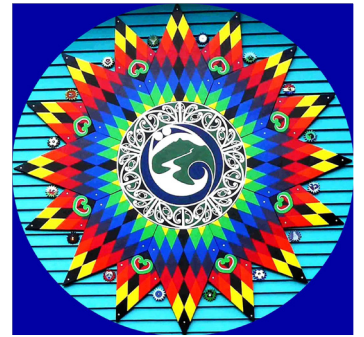


It Is Not *THEM* and *US* – Working together for sustainable outcomes for children with autism

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ABSTRACT

With a conservative estimate of 1 in 100 children thought to be on the autism spectrum (Ministry of Health, n.d.), this article reports on findings from a preliminary exploratory national study of parents of children aged 0-21 with ASD. Using an e-survey questionnaire and focus groups, the study sought to understand the supports that were available to children with autism and their families. More importantly, it explored the supports parents perceived were most useful and effective for their children at home, after school, and in educational settings. The key findings highlighted the need for autism-specific knowledge and training for educators and caregivers, and flexibility of funding for parents to access supports and services that they perceived to be the most useful. These findings were juxtaposed by issues of *availability*, *accessibility* and *affordability* of services and supports. There was unequivocal support from participants for a one-stop-shop for better coordination of services, funding flexibility and closer partnerships with families. Implications are discussed and limitations identified.

Research paper

Keywords:

autism, collaboration, education, funding, training

INTRODUCTION

It is now beyond doubt that the prevalence and awareness of autism, a complex neurological condition, is increasing exponentially worldwide. The data from Centers for Disease Control and Prevention in the USA estimates that 1 in 54 children in the USA are diagnosed with autism (Maenner et al., 2020). In Canada, the figures are 1 in 66 (NASS, 2018), while it is 1 in 100 in the UK (National Autistic Society, n.d.); 1 in 70 in Australia (Autism Spectrum, n.d.), and affecting around 1 in 100 individuals in New Zealand (MoH, 2016). While these statistics have huge implications for

education, health and other social services, it is also a stark reminder that there are increasing numbers of families under undue stress trying to cope with the idiosyncratic cognitive, physiological, physical and behavioural challenges of their children (Crane, Chester, Goodard, Henry & Hill, 2016; Myers, Mackintosh & Goin-Kochel, 2009; Pennington et al., 2013). Familial stress begins early when parents start to notice certain anomalies in their children's developmental trajectories, and this is often compounded by a lack of acknowledgement by professionals (Coogle, Guerette & Haline, 2013; Crane et al., 2016; Mulligan, MacCulloch, Good & Nicholas, 2012; Renty & Roeyers, 2006). A national study in Australia in three major areas of diagnosis, education and adulthood of individuals with autism identified that:

- Parents' concerns since their child was 12 months old were dismissed
- GPs reluctantly refer children to paediatricians at 3.5 years of age
- Autism was undiagnosed before age 4-5 years, (www.autismcra.com.au).

Once diagnosed, families need access to various social supports; parent training and, more importantly, it is critical that parents have input into what is needed for their children and themselves (Brewin, Renwick & Fudge Schormans, 2008; Coogle, Guerette & Hanline, 2013; Pellicano, 2014; Pennington et al., 2013). The reality, however, is that many families are often left to their own devices to seek information about services and supports at a time when they are forced to make major re-adjustments to their day-to-day life (Crane et al., 2016; Dillenburger, Keenan, Doherty, Byrne & Gallagher, 2010; Herbert, 2014; Starr & Foy, 2012).

This early lack of support for families is often exacerbated when children begin their formal education. The relationship between parents of children with disabilities, particularly autism, and

educational professionals over the years have been fractious (Brewin et al., 2008; Starr & Foy, 2012; Stoner et al., 2005; Whitaker, 2007). Parents are often frustrated with the low expectations teachers have of their children, mainly due to lack of autism-specific knowledge and professional development (Brock et al., 2014; Humphrey & Parkinson, 2006; Odom, Cox & Brock, 2013; National Professional Development Centre, 2013). Such discord between families and professionals must be addressed as evidence tells us that trusting, reciprocal and collaborative relationships between professionals and families are fundamental to improve the quality of life for those with autism (Coogler et al., 2013; Herbert, 2014; Marshall & Goodall, 2015; Parsons, 2014).

RATIONALE FOR THE STUDY

A concerted effort towards partnership between professionals and families of children with autism will enable professionals to have a more comprehensive understanding of the needs of children with autism and their families. Such understandings can also inform better ways to target the finite public funding available for supporting them. However, over the years there have been very few New Zealand studies in the field of autism that have focused on understanding parents' perspectives of supports that are most effective and useful for them and their autistic children. The first study of 19 Māori parents' perspectives was undertaken more than a decade ago by Bevan-Brown (2004) which identified the need for expanding the capacity and capability of services offered, increasing financial assistance for parents, working in partnership with parents in culturally-appropriate ways, on-going professional development for educators, and raising awareness of autism and its impact on children, young persons and their families through media campaigns. Subsequently, Bevan-Brown (2010) surveyed 137 parents as part of producing a DVD resource for schools. Key messages from parents of children with autism in this survey were to 'accept and accommodate the differences' in their children and for their children to be treated with "dignity and respect" (p.17). Other studies to date involving families of children with autism in New Zealand are evaluation of the early intervention programme *EarlyBird* (Anderson, Birkin, Seymour & Moore, 2006), and the *Tips for Autism*¹ training package (Bevan-Brown et al., 2011). Given the paucity

of research, the New Zealand ASD guidelines identified the need for further research on "what parents need" (MoH & MOE, 2008, p.63). Together, they provided the rationale for the study reported here, which explored the nature of supports and services that parents of children with autism between the ages of 0-21 accessed at home, out of home/after school, and educational settings. More importantly, the study focused on the nature of supports and services that parents perceived would be *most* useful and effective in these contexts.

METHODOLOGY

A qualitative study in three phases was undertaken to identify "contextual and setting factors as they relate to the phenomenon of interest" (Johnson & Onwuegbuzie, 2004, p.20). Participants for all three phases of the study were members of Autism New Zealand.

Phase One

E-survey

Convenience sampling was used in the study with the e-survey distributed to families through the Autism New Zealand database². The e-survey consisted of 32 items in three sections to obtain a mix of quantitative and qualitative responses.

- Part A was quantitative in nature. It consisted of eight questions to gather demographical information such as ethnicity, marital status, employment status, educational levels and geographical location of families, gender and age of children with ASD, and their levels of severity
- Part B consisted of 11 questions related to the home context including current home-based and out of school supports and services for their child/children, as well as the family, and supports and services that would be most useful and effective
- Part C consisted of 13 questions related to educational contexts and the interventions, programmes and supports and services their children were currently receiving, and what parents perceived would be *most* effective supports and services.

¹ An individualised programme involving home and school. See <https://www.tipsforautism.org.nz/>

² *Autism New Zealand Inc.* provides a range of support to individuals and families nationally that includes support, training, advocacy, and resources autism spectrum disorders including Asperger's Syndrome. www.autismnz.org

Phase Two

Focus Groups

As focus groups provide a deeper understanding of 'how people feel or think about an issue, idea, product or services' (Krueger & Casey, 2015, p.2), three focus groups were conducted to further explore the needs of the families. The participants were selected through a separate self-nomination link at the end of the e-survey to preserve the anonymity of the survey data. Thirteen families participated in focus groups across three different locations in the country. The participants included nine New Zealand Europeans, one Māori, one Samoan and two Asian families. They were mostly mothers, with the exception of two families in one of the focus groups, where both parents attended. The focus group discussions were guided by two broad questions:

What did parents perceive to be the most useful and effective programmes/interventions for their child/children out-of-school/at home?

What did parents perceive to be the most useful and effective programmes/interventions for their child/children in the educational settings?

Phase 3 involved five in-depth case studies of families. Four of the five case study families were from the North Island, while one family lived in the South Island.

This article reports on the findings from phases 1 and 2 of the study in relation to two key questions: 1) What supports and interventions were *currently receiving* at home, out- of-school and educational settings; and, 2) What did parents *perceive to be the most useful and effective* in these contexts?

Ethical Considerations

A critical friend approach was used to peer review the e-survey for relevance and cultural appropriateness, although the e-survey was not aimed at any specific cultural group. The author's institutional ethics committee approved all phases of the study. Participation in the e-survey implied consent and focus group members were self-selected. All focus group members signed a confidentiality agreement. Anonymity was maintained in all three phases of the study, and all resulting presentations. However, total anonymity could not be guaranteed as participants could choose to discuss their involvement in the study with other fellow members.

Data Analysis

E-survey

Responses to the two questions related to this article were extricated from Sections B and C of the e-survey and the quantitative results are reported as frequencies in the tables further down. The e-survey questions used broad categories of supports such as 'Behaviour', 'Communication', and 'Medical', and did not include specific types of interventions and programmes. It must be noted that respondents included more than one type of support and although some had more than one child with autism, the responses were not reported against each child. Analysis of quantitative demographical information from the e-survey was exported both as tables and graphs from Survey Monkey®.

Individual responses to open-ended questions in the e-survey were exported as an Excel document to NVivo 10. The software's features of word frequency and text search became critical tools as responses to some questions were inter-changed. For example, some respondents included teacher-aide supports in the home/out-of-school settings, and some home-based support needs were mentioned in the educational category. Thus, analysing the survey data was challenging, but highlighted an important fact that the compartmentalised survey sections were more of an academic imposition rather than everyday realities for families, for whom the support needs merged between settings. The rate of response to every section and questions within the sections varied in the survey. Part A response rates varied from 334 to 279, while there was a wider range in the number of responses for each of the questions in Parts B & C, which ranged from 235 to 29 responses. Given this varying range of response to each question and the fact that 'statistical inference is problematic' in convenience sampling (Sue & Ritter, 2012, p.32), it was not undertaken.

The demographics of respondents indicated a representative sample. There was a wide geographical spread among respondents with participants located in different parts of both islands. There was wide-ranging socio-economic diversity with respondents ranging from full-time employed to being full-time caregivers for their children. The severity of the autism of their children ranged from Asperger's³, to those who required high levels of support. The ethnicity of respondents is a reflection of the nature of membership of Autism New Zealand

³Many of the respondents' children would have obtained their diagnosis prior to the implementation of DSM 5

with more than three quarters of the respondents being New Zealand Europeans.

Focus Groups.

Focus groups provided more in-depth understanding of the nature of supports that parents were currently accessing, and what were seen to be most useful and effective for their children at home, out-of-school and in educational contexts. Data from the focus groups were analysed along the lines of *importance* and *consistency* (Krueger & Casey, 2015).

FINDINGS

E-Survey Responses

Supports received - Home and Out-of-school.

Tables 1 and 2 show the supports currently in place and those that parents perceive to be most useful at home and after school contexts.

Table 1
Supports Received at Home and After School Contexts

	N = 235**
For children	
Behavioural Supports	76
Communication Supports	66
Medical Support (<i>Mental Health services, Medication, Psychiatrists, Paediatrician</i>)	23
Occupational Therapy	20
Social Skills	17
Music Therapy	14
Holiday Programme	10
Riding for the Disabled	8
Other (<i>Buddy programme, Private tuition, Group working skills, Art, Play therapy</i>)	9
For Parents	
Funding (e.g. Respite care; Carer relief/support)	77
** Respondents could select more than one support category	

Table 2
Supports Perceived Most Useful at Home and After School Context

For children	N = 175**
Social Skills	67
Communication Supports	44
Behavioural Supports	44
Occupational Therapy	14
Holiday Programmes	13
Mentoring and Buddying	12
Sport & Recreation	11
Life Skills	9
Music Therapy	8
Medical Support (<i>Mental Health services, Medication, Psychiatrists, Paediatrician</i>)	8
Other (<i>Sensory processing disorder assessments and intervention programme; Assistance for daily living skills; Pet assistance; Anger management, Time and self-management, Play and Art therapy, Riding for the Disabled; Sensory eating programme</i>)	16
For Parents	
Support Groups	57
Funding (e.g. Respite care; Carer relief/support)	44
Training	23
** Respondents could select more than one support category	

One of the most striking differences in the responses between supports they were receiving and what parents felt would be *most* useful for their children were interventions that enhanced their child's social skills and abilities:

I would like to see my son have more confidence in spending time in social situations. (R. 36)

More social programmes and activities (afternoon/evening/weekend/holidays) for teenagers. (R 292)

Recreation activities to improve and find new interests - music, dancing, painting, electronic, building, computer programmes, sports, etc. (R. 301).

Although social skills are inseparable from communication skills, the parents identified them as a discrete skill category that required intervention and support. Together with an increased number of responses for *holiday programmes, mentoring/buddying, sport and recreational activities* as useful and effective interventions, it was evident that these parents were keen for their children to be socially competent and be able to participate in a range of activities and integrate with the wider community.

Respondents also wanted more publicly funded programmes for behaviour interventions, and communication support that included technology. They wanted flexibility to access what was required for their children, as some of them were personally funding therapy and other leisure activities:

We do a lot for our son to give him the best opportunities to be able to both fit into and contribute to society once he leaves school. Our biggest problem is funding these activities. (R.197)

Another noticeable category with variation in responses from what was available to what was perceived to be most useful was to train caregivers. Here, parents expressed their concerns about the shortage of qualified caregivers:

We get respite hours but have been unsuccessful in finding a carer [who understands autism]. (R. 324)

Most concerning among the survey responses were the large number of families that were not getting any form of support or interventions:

My daughter practically receives none. (R 37)

We moved from [overseas] to New Zealand to receive absolutely no assistance with our autistic son. (R. 133)

However, it must be noted that included in these responses were families who had interventions in the recent past, rather than at the time of the survey. But what was evident was that parent support groups were extremely important for these families, as it provided a non-judgemental environment for these parents to share their trials and triumphs.

Supports in Educational Contexts

The table below shows the supports currently in place and those that parents perceive to be most useful in early childhood settings and schools.

Table 3
Supports in Educational Contexts

Current supports	(N = 175)	Supports that will be most useful and effective	(N = 168)
Teachers & Staff Training	44	Teacher Training	58
Parent involvement	41	Programmes	45
Teacher-aide support	34	Teacher-aide Support & Training	38
Home/School Communication	33	Funding	25
Knowledge of SENCO	23	Parent Involvement/IEP	13
Funding & Training	16	Specialists/ SENCO	11
		Home/School Communication	7

Supports that parents found were useful currently for their children were capable teachers with positive attitudes that welcomed the presence and involvement of parents. Teacher-aides were seen as being effective only when they had autism-specific training. Schools with an ethos that had open communication and collaboration with parents, and regular IEP meetings with clear agreed goals for their children were seen as useful and effective by the parents:

Supportive teachers, good open, two-way communication. (R. 324)

The current acting HOD is supportive; involves parents in IEPs. Parents are consulted and have access to the school. (R. 81)

Teacher really knows him, uses humour, distraction and special interests to help him; is very patient; realistic, high but achievable expectations - happy to try any strategy. (R. 216)

What Would be Most Useful and Effective in Educational Contexts?

While a few respondents wanted specialist teachers and special needs coordinators in every school, one third (N = 58) advocated strongly for classroom teachers to have autism-specific training in teaching children with ASD. They wanted teachers, both in early childhood and school settings, to have basic knowledge and understanding of the condition, and also receive ASD-specific training to better support the learning needs of their children.

Teachers who are better educated about ASD [sic] in all areas, such as what the parents deal with at home, physical challenges, sleep issues, health issues, etc. (R.258)

Teachers using visual aids in class for establishing routine; teachers using a routine and teachers speaking plainly and without verbosity. (R. 274)

There were also many respondents (N = 38) that stressed the importance of having teacher-aides who were trained:

Training for teacher-aides – communication skills specifically. (R. 29)

More training made available for teacher-aides. Take the training to them so that they can attend. (R. 243)

Some respondents wanted specific school programmes targeting social skills, life skills, behaviour and communication, while some wanted the curriculum to be flexible, to have a mix of academic subjects as well as music and art, and other life skills programmes. Other useful supports identified were funding for technology, which is increasingly unlocking the potential of those with autism. 'Upfront funding for technology devices that assist in early learning' (i.e. iPad) (R 25). Although parents wanted specialist support and the availability of SENCO in schools, their top priority was for trained teachers and teacher-aides. Parents who felt less included by the school community wanted more parental involvement and input in their children's learning, some through IEPs, and some wanting to improve home-school communication. Interestingly, parental involvement was also included as part of programmes and training for teachers, as families wanted to have joint and collaborative professional development, which was further emphasised in the focus group

discussions. Among those who were currently eligible for funding wanted more flexibility in its use, depending on the needs of their children.

In essence, the qualitative data from the e-survey showed that parents were keen for improved social and learning outcomes for their children. They wanted their children to be active participants, as their peers, in both school and in wider community activities, A warm and welcoming school that worked collaboratively with parents, with well-trained staff with an understanding of autism, were seen as being most useful and effective for the learning of their children (Falkmer, Anderson, Joosten & Falkmer, 2015; Reupert, Deppler & Sharma, 2015). They wanted more joint training for parents, as well as training for respite caregivers. They wanted flexible funding arrangements to access what they knew to be effective, rather than accessing what was on offer.

Focus Group Findings

Across the three focus groups, *being proactive* emerged as the key theme that was currently useful and effective for families, while the themes of *training and support* and *cohesion* emerged as being those that would be most useful and effective for these families and their children. These three themes were underpinned with the reality of availability, accessibility and affordability.

Predominantly, the discussions in the three focus groups were centred on systemic and collaborative processes and practices, rather than specific programmes. Parents in the focus groups emphasised that they had to be *proactive* right from the point of getting the diagnosis to be able to access the necessary supports and interventions for themselves and their children. Therefore, it was not surprising that given their experiences to be proactive in dealing with professionals, *training and support*, and *cohesion of services* emerged as the other major themes that parents perceived would be most useful and effective in supporting their children and families.

Being Proactive

One of the unintended findings from the focus group was that parents repeatedly referred to the time of diagnosis, although neither the survey, nor the focus group questions, particularly focused on the diagnostic phase. Despite the wide age range between their children (4 -16years), the issues surrounding pre- and post-diagnosis were foremost

in the minds of all the parents (Reed & Osborne, 2012). It was a critical stage in the lives of parents from which point parents felt that they had to be proactive in seeking support for themselves and their children.

We got our diagnosis; this is what he has got and that was it. It wasn't sort of come into this room, here is the condition, and we know of groups you need to contact, these are the people that can help. You were left out to hang. (FG 3)

When you get the diagnosis [for your child], the mental health people should take the family to one side and say, 'Right, you are going to need help as well. You need to be taught coping skills, you need to be taught anger management skills, and extra parental skills and these are not offered to you. (FG 1)

Accessing Therapies

Parents also had to be *proactive* in terms of accessing therapies, often having to self-fund. There were wide disparities among the families in terms of affordability to access therapies. Some families could afford therapies for a prolonged period of time, while others paid for expensive therapies for shorter periods of time. They found publicly funded therapies to be extremely inadequate in terms of qualified therapists and their availability. Often parents mentioned the use of their carer-relief funds to pay for therapies, thus reinforcing the e-survey responses. Only a couple of parents mentioned paying for specific therapy such as Applied Behaviour Analysis (ABA) or the *DoreProgramme*⁴.

The money we get for the carer support, we often use it to pay for ABA, which we are not supposed to do, but we do. (FG 1)

Parents also mentioned being proactive in sharing their knowledge with wider family and educational settings to ensure that their child was better understood and accepted within the culture of the family: 'Being Pasifika, we try to include him in our cultural settings and also extended families. We had to raise awareness of what autism was for them, because we like our son to be engaged with his other extended family members. (FG1)

Self-Upskilling

In the aftermath of diagnosis and self-searches for appropriate interventions, these parents often were *proactive* in upskilling themselves about autism. This included learning sign language, teaching listening and communication skills, and attending autism seminars regularly to keep abreast of latest information that would support their children.

I have done a couple of courses through Autism NZ which were trying to teach 'W' skills of listening and watching people's face and figuring out what their emotions are. (FG 2)

I went to every site I could get hold of because we were new to the country as well. Tried to read into the books like the autism library and do as much as we can. (FG 2)

Whether it was turning to 'Dr. Google', or attending seminars by experts, their journey for upskilling always began with their own efforts before they could get any kind of external support.

Education

Being proactive was very much the norm when it came to the education of their children. It was not only to find a school that would accommodate the needs of their child, but also to regularly provide school staff and children with information on ASD specific to their children.

The main fight we had with that was we had to find a school that was willing to take the private therapist on board because not all schools do. (FG 1)

I provided my own presentations to the teachers, so I presented a profile of my son. (FG2)

Being proactive was a default position for these parents, whether it was accessing necessary supports and services for their children, or upskilling themselves, or finding accommodating and welcoming learning contexts. One parent who became quite skilled in preparing resources had made that a small business. 'You have got to be pro-active; I have made a lot of resources for my son, which has ended up turning into a business for myself. So now I make resources for other people and give advice, give talks and things'. (FG 1)

⁴ An exercise programme designed to increase attention and focus to support students having ADHD, Dyslexia and Dyspraxia.

Despite being proactive, these parents were faced with inconsistency in, and inadequacy of, service provisions. They were often faced with a lack of continuity of funding to support the learning of their children.

He has only been at kindy for two years and everything stops when they turn five if they do not have ORS [on-going resource scheme]. (FG 1)

We have had probably about six or seven assessments done by different organisations and non-government organisations, who got funding, but at the end of the day we have had to go out and source stuff ourselves. (FG 3)

As a result, the parents were keen to maximise the finite, and often inadequate, funding through autism-specific training and support for teachers, teacher-aides, caregivers, and also for themselves.

Training and Support

Training for educational staff. The limited awareness and understanding of autism in educational settings meant that the parents often had to 'shop' for schools and early childhood settings that would best-support their children's learning. They wanted a welcoming school culture with sympathetic staff who were knowledgeable about autism-specific pedagogy. The following comments summarise the sentiments expressed by parents across the focus groups:

I would like to see all teachers taught about ASD needs. They need to understand that they vary from day-to-day and lack of performance is not necessarily an unwillingness to perform; there may be many other reasons. (FG1)

Professional development for the teachers around autism as the numbers are growing ... our choice is for mainstream; we need teachers there and school principals and leaders to be on board together with families. To hear us and not to try and have an answer for everything we come up with. It almost feels like these schools can either break, or really raise up, a child. (FG 1)

Parents repeatedly emphasised the importance of having joint professional development sessions with teachers (e.g. *Tips for Autism*), as they felt it afforded more consistency for children and young persons, which could result in more sustainable long-term outcomes. This was also reflected in survey

responses. 'Teachers to attend programmes that parents go to in order to have both parties teach the child the same strategies'. (R.150)

Training for Caregivers. There were significant concerns about the lack of adequately trained caregivers, resulting in some of them relying on their own family members and friends to provide them with respite.

My friends are probably my best support. We don't have family here, so friends are whom I use. (FG 2)

We found after a couple of occasions, because of the anxiety levels, it just wasn't going to work. (FG 3)

Training and Support for Parents. Parents wanted more training for themselves and the creation of support networks that would enable them to share and learn from one another:

A support group, because since I have started doing the Hanen programme, I don't feel like I'm alone anymore. (FG 2)

I found the most useful thing really was initially when my son got diagnosed at three. Autism New Zealand, was starting up a playgroup. I was able to mix with parents and learnt from each other. (FG 1)

Mentor Support. There was an emphasis on supporting the social and leisure activities of their children, particularly by the parents with adolescent or teenage children in the focus group that reiterated the survey responses. 'I would like to see my son have more confidence in spending time in a social situation, and the skills to make friends and recognise potential friends'. (FG3)

Whatever the context and nature of the supports needed, parents were confronted with the issues of availability, accessibility and affordability. In both the e-survey responses and focus groups, parents were unequivocal in wanting a 'one-stop-shop' to coordinate services and provide information, guidance, support and advocacy for families. They wanted continuity and seamless services and support for their children: 'Somebody who understands the many processes; someone who can access the assessments to be done and understands where funds are required' (FG3). A single point of contact from the point of diagnosis onwards was seen as being essential and *most* effective and useful in supporting families.

DISCUSSION

The findings from this study bear similarities to other international studies over the past two decades, underscoring the ubiquitous nature of the needs of families in terms of the lack of timely diagnosis, post-diagnostic supports, advocacy and ongoing ASD-specific knowledge for parents and professionals (Brock et al., 2014; Crane et al., 2016; Parsons, 2014; Stoner et al., 2005; Whittaker, 2007). Even more striking was the similarity in the findings from the study of Māori families more than a decade ago (Bevan-Brown, 2004). The idiosyncratic nature of autism meant that the nature and extent of supports, both experienced and needed by parents, were wide-ranging. In the absence of timely availability, accessibility and affordability of various medical, educational and social supports for their child and themselves to cope with the impact of the immediate and long-term consequences of autism, these parents tended to drift instinctively towards other parents of children with ASD (Banach, Iudice, Conway & Couse, 2010; Murphy & Tierney, 2006). The non-judgemental and empathetic environment of informal parent support groups was cathartic for families as it allowed for “discursive constructions and interpretations” and shaping of the realities of autism in their everyday life (Huws et al., 2001, p.582).

As the period following diagnosis for families involves making major adjustments to their day-to-day lives (Gray, 2002), having a key worker for coordinating services (Osborne & Reed, 2008; Pennington et al., 2013), was strongly endorsed by parents in the study. They wanted a one-stop-shop where services could be coordinated with clear lines of communication between families, funding and service provision at home, school and other contexts such as respite care, community and leisure activities. At the same time, parents were wary of the fact that public funding was often reduced when parents paid for services. Whether the current Ministry of Education’s *Learning Support Delivery Model*⁴ could be a systemic approach to address the concerns of these parents’ desire to have coordinated services remains to be seen, as conceptually the plan aims at providing a single point of contact for parents, and seamless collaborative services.

In terms of their children’s education, while some parents were positive about schools that worked collaboratively with them, equally there were those who were dissatisfied with teachers’ lack of

understanding of autism (Starr & Foy, 2012; Stoner et al., 2005; Whittaker, 2007). Parents stressed the need for upskilling teachers and support staff in pedagogical approaches that would be effective for their children. As noted by a parent in one of the focus groups: ‘Even if they get a teacher-aide and that teacher-aide is not qualified in autism, she is a baby-sitter’. Parents were willing to work alongside schools but felt that they were often seen as being ‘pushy’.

IMPLICATIONS

The study highlighted the fact that accessing support and interventions relied heavily on parents being proactive and able to afford effective interventions. The implications for families were directly related to issues of availability, accessibility and affordability of interventions that they knew were effective and useful for their children, even if it meant accessing programmes that may not have a well-researched evidence base. However, robust evidence-based autism guidelines for services from diagnosis to adulthood (Ministry of Health & Ministry of Education, 2016), are difficult to implement when *availability* of services for those with autism across the country can, at best, be described as patchy. Families in rural and remote areas often have very limited access to professional supports and parent groups unless they travel long distances, raising issues of *accessibility* and *affordability*. Often it is parenting styles, culture and knowledge of their children that determine the type of interventions that parents chose to access (Bevan-Brown, 2004; Carlon, Carter & Stephenson, 2015; Dillenburger et al., 2010; Herbert, 2014; Perepa, 2014), which warrants increased cultural responsiveness among providers.

The parents in the study were astute in their knowledge of evidence-based supports such as early intervention, therapy interventions, and use of technology. They had sophisticated knowledge of the benefits of combined teacher-parent professional development opportunities in terms of not only the consistency it can provide in supporting their children across home and school, but also as a means to share and grow collective expertise. While it is possible that some participants in the study would have expressed their support needs based on availability rather than its effectiveness, families do not want to be in a position to accept supports and services that they perceive to be less effective. So it is not surprising that there was a groundswell of support from parents for a centralised point of contact for coordinating services,

⁴ <https://education.govt.nz/assets/Documents/Ministry-/Changes-in-education/Learning-Support-Delivery-Model-working-together-Nov-2020.PDF>

with greater flexibility in the use of publicly funded services. Parents wanted to be in a position to access what they needed.

From an educational perspective, the findings forge the imperative for teachers to have the pedagogical expertise for maximising the learning of those with autism (Ministry of Health & Education, 2016), and for schools to embed policies and practices that embrace diversity and inclusive values with a strong collaborative culture (Booth & Ainscow, 2011; Falkmer et al., 2015; Reupert, Deppeler & Sharma, 2015). The need to increase the focus on social aspects of their children by parents warrants more attention, as social isolation can result in significant mental health issues for this already vulnerable population (Orsmond, Shattuck, Cooper, Sterzing & Anderson, 2013).

CONCLUSION

This exploratory study provided evidence from families of children with ASD of *what supports they need* and *what they perceived would work most effectively* for their children at home, after school and at school. An underlying concern from these parents was that the current systems of accessing supports relied primarily on proactive parents and affordability, rather than appropriate supports being readily available and accessible by families from the point of diagnosis, or even earlier. The strong emphasis the parents placed on professional development for educators and parents, adequate and targeted resourcing, increased collaboration between professionals, service providers and families are points that warrant immediate attention, as families can feel frustrated in being researched upon repeatedly, but not being heard (Pellicano, 2014). It is time that their voices and aspirations, summed up below, are acted upon:

I think to me the most effective thing is knowing my child's well-being; able to adapt his resources and learning environments. It is also about making him a part of life, so there is no reason he misses out on things. (FG 1)

LIMITATIONS OF THE STUDY

Using convenience sampling from an organisation where membership is voluntary and not always accessed by parents is one of the limitations of this study. The focus group was reduced from 18 to 13 families due to adverse weather conditions on the day of the focus group meetings in two locations that prevented families travelling to the venues. Another

significant limitation is the absence of the children and young persons' voices.

LOOKING AHEAD

There have been some positive steps in the field of autism research following this exploratory study. With the approval of *Autism CRC* in Australia, an adapted needs analysis survey similar to the Australian study has been undertaken in New Zealand in phases over a two-year period. The *Educator's Needs Analysis Survey* and Parent and Children survey have been completed. A more comprehensive New Zealand evidence-base on ways to best support teachers, families and children with autism will emerge once the children and young people voices are gathered in the coming months.

Moving forward, we need more collaborative research to add to the body of knowledge of *what works* in our unique bicultural context. Particularly, there is a need to capture evidence of effective practices that occur in various parts of the country that break the barrier between parents (*them*) and professionals (*us*) in Aotearoa New Zealand. More importantly, we need research that looks at the children and young people's learning and social requirements more holistically across educational, home and community settings. The compelling nature of partnership between professionals and family members has its own complexities, and if interventions both at school and home are to be successful, then a clear understanding of how the supports are perceived by families is fundamental to their success.

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