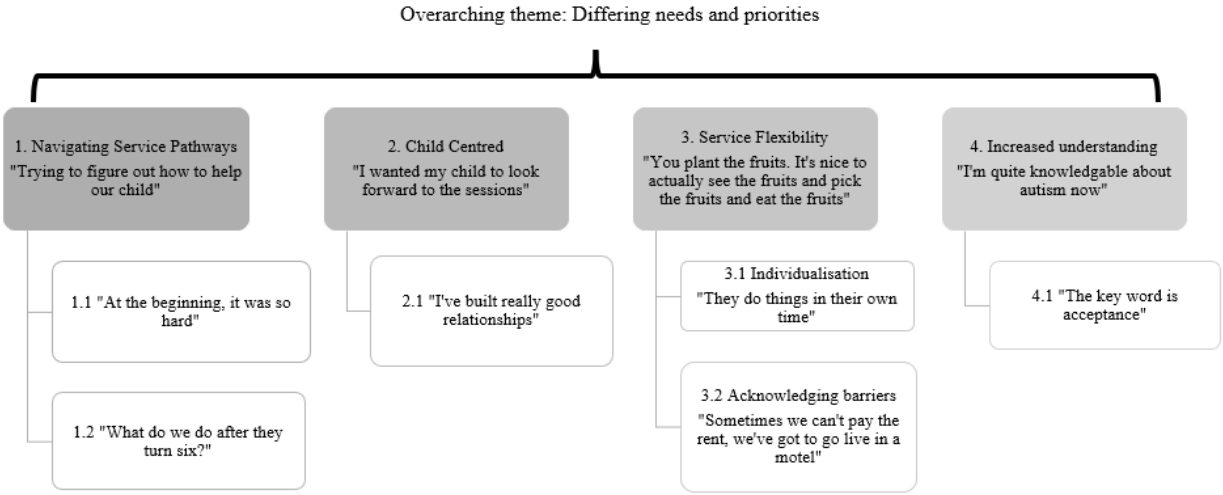
Ethical approval was obtained from Victoria University of Wellington's Human Ethics Committee (#30539). Participation in the study was voluntary for both parents and community partners. Parents were provided with information relevant to the study and a consent form prior to giving informed consent to 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, proposed timeframes, an information sheet, and a consent form. 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.

Data Analysis

Data were analysed using template analysis (King, 1998; 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 (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.

Template analysis was conducted by the first author following the six steps outlined by 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 organised into meaning-based clusters and an initial template was developed. This template was then applied to the three remaining transcripts with modifications made (i.e. redefining, adding, and/or removal of themes) as needed.

Figure 1. Resulting themes of the template analysis



The second 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 seventh 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 improvements 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. Both 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.

Positionality

In qualitative research, it is particularly important to note the perspectives that the research team brought to the study (Patton, 2015). Members of the research-community Partnership team included those with lived experiences as an autistic person and/or family members of an autistic person. Some members of the team also currently, or have previously, provided support services to autistic children. Both authors view autism with a neurodiversity lens, recognising that autism is a brain-based difference rather than a deficit or disorder. Some members of the research-community partnership team had previously received training or education that was based on a predominantly deficit focused, medical-model view of autism, and have actively worked to change their understandings to a more affirming approach. A full positionality statement for the first author is available in Table S2 of the Supplementary materials.

Community Involvement

Community involvement was a key consideration for this study. Community partners included an autistic person and individuals who were experienced in working with autistic children and their families. Interviews included parents of autistic children. Additionally, both 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).

RESULTS

Themes were structured hierarchically. One overarching theme, four top-level themes, and six subthemes (see Figure 1) were identified. Themes are explored below.

Overarching Theme: Differing Needs and Priorities

A common thread connecting themes was the diversity of needs and priorities expressed by parents. What was important for one family and/or child while receiving ESDM services did not necessarily align with the needs of other parents. For example, parents expressed differing preferences for additional educational topics, with some parents wanting more "...information about neurodiversity" (Grace, Rose); while others prioritised practical strategies: "I always think of the most practical way to do it and is it necessary to understand all of the basics, sorry, all of the theory behind it?" (Liam). Disparities in preferences extended to logistics, with Lyla

and Liam advocating for telehealth services describing these as "perfect" (Lyla); while Rose "preferred to come in [to the clinic]". The variation of parental preferences throughout the dataset underscored a wider necessity for flexibility and individualisation of services.

Theme 1: Navigating Service Pathways: "Trying to Figure Out How to Help Our Child"

All five of the parents interviewed discussed the challenges they had faced directly after receiving their child's autism diagnosis prior to starting in the ESDM service. This period of time was described collectively as "hard", "overwhelming", and a "struggle". All five parents felt as though they were responsible for "trying to figure out how to help" (Grace) their children. Each of the parents described there being "limited" support service information available, however both Liam and Aaden stated that the information they had received upon their child's diagnosis had gone "unread" or had been "misplaced". Four parents stated that the information they had received was not directly related to autism and/or had been ill-timed due to parental feelings of "overwhelm". As part of searching for support, the desire to locate autism services with a strong research base was discussed by the majority of parents, with Grace emphasising that this was part of her "due diligence". The ESDM service being provided by the university-affiliated clinic as part of research was seen to be both "a positive" (Rose) and "reassuring" (Grace).

Parents had several suggestions for specific changes which could be made to support their search for appropriate services for their children. Rose recommended the clinic use "more advertising", while several parents described a need for more process-related information such as how long the waiting lists were. For two parents, general information such as a hand-out or video which outlined what to expect in an ESDM session would have been helpful. Not knowing what to expect had caused Lyla to feel "really awkward" and had led to Aaden feeling "quite nervous".

Subtheme 1.1 "At the Beginning, It Was So Hard"

Once parents had located a support service, accessibility factors became a consideration. Though all five parents stated that waiting lists were not a barrier to their participation in ESDM services, all had experienced challenges in attempting to access other services due to lengthy waiting lists: "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). Parents also described needing to consider the costs of services. All five parents had received ESDM services at no cost as part of research participation, with Lyla explaining that the lack of fees meant the service was "the best option to take". However, for Lyla and Aaden, whose children were about to complete their allocation of free ESDM sessions, there was concern as to whether they could afford to access ongoing support "at full cost".

The location of services as well as transport-related challenges posed a significant barrier to ESDM service accessibility for four parents (all except Aaden). These four parents lived at least a 20-minute drive from the clinic, with the commute posing a "barrier" (Rose), a "challenge" (Grace), and a "downfall" (Lyla) of the service. 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 of the parents (all except Liam) described enjoying aspects of attending sessions at the clinic, particularly their child's enjoyment of the centre. 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 (Liam).

Subtheme 1.2 "What Do We Do After They Turn Six?"

Challenges with locating support and navigating service systems recommenced for the three parents whose children had completed their ESDM services (Grace, Rose, Liam). For the remaining two parents (Lyla, Aaden) whose children were coming to the end of their funded sessions, each had concerns for "what comes next?". Two parents (Rose, Aaden) reported positive experiences with local community groups which were created "specifically for autistic children". However, all the parents spoke about the experience of their search for support starting all over again. Grace, for example, noted that her struggle with locating support meant that "...right now, it feels like we're fumbling". Aaden and Grace both mentioned additional supports they would like to have access to, including mental health support, access to a family case worker, and respite care. All the parents reported feeling gratitude for their time participating in ESDM services, noting it "gives people more hope (Aaden) and had "changed [the family's] lives significantly" (Rose).

A significant concern discussed by three of the parents interviewed was their child's transition to school. Aaden's experience of early childhood education had been that he and his child were "just a number", which caused him to feel "concerned" about his child starting school and uncertain as to how to 'make sure education is a bit more inclusive". For two parents whose children had started school (Grace and Rose), the search for support was ongoing. Grace felt the end of her child's ESDM services were "abrupt", 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?". Once her children had turned six, Rose felt as though her family had been "left alone… my son had no supports, not through school, not through anything".

Theme 2: Child Centred: "I Wanted My Child to Look Forward to the Sessions"

All of the parents interviewed discussed their child's experiences in the ESDM services, with a clear focus on their child's enjoyment of sessions. For example, Grace described wanting 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 during sessions that their child had been "a bit stroppy" (Rose), "disengaged" (Liam), or had shown distress through crying (Lyla). One parent (Lyla) noted that over time, their child's comfort level increased, and the clinic became their "happy place". Grace found the child-directed nature of ESDM to be a highlight, 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...I took her out of some of those therapies".

All of the parents described enjoying opportunities to focus on their child's strengths during ESDM services. Grace and Rose both described noticing their children's strong memories and ways of communicating, with Grace sharing that her child "...amazes me with how much she knows" and Rose sharing that her daughter "walked away [from ESDM services] with pointing, which is amazing… for a nonspeaking autistic person that is huge". Liam and Lyla both noted their children's increased engagement when play "...followed [their child's] lead", while Aaden was impressed with the range of activities his child took part in during ESDM sessions. Liam suggested that receiving information on supporting his child's skill acquisition while maintaining current skills would have been helpful.

Subtheme 2.1: "I've Built Really Good Relationships"

All five parents valued the relationships they and their children had built with therapists delivering ESDM services. Parents collectively described the therapists they had worked with as "accommodating", "amazing", and "awesome". Parents felt their child's enjoyment of ESDM sessions was facilitated by positive relationships formed with therapists. For example, Grace stated that her child "looked forward to [direct therapy], like she's going on a play date with her very big friend", while Aaden felt his child learnt more due to feeling "safe" and comfortable with their therapist. One concern expressed by Rose was a lack of therapist consistency, stating that for her child '…consistency is key". One potential method to mitigate therapist turn-over was described by Lyla, who mentioned that opportunities to meet and get to know other therapists in the clinic had helped her "…build really strong connections with all the therapists" so that "now we don't mind when it changes to a different therapist". The formation of positive relationships appeared to have an impact on parents' decisions for choosing future services. For example, Aaden mentioned being "referred to another thing at [a different clinic]. We chose [ESDM services] because with this … we know you guys".

Theme 3: Service Flexibility: "You Plant the Fruits. It's Nice to Actually See the Fruits and Pick the Fruits and Eat the Fruits."

All five parents reflected on the need for greater flexibility within the ESDM service. Generally, parents reported being happy with the length of ESDM sessions (approximately 45min) sharing it was "exactly enough" (Lyla) or "perfect" (Aaden and Rose). Parents were in less agreement on other factors related to the overall programme length and frequency of sessions. For example, Aaden felt having direct therapy sessions "once a week" was preferable as "two or three [sessions] every week, can be a bit much…". In contrast, Liam preferred "Three times a week" as "that's actually very intensive and that's what makes it work". Aaden preferred sessions which were within school hours due to having school aged children, whereas Grace stated "weekends would have been really, really helpful" to fit services around 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 also reported mixed preferences for service delivery format. While Liam found parent coaching helpful, stating "I did the first [parent coaching] session and I can see the results straight away", Grace shared her enjoyment of group sessions as she "appreciated meeting other parents". Both Liam and Lyla, who had not received group services, expressed concern for this approach, with Lyla reflecting that her child felt more comfortable when with the therapist "one on one". One point all five of the parents agreed upon was the helpfulness of observing a therapist work with their child, with Rose stating that the experience had shown her "how play really helped my children learn".

Subtheme 3.1: Individualisation: "They Do Things in Their Own Time"

Four of the parents (all except Lyla) discussed the importance of further individualising the goal setting and review process for ESDM. Parents had similar goals for their children, including increasing communication skills, independence, and happiness. There was reflection from two parents that their children did "things in their own time" (Grace) and that progress towards goals often felt like "crawl[ing] forward, every little milestone" (Aaden). Having a set timeframe in which to review goals had been a conflicting experience for Grace who stated that: "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". Three parents wanted to add goals which related to their child's happiness and well-being (Aaden, Grace, Rose), while Liam would have liked ideas for ways parents could work towards goals within activities at home.

The need for individualisation of the ESDM service extended to the types of social supports parents desired during their time within the program. Two of the parents described wanting additional people included in their child's ESDM services. For example, Grace would have liked her child's preschool teachers to be involved, while Lyla mentioned she would have "love[d] to include family". 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. Grace enjoyed the support she had found from other parents of autistic children during her time in group sessions, explaining that "speaking with [other parents] is very therapeutic because

we would sometimes even just trade our war stories, or just talk about our children" (Grace). In contrast, Lyla felt she needed time to "gain confidence" before taking part in group sessions. Though Aaden did not express a desire to include others in his child's ESDM services, he noted that coming into the clinic and seeing other families with autistic children helped him to realise: "You are not just alone. There are millions and millions of kids around the world who have this, and the parents haven't done anything wrong".

Subtheme 3.2: Acknowledging Barriers: "Sometimes We Can't Pay the Rent, We've Got to Go Live in a Motel"

While service flexibility was important, several parents discussed obstacles to accessing services which were beyond the scope of the ESDM service. For the two parents currently receiving income tested benefits, unstable housing was a factor which seriously impacted their ability to participate in support services: "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" (Rose). 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". Both Liam and Aaden discussed needing to make sacrifices to support their child's participation in ESDM services with Aaden explaining that "we have to come to [ESDM sessions]. [My wife and I] both have to sacrifice out work". Liam had prioritised attending sessions above all "other routines", reasoning that: "It's a force multiplier. If you don't do it, it would be shooting yourself in the foot".

All five of the parents interviewed had been impacted by the Covid-19 pandemic. 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 4: Increased Understanding: "I'm Quite Knowledgeable About Autism Now"

All five parents expressed that their participation in ESDM services had led to increases in their knowledge and understanding of autism. For the four parents (all except Rose) who had participated in parent coaching, it was noted that this had been helpful for gaining "strategies" (Liam, Aaden, Lyla) and "tools" (Grace) to support their children's learning and development. Rose, who had not received parent coaching, noted that simply observing direct therapy had given her ideas for how to "play and interact" with her children. Parents also collectively had ideas for further topics they would have liked included in the ESDM service sessions, for example education on toilet training (Liam, Aaden), eating and feeding (Grace), supporting executive functioning (Rose), information for extended family and friends (Lyla), and assistance in locating sensory items (Rose, Grace). All parents expressed a desire for greater community knowledge of autism, with Rose suggesting an increase in educational workshops presented by autistic adults would be helpful.

All the parents described encountering challenges related to putting their newfound knowledge of ESDM strategies into practice with their children at home. This included factors such as being unable to find the same items, such as toys, as those used in the clinic (Rose, Grace), difficulties being consistent with techniques (Lyla), and the use of technical phrases in resources (Aaden, Liam). Liam specifically noted that the expectations for parents to deliver ESDM teaching strategies "every 30 seconds" caused him to feel as though 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.

Subtheme 4.1: "The Key Word Is Acceptance"

Parents appeared to link their increased knowledge and understanding of autism with an increased acceptance of their child's diagnosis. Lyla stated that the knowledge she had gained in ESDM services helped her to understand her child's diagnosis was not "bad news", but simply "a confirmation of what we're waiting for, for so long". Aaden reflected that his journey through ESDM services had led him to believe that "it's hard at the beginning, but now, acceptance. I think the key word is acceptance". All five parents expressed the desire for other parents to have the same opportunity to access education on autism, with Liam sharing that he would "Highly recommend [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". Rose continued to actively seek out education beyond her participation in ESDM services, finding information on neurodiversity and the experiences and knowledge shared by autistic adults particularly useful. All parents reflected positively on their experience within the service. Feedback included enjoyment of the "child-directed" nature of the service (Grace), Aaden's statement that the service "gives people more hope…", and Rose mentioning the programme had "changed my children's lives and my life significantly".

Adaptations

The list of potential adaptations for ESDM services is presented in Table 2. Adaptations were developed based on the themes identified through data analysis and suggestions made by parents, community partners, and researchers (both authors, 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.

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 parent experiences were located. An overarching theme, differing needs and priorities, indicated a need for individualisation and flexibility within the service. Parents reported both

Table 2. Adaptations by theme and stakeholder group

	Suggested Adaptations		
Theme Name	Parents	Community partners	Researcher
Differing needs and priorities			• Choice offered to enable parents to build a programme to suit their needs and priorities.*
1.Navigating service pathways	• Increase advertising of services. • Develop online educational videos on the topics of autism/neurodiversity. • Develop online videos describing the service, include past parent experiences. • Free services • Payment plans for paid services • Regular (e.g. monthly) parent well-being check-ins while on waiting lists. • Extend distance therapists can travel to cover the entire region.	• Develop a phone application w/educational videos for parents of autistic children. • Designate a staff member to give info & support with funding applications • Use time on waitlist to build rapport. • Emphasise parent selection of a comfortable, safe location for service delivery. • Extend distance therapists can travel to beyond the local region. • Develop ESDM-based school readiness workshops	• Reimburse travel costs • Welcome pack expanded to include clinic floorplan, timeline of services, options to build programme.* • Reduce time on waiting lists.* • Parent chooses location of service delivery.* • Optional parent and child clinic visits prior to starting services. • Increase accessibility of clinic resource booklet (e.g. online).*
2. Child centred	• Consistency in therapists. • Provide parents opportunities to meet all therapists. • Add child wellbeing, safety, and happiness goals. • Provide wall chart with examples of teaching during play and daily routines.	• End sessions early if needed (e.g. child is tired). • Provide personalisable hand-outs and visuals e.g., social story template about attending sessions. • Photos/brief bios of clinic staff as a hand-out. • Offer intro workshops to parents starting with the service. Have all therapists present. • Emphasise parents know their children best. • Remove goals which prioritise teaching neurotypical skills (e.g. eye contact). • Reduce # of goals targeted to promote success. • Provide basic checklist for parents to monitor their weekly use of strategies.	• Therapist to focus explicitly on relationship with child before implementing teaching. • Therapist focus is building and preserving relationships with family. • Therapist to regularly share child strengths with parents*

Table 2 (continued). Adaptations by theme and stakeholder group

	Suggested Adaptations		
Theme Name	Parents	Community partners	Researcher
3. Service flexibility	• Extend programme length (e.g. to one year). • Offer weekend sessions. • Option to include extended Whānau (Family). • Modelling of strategies by therapist • Playgroups offered at conclusion of 1:1 services.	• 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. • Weekend and evening services.	• Set number of sessions provided.* • Flexible rescheduling • Choice of delivery method (e.g. parent coaching, direct therapy)* • Therapists to be mindful of parent wellbeing, refer on for additional services as needed.*
4. Increased understanding	• Remove technical language. • Increase parent education on Autism/neurodiversity, including offering education led by autistic people. • Provide information on skill maintenance. • Develop: ○ Videos capturing autistic adult experiences of daily life. ○ ESDM-based online educational courses. ○ Templates for building strategies into everyday routines.	• Offer choices of educational topics. • Have hand-outs available online. • Add strategies for teaching within everyday routines to parent coaching booklet.	• Referrals to appropriate services for information on specific topics (e.g. sleep, nutrition)*

Note: *this suggestion is researcher interpretation of parent data

benefits and challenges of participating in the service. The majority of challenges related broadly to the navigation of support service pathways, with factors including limited service visibility, location, costs, and waiting lists. Benefits were more specific to the early autism support service and included positive child experiences, the child-centred nature of the service, 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 from parents, community partners, and researchers (both authors, a 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 support services 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 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 et al., 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 by parents within the present study were also similar to those made in prior research. For example, suggestions made by parents and providers in research conducted by Pickard et al., (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 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 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 therapists 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 caution due to 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 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, 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, there is a need for broader representation. It would 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

Carla Wallace-Watkin 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. Hannah Waddington is the clinic lead of this same service.

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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