



Children's Autism Foundation

Final report for
research on the need for
autism support services
in Northland

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N.Z. Lotteries Community Sector Research Fund

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Executive Summary

Many Northland communities are relatively geographically isolated from urban centres. Because of this, services can be limited and travel, housing and the general cost of living are expensive for many. In 2015 there were clear indications from families that the Children's Autism Foundation (CAF) services were needed in Northland. This feedback came from families who had travelled many hours to attend Auckland workshops.

In May 2016, CAF held three days of introductory workshops in Northland with leading paediatrician Dr Paul Taylor. The workshops were titled 'A Guide to Autism'. These workshops attracted over 270 people. This included over 150 families and 34% of participants were Maori.

The Children's Autism Foundation is very thankful for the New Zealand Lotteries Community Sector Research Fund which enabled CAF to evaluate the feedback from the workshops and comprehensively research the need for autism related services in Northland.

The Children's Autism Foundation evaluated existing services and how beneficial further support services would be for the participants. This was achieved through surveys, given to participants at the workshops or via an online survey. These surveys requested feedback on how each participant enjoyed the introductory service and evaluated potential interest in other autism support programmes.

Feedback from families, community organisations and government organisations are crucial when planning further services for Northland. The results offer perspectives on the difficulties in accessing services for both families of children with autism and their communities. By most measures many of those surveyed were coping but stresses were showing within families. Many people were unaware of the importance of diagnosis and the possibility of health and education services that can be accessed after achieving the diagnosis. The workshops and associated consultations helped the community with an understanding of autism and emphasised the benefits for a child of being formally diagnosed.

The research showed that earlier diagnosis and further corresponding support services in the community would be beneficial for the family who has a child with autism. These services should cater for families/whanau and also provide professional training for those working with young people with autism. Workshop topics should be based on empowering the community and further understanding about the complexities of the Autism Spectrum.

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1.0 Introduction to the Children's Autism Foundation

1.1 Background

The Children's Autism Foundation (CAF) was registered as a charity in 2003, and with the Charities Commission in October 2007.

The Foundation has traditionally provided services across the Auckland region to over 2500 families/whanau and professionals of young people aged from pre-diagnosis (age 1) to 21 years.

The direct support to families is provided in the home and at workshops and programmes. These services include: workshops on understanding autism, strategies for behaviour, dealing with anxiety, sensory issues, developing social and friendship skills; outreach support to families through regular home visits/phone calls and providing guidance for implementing strategies learned at workshops; and lastly, parenting programmes and professional training for staff in health and education.

CAF helps families to manage the challenges they face by taking a practical, whole family approach. CAF helps each family through major transition periods such as: coming to terms with the diagnosis of autism spectrum disorder (ASD), changing schools, friendship and social interaction, being part of the community and entering the workforce.

CAF works collaboratively with other service providers to ensure that ASD services in Auckland communities are coordinated and accessible. Because children with ASD often have additional diagnosis such as dyslexia, dyspraxia, Asperger's, anxiety, ADHD, depression and intellectual disabilities, CAF works with other organisations who specialise in these areas. CAF is proud to be part of the Invisible Disabilities CUBE (a collective of providers in the community).

The Foundation is governed by a Board of Trustees, employs eight staff and contractors, and has a team of active volunteers. CAF consultants are ABA, Stepping Stones and/or tertiary degree-qualified.

In 2015 there were clear indications from families that the Children's Autism services were very needed in Northland. This feedback came from feedback from families who had travelled many hours to Auckland to come to our workshops. CAF therefore approached the New Zealand Lotteries Community Sector Research Fund to assist in researching this feedback more comprehensively.

CAF was successful and funding was provided by the Lottery Community Sector Research Committee to research the need for autism services for families in Northland. We hope this research will provide a basis for providing ongoing services to families and communities in Northland.

2.0 Methodology

2.1 What happened in the research?

Preliminary work was carried out in early 2016 to recognize strategic relationships in Northland. This was conducted by Teresa Moore (General Manager) and Elisa Slaat (Services Manager). Two visits were made to build relationships, discuss with community groups about our online survey and invite communities and whanau to upcoming workshops. The first meetings were carried out in Whangarei with the Northland DHB and Parent to Parent (operating as Altogether Autism). These meetings were very informative and provided CAF with further contacts and information about services available (or in many cases the need for services).

After these initial meetings, contact was made with key stakeholders including: local Iwi, whanau, community services, health services organisations and education staff. Throughout this exercise we were mindful of where the need in the community was and the 'gaps' in the services available.

Questions for our online survey were drafted and feedback was requested from the key stakeholders we had identified. This included He Iwi Kotahi Tatou Trust in Moerewa who advised us from a community and cultural perspective. This feedback provided the framework for the online survey to be finalized and posted online.

The purpose of our second visit to Northland was to have face to face meetings with key stakeholders in order to establish further relationships and to start organizing our upcoming 'Guide to Autism' Workshops. We concentrated on high population areas such as Whangarei and Kerikeri, as well as smaller centralized communities (in order to make attendance of the workshops as accessible as possible). Teresa Moore and Elisa Slaat met with: community service groups and whanau in Moerewa (who also represented the Kaitiaki community), family members in Kerikeri, Ministry of Education and Parent to Parent in Whangarei.

The third visit was to hold our 'Guide to Autism Workshops'. In order to attract large numbers, we engaged Dr Paul Taylor as our key speaker. Dr Taylor is a leading consultant paediatrician with a strong interest in autism and has also worked in Northland. We also engaged our family consultants Elisa Slaat and Arletta van den Bosch to facilitate the 'strategies for behavior' and 'practical strategies in schools' section of each workshop, as well as provide question and answer time for participants to ensure families could receive advice and information about their specific situations. Feedback evaluation forms were given to all participants to complete at the end of the workshops. These written evaluations were formatted identically to the online survey and were later manually added to the survey data.

3.0 Data analysis

3.1 Who participated or benefited?

In total, 270 participants attended our 'Guide to Autism' workshops in May 2016, which were held in the following areas: Whangarei, Moerewa, Kaitaia, Kerikeri and Kaiwaka. All data from our evaluation feedback forms were entered online.

Combining workshops for the community with survey collecting enabled CAF to provide much needed services and knowledge sharing opportunities. It also enabled CAF to collect 278 survey replies and comprehensive feedback.

A summary of the results is as follows:

- 46% of the participants had a child with autism in their family/whanau
- 13% of the participants knew of a child with autism in their community
- 17% of the participants knew of a child with autism in their workplace
- 22% of the participants knew of a child with autism in their school
- 2% knew of a child with autism other than the above places

The ethnicity of the participants:

- 61% Pakeha
- 34% Maori
- 12% European
- 2% Pacific Island
- 0.7% Indian
- 0.3% Chinese
- 2 % Other

Participants came from near the following areas:

- 20.3% Kaitaia
- 9% Kawakawa
- 6.2% Moerewa
- 2.5% Kaikohe
- 8% Kerikeri
- 25% Whangarei
- 4% Dargaville
- 2.5% Ruakaka
- 18% Rodney district
- 4% Other

4.0 Key results and discussion

4.1 What was achieved?

All workshop participants received a workbook containing information about autism from the Children's Autism Foundation. Family members also received a copy of the book *A Beginners Guide to Autism – Essential Information for Parents and Professionals* by author Dr. Paul G. Taylor.

Facilitators of the workshops Dr Paul Taylor, Elisa Slaa and Arletta van den Bosch gave participants information on understanding autism and strategies for behaviour. This was followed by feedback time to allow participants to talk about their challenges and/or concerns about a child they know with autism.

Each of the six workshops were on average three hours long and had an average of 45 participants per workshop (270 participants overall).

All participants were asked to complete feedback forms, which helps CAF understand the needs for services and information about working and living with a child with autism.

The quantitative responses from Survey participants showed key topics emerging, which helped CAF to identify areas of need. The main outcomes include:

- The majority of the participants were family/whanau
- A large majority know of children with autism in the 5-10 year age group, however, there was a good response in the other ages
- The majority of people surveyed were European/Pakeha and 34% Maori
- Participants were from throughout Northland with Kaitia, Whangarei and Rodney being the main population areas
- Anxiety was the greatest concern and other areas also needed support such as: Strategies for behaviour, Social skills, sensory issues, general understanding of autism and professional development especially for teachers
- Barriers for receiving support included the timing of the services, large distances to travel and costs to get the support
- Email was considered to best way to stay in contact

Quote from a participant: "Teachers need more understanding of kids who are different. Some teachers [are] disengaged due to knowledge deficits. They are the ones who don't cope with challenging children. [There needs to be] Support [for] families who are fighting to get help for their children."

The Qualitative responses from Survey participants showed key topics emerging, which helped CAF to identify areas of need. The main ones being:

- Education
- Dealing with Anxiety
- Support for Whanau
- Professional Development required
- Large travelling distances to get support services especially from Rural areas were a concern and inhibiting access to services
- There is a need for localised support
- There are challenges in getting a diagnosis
- There are large stresses on family
- There is a lack of government support

“Understanding from Government departments around the requirements of being a parent with a child on the spectrum [is crucial]. Acceptance and more training for professionals who work with our children [is essential], but not priced so high that they can’t afford to attend.”

The participants of the workshops were from families of a child with autism, or professionals working in the community with a child/children with autism. It is estimated that at least five other people in the community would benefit from the knowledge they learnt during the workshops about autism and associating with people with autism.

Therefore, it is estimated that over 1390 people in the community benefited from the workshops provided and will continue to benefit if Children’s Autism Foundation continues to provide ongoing services.

Quotes from participants:

“Being in a rural community I am concerned that families are not getting support and assistance.”

“Very much appreciated that you have come to Moerewa.”

“Workshops are essential to help other whanau understand.”

4.2 What other community benefits or outcomes were achieved?

Diagnosis and support concerns

Comments from participants expressed the challenges of getting a diagnosis. This was recognised by Dr Paul Taylor who compared what is happening today to 20 years ago, when awareness of autism was much more limited than it is today. At that time, there were very limited child and adolescent mental health services in Northland. Paediatricians took the lead role in assessment and diagnosis of conditions such as autism and attention deficit hyperactivity disorder.

At the 'Guide to Autism Workshops' Dr Paul Taylor heard a constant refrain that waiting for 'assessment' and then 'intervention' may take up to two and a half years. This contrasts with the 90s when the paediatrician-led service was capable of making a confident diagnosis, with the aid of standardized behavioural assessment forms filled out by the child's parents and school teacher, at the very first paediatric appointment, for which the waiting time was around six to eight weeks. Since then we seem to have made autism much more complicated and difficult than it needs to be. Is this progress?

Quotes from participants included:

"Just having services available to people in my area and maybe place to get diagnostic [diagnosed as] most people won't get diagnosed here."

"Diagnosis [needs] to happen more, or the parents are flapping like a fish out of water. Help us help children."

"Why is it so hard to get a diagnosis from professionals?"

"[The] Government/Ministry of Education needs to recognise how they could have [a] more positive impact on children's lives with funding."

Justice system

Conversations with community leaders included concerns about young people who may have autism and co-occurring conditions who have ended up in justice system. There are some marked commonalities in how individuals with autism may present in the justice context. In the justice system, where all procedures are essentially word-based, a person's inability to quickly process and comprehend information (written or verbal) leaves them open to misunderstandings and entrapment. Tendencies to take statements literally, to become confused by information and sensory overload, to act impulsively and to speak before thinking make it difficult to navigate the complexities and nuances of the legal process.

For example, a lack of eye contact is another common characteristic of autism. While this is indicative of anxiety or nervousness in the individual, it can be misinterpreted as guilt, disinterest or belligerence. Or a highly anxious teenager with ASD might lash out at a police officer when being touched unexpectedly. If there is no understanding of ASD this can lead to all sorts of unnecessary complex situations.

5.0 Recommendations

5.1 What was achieved?

There is a distinct lack of autism support services in Northland. There is also a strong need for support services around co-existing conditions such as: mental health issues, ADHD, Dyslexia. The participants in our survey requested ongoing assistance in the following areas: autism awareness, behavioural support, dealing with anxiety and sensory issues, transitioning and advocacy in schools. Professional development for education staff and community workers, parenting and whanau support and social and friendship skills training is required.

“Resources/services in the mid North are limited [to] non-existent for supporting whanau, children and young people with autism. Teachers lack information/strategies/support on how to support students in the school. There is a huge need for a provider in the mid north to co-ordinate/provide support.”

CAF was invited to return to every venue and we have been receiving many requests for ongoing support since our workshops were held. CAF are now seeking additional funding to support a further range of workshops and support services. CAF would like this work to include empowering communities to set up support groups and to address the fundamental needs of families of children with autism in Northland.

The research has provided CAF with a database of over 300 people in Northland and we can now send a regular e-newsletter to this database which can communicate support services in the community from CAF and other Autism friendly organisations.

Through the implementation of these services, children are given the opportunity to build their skills and knowledge which help them better interact within their communities. This in turn may help them gain resilience when dealing with issues such as bullying and mental health issues. Overall, our services help children with their developmental milestones. Likewise, parents and caregivers are provided with opportunities to interact with like-minded families, thereby reducing their sense of isolation.

We would like to thank Lotteries Community Sector Research Committee for funding this important research and the participants involved in the research. The outcomes and future service delivery will be built on the stories of the people who access our services, it comes from the heart of the community, the parents and students who are living with autism and their experiences within the health and education system.

Appendices

Appendix 1: Qualitative responses from survey participants

The Qualitative responses from Survey participants showed key topics emerging, which helped CAF to identify areas of need. The main ones being: Education, dealing with Anxiety, support for Whanau, Professional Development required, the large travelling distances to get support services especially from Rural areas, the need for localised support, the challenges in getting a diagnosis, stresses on family and the lack of government support.

Education - School

"We find that a lot of students struggle with anxiety in regards to friendships and how to deal with school life."

"All schools need to have this course around understanding [autism]. Often it is parents teaching schools because they live it but [they] don't always have the answers."

"We need more courses/workshops for families. Schools need more support in understanding and working with the wide range of children with ASD."

Education in the schooling system is crucial. In [my] six years of being a caregiver and teacher aide, teachers have little or NO understanding of autism."

"The main thing is understanding and acceptance. It is also very hard as a parent to have to fight the ministry of education for [support] hours. The less hours the more stress for everyone involved."

"More education in our health services especially child mental health [is paramount]."

Anxiety

"Strategies [are] needed for dealing with anxiety and challenging behaviours."

"I am a school counsellor and see the need for families and educators to have further support with children/students affected by autism/anxiety."

Whanau

"Whanau centric workshops - marae based [are necessary]."

"Whanau community support for children and teens with autism [is vital]. How can we engage this type of support, more 'respite care' for parents and whanau?"

"Would love to have more course[s] available for whanau up here to spread awareness."

"We need to let ALL WHANAU learn about this and make EVERYONE aware of autism maybe [through] TV promotion, like advertising."

Support for parents

"For many parents, like myself, it's just having the information and [knowing] you're not the only one dealing with the 'back end of the elephant'."

"Parent coffee group has been my life saver. There needs to be more of this."

"For us, we have had continuous problems with schools. Parents need to know who they can turn to for help."

Professional Development

"This is a great program for any parents organisation, [and] this would be great for professional development."

"Teachers need more understanding of kids who are different. Some teachers [are] disengaged due to knowledge deficits. They are the ones who don't cope with challenging children. [There needs to be] Support [for] families who are fighting to get help for their children."

Location of services

"Workshops [are essential] to help other whanau understand." (Moerewa)

"Very much appreciated that you have come to Moerewa."

"More course[s] in the Kaitia region [are crucial]."

"Ahipara Primary School needs workshops on awareness and management [of autism]."

"I have a grandchild who has autism. It is heart-breaking to see some of the challenges that he faces re socialising, sensory, anxiety etc. and for which help is not available in our area (Warkworth). His best friend also has autism, as does HIS brother. My great nephew also has autism (West Auckland) but the help he gets is far better, including his parents have been able to go to workshops. I have seen how he has gone ahead in leaps and bounds. It is really criminal that other children aren't afforded the same help, just because of location. It is criminal (not blaming the Autism Foundation, but rather the funding) that our children are falling through the cracks. I have seen how my grandson has been put in potentially dangerous situations at school, and that is down to lack of help/understanding in the education sector as well as privately."

Local support

"[We need] local support groups or [knowledge of] parents of children of autism groups in our area."

"Being in a rural community I am concerned that families are not getting support and assistance."

Availability Diagnosis

"Just having services available to people in my area and maybe place to get diagnostic [diagnosed as] most people won't get diagnosed here."

"Diagnosis [needs] to happen more, or the parents are flapping like a fish out of water. Help us help children."

"Why is it so hard to get a diagnosis from professionals?"

Government

"[The] Government/Ministry of Education needs to recognise how they could have [a] more positive impact on children's lives with funding."

"Understanding from Government departments around the requirements of being a parent with a child on the spectrum [is crucial]. Acceptance and more training for professionals who work with our children [is essential], but not priced so high that they can't afford to attend."

Need

"Resources/services in the mid North are limited [to] non-existent for supporting whanau, children and young people with autism. Teachers lack information/strategies/support on how to support students in the school. There is a huge need for a provider in the mid north to co-ordinate/provide support."

"Help [is needed] for parents and teachers with ASD in college, especially in terms of [children] having other issues such as ODD + ADHD."

Tired families

"Families with autistic children work tirelessly and they should receive all the help they can get."

"Being able to access providers who can offer further education [is vital]."

"[There is a] stigma attached."

"Just being conscious about labelling as I not have the qualifications I liked the 4 points so autism is recognise symptoms."

"Would love to see more workshop[s] in our community and schools."

"I would encourage as much [many] of these workshops [as possible] for people like me that haven't got much [a lot of] knowledge for [of] strategies to use."

"Help with sibling's strategies [and] strategies understanding [is essential]."

"A better transition system between early childhood to school [should be implemented]."

Appendix 2: Quantitative responses from survey participants

The Quantitative responses from Survey participants showed key topics emerging, which helped CAF to identify areas of need. The following were the results from the survey.

Question One: Do you know of a child with autism

Answer Choices	Responses	
In your family/whanau	45.88%	117
In your community	12.94%	33
In your workplace	17.25%	44
At your school	21.96%	56
Other (please specify)	1.96%	5
Total		255

Question Two: What is the age-group of the children you know with Autism?

Answer Choices	Responses	
0 -5 years	24.09%	66
5 - 10 years	43.43%	119
10 - 15 years	22.63%	62
15 - 21 years	9.85%	27
Total		274

Question Three: Which ethnic group do you belong to?

Answer Choices	Responses	
Māori	33.82%	93
Pacific Island	2.18%	6
NZ European/Pākehā	61.09%	168
European	12.36%	34
Indian	0.73%	2
Chinese	0.36%	1
Other (please specify):	2.18%	6
Total Respondents: 275		

Question Four: What area is closest to you?

Answer Choices	Responses	
Kaitiaa	20.29%	56
Cable Bay	0.00%	0
Kawakawa	9.06%	25
Moerewa	6.16%	17
Kaikōhe	2.54%	7
Kerikeri	7.97%	22
Whangarei	25.00%	69
Dargaville	3.99%	11
Ruakaka	2.54%	7
Rodney	18.48%	51
Other (please specify):	3.99%	11
Total		276

Question Five: What information would you like Children's Autism to include in future workshops?

Answer Choices	Responses	
One-on-one direct support services for families	44.62%	116
Understanding Autism (ASD)	49.23%	128
Strategies for Behaviour	64.23%	167
Dealing with Anxiety	67.31%	175
Sensory Issues in relation to autism	55.00%	143
Social & Friendship Skills	62.69%	163
Understanding ASD in Schools	5.00%	13
Professional development for health providers & Community workers	31.92%	83
Professional development for education providers	58.46%	152
Other (please give more details):	4.62%	12
Total Respondents: 260		

Question Six: What are the main barriers that could prevent you from attending a workshop or programme?

Answer Choices	Responses	
Timing (day/evening or week/weekend)	73.68%	168
Duration (two hours or full day)	11.40%	26
Travelling distance	44.30%	101
Costs related to attending (i.e transport, childcare)	25.88%	59
Availability of childcare	11.84%	27
Other (please give more details):	7.02%	16
Total Respondents: 228		

Question Seven: What is the best way for Children's Autism to stay in contact with you?

Answer Choices	Responses	
email	82.35%	210
phone	4.31%	11
post	2.75%	7
monthly e-newsletter	8.24%	21
mobile phone text message	2.35%	6
Total		255

7.0 References

Bevan-Brown, J. (2004). Māori Perspectives of Autistic Spectrum Disorder: A Report to the Ministry of Education. Massey University College of Education.

Bevan-Brown, J; Bourke, R; Butler, P et al. (2011). Evaluation of the 'tips for autism' Professional Learning and Development Programme: Summary Report. Massey University College of Education.

Broadstock, M. (2014). Broadstock, Marita. New Zealand Autism Spectrum Disorder Guideline supplementary paper on implications of DSM-5 for the diagnosis of ASD. Christchurch: INSIGHT Research.

Disability Connect (2016) Disability Support Guide.

Ministries of Health and Education. (2008). New Zealand Autism Spectrum Disorder Guideline. Ministry of Health.

Ministry of Health. (2013). Disability Workforce Action Plan 2013-2016. Wellington: Ministry of Health Disability Support Services.

Searing, B.M.J. (2014). Support needs of families living with children with autism spectrum disorder in New Zealand. A thesis submitted for the degree of Master of Health Sciences (Rehabilitation) at the University of Otago, Dunedin, New Zealand.

Statistics New Zealand (2015). *He hauā Māori: Findings from the 2013 Disability Survey*. Wellington: Statistics New Zealand. Available from www.stats.govt.nz.

Taylor, Paul G (2011) A Beginners guide to Autism Spectrum Disorders – Essential information for parents and professionals

<https://www.mcnz.org.nz/assets/News-and-Publications/Statements/Best-health-outcomes-for-Maori.pdf>