

Getting it Right – Provision and Access to Timely and Appropriate Supports for the Tāngata Whaitakiwātanga/Autistic Community Before, During, and After Diagnosis.

July 2024

Autism NZ Diagnostic Service Research

Our aim was to evaluate the needs of Autism NZ’s newest service within the Autism Resource Centre – the [Autism Diagnostic Service](#). The diagnostic service was established in January 2022 and offers autism diagnosis at a reduced cost to increase accessibility to diagnosis for both children and adults. The Autism Resource Centre in Petone was developed as a place where people who identify as tāngata whaitakiwātanga/autistic can access a range of diagnostic and support services, enabling choice and control over supports to live a good life. Autism NZ continues to increase the services we provide based on priorities indicated by community engagement and [research](#).

Background and rationale

The purpose of this research was to clearly identify any key areas of need and whether these are being met by our service, external agencies and service providers, or by other means. Our previous [research](#) indicates diagnosis occurs too late, taking on average 2 years to complete. There is no specific pathway for diagnosis and support, resulting in an ad-hoc, uncoordinated, difficult, and time-consuming process. Diagnosis and identification across the lifespan has been indicated as a priority area for autism [research](#).

As a diagnostic team we get regular verbal feedback around the disparity or lack of services for tāngata whaitakiwātanga in the community, the lack of support for seeking diagnosis, the lack of understanding of takiwātanga by medical and mental health practitioners, and their challenges accessing services. We want to collect this invaluable information in a quantifiable way to facilitate our advocacy and provision of improved and accessible services.

Aims and approach

A mixed method survey and interview research project was implemented to identify the needs of tāngata whaitakiwātanga/autistic people and whānau at different stages of their autism diagnostic journey and navigating the services that are available post diagnosis.

We gathered information at the time of referral, directly following assessment, then 3- and 6-months post assessment through four separate surveys hosted by SurveyMonkey®. We also conducted interviews 3-6 months post assessment. For this a small sample of participants were selected, prioritising Māori to ensure meaningful collaboration. Individuals and whānau who accessed our diagnostic service between September 2022 and March 2024 were given the opportunity to participate in the research.

The research was approved by the Aotearoa Research Ethics Committee – Te Roopu Rapu I Te Tika (AREC Application 2023_05). Participation was voluntary. Surveys were anonymous and informed consent was obtained for confidential interviews. All questions were optional. Surveys and interview questions can be requested from the research team.

Total numbers and percentages were calculated for quantitative data. Qualitative analysis included coding and development of key themes. The 3- and 6- month survey and interview data were analysed together. Reliability of qualitative analysis was conducted and determined. The purpose was to clearly

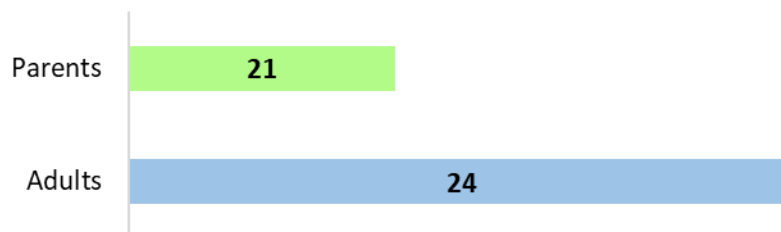
identify any key areas of need and whether these are being met by our service, external agencies and service providers, or by other means.

Findings

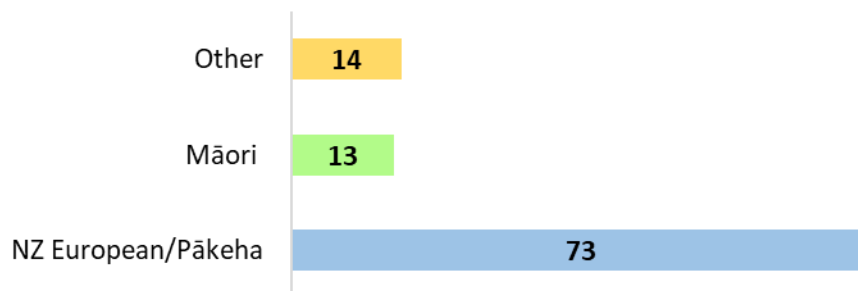
Who participated

Between the pre-assessment and diagnostic service feedback surveys, we received a total of 45 responses. 24 responses were from adults and 21 responses were from parents of children accessing our service. Of these, 73% were NZ European/Pākeha, 13% were Māori and the remaining ethnicities included South African, German, European and Pacific Peoples.

Total responses (pre-assessment and diagnostic service feedback surveys)



Ethnicity of participants



3-6 months post diagnosis surveys and interviews

We received a further 11 responses to surveys aimed at understanding experiences 3- and 6- months post diagnosis. Seven of these responses were from adults and 4 responses were from parents of children accessing our service. Ten further people (4 adults and 6 parents) completed interviews aimed at understanding the same. Seven participants were Māori, and the remaining 3 participants were NZ European/ Pākeha.

This research enabled us to understand the following about people's diagnostic journey:

Why do people seek an autism diagnosis?

- Parents seek a diagnosis for their child to find, and access help and tools to better support their child and their development as early as possible.
- Adults seek a diagnosis to learn more about themselves and understand who they are so they can be more accepting of themselves and find the right tools to reduce their struggles.

Why do people choose the Autism NZ Diagnostic Service?

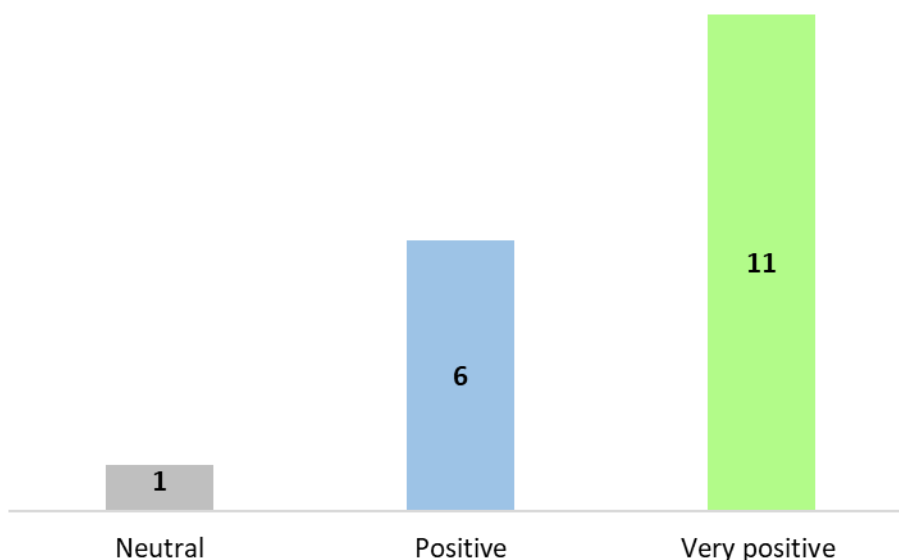
- Parents seek out our diagnostic service for their children because they felt it might be faster than other options and may be more connected to other networks of support.

- Adults seek out our diagnostic service because they cannot access diagnosis through the public system, our service is subsidised, and provides a robust and accurate diagnosis.

How satisfied were people with their diagnostic experience at the Autism NZ Diagnostic Service?

- Participants positively rated satisfaction with the registration of interest process, the wait time, the diagnostic interview and other assessments, the feedback session as well as follow-up resources and support. Overall, 94% of participants rated their experience with the Autism NZ Diagnostic Service as positive/very positive.
- From the qualitative data, both parents and adults were very positive about the diagnostic service. Parents reported feeling comfortable, reassured, and informed about what was happening. They felt that the process was easy; that questions about their child were asked in a sensitive way; and that they felt their children could be themselves without being judged. They were particularly positive about the staff’s ability to accommodate and engage with their children.
- Also from qualitative data, adults said that the diagnostic service felt neuro-affirming and mana-enhancing. They said that the clinic and staff made them feel comfortable; both in terms of the environment being appropriate and accommodating, and the staff being compassionate and understanding, as well as sharing their own neurodivergence. Multiple adults mentioned feeling that the clinical aspects of the assessment and report were in the background, and that the focus was on them as a person; they felt seen and celebrated as an autistic person. One Māori adult talked about the idea that in Te Ao Māori people are not segmented into different parts (e.g. physical health, emotions, neurodivergence), and that the Autism NZ Diagnostic Service was the first service they had accessed that treated them as a whole person.
- Several adults did find the lack of a concrete timeline difficult, and struggled with not knowing how long it would be until they got an appointment. Others had difficulties with the pre-assessment forms, finding them exhausting, time-consuming, and in the case of the form that asks about their parents’ experience of their childhood, emotionally difficult.

Overall satisfaction with Autism NZ Diagnostic Service



“I did not feel intimidated or anything like that and when you walk through those doors, my God you just feel like you’re at home... The main thing for me was that you can walk through those doors and you can be yourself, not feel judged and I had more faith in them than probably anyone to diagnose my girls”. – *Parent of an autistic child*

“[The] kaiarahi made the difference for us. Yeah, just bringing an extra cultural dimension. It meant that we were more comfortable with the process. It would’ve been much harder for us to engage with the process if it wasn’t for [the Kaiarahi] ability to bring that Te Ao Māori lens. So I’m hoping somewhere in the future, that that sort of funding for that sort of support will be made available. Because it’s about everyone having equity of access to their best life. Yeah, their best life. That really helped us. It made it more comfortable for us to engage in the process. I see it as being of value, as a person of Māori descent. I see it as being of value... I would’ve found it more daunting, a hell of a lot more daunting, if I didn’t have that cultural support”. - *Autistic adult*

What support services do people seek?

- Recently diagnosed autistic adults mentioned accessing Autism NZ Outreach Coordinators; Taikura Trust NASC (Needs Assessment Service Coordination); Yellow Ladybugs; the book *I Am Autistic* by Chanelle Moriah; and podcasts by autistic adults. The services they believed were most helpful were Outreach Coordinators, podcasts by autistic adults, and the *I Am Autistic* book.
- Parents of recently diagnosed autistic children mentioned accessing NASCs (specifically Kia Roha and Capital Support); Child Development Service; Autism NZ services (including Outreach Coordinators, the FANZ workshop, Kaiarahi services, and Employment Support); the book *I Am Autistic* by Chanelle Moriah; the IHC library; private occupational therapists and speech language therapists; Child and Adolescent Mental Health Service (CAMHS); Work and Income; Facebook groups; and the Spectrum playgroup in Naenae. The services they believed were most helpful were NASCs (specifically Capital Support); Child Development Service; Autism NZ’s Outreach Coordinators, Employment Support Service, Diagnosis Service, FANZ workshop, and Kaiarahi service; the IHC library; the *I Am Autistic* book; and private occupational therapy.

What do people want help with?

- Parents’ top priorities following diagnosis included learning how to manage their child’s behaviour and reduce meltdowns; better understanding their child; making sure their child is happy and not ashamed of being autistic; finding educational settings that work for their child; and accessing respite and other supports.
- Other priorities parents mentioned included changing their home environment to suit their child; finding social groups where their child feels comfortable; using more visual tools, predictable routines, and/or sensory toys at home; learning to communicate better with their child; being open to learning from the child what they need; and supporting their child to be their best self.
- Adults’ top priorities included learning more about themselves and their identity; gaining compassion for themselves; learning to unmask; accessing support and/or funding; and changing their approach to their daily lives with the new context their diagnosis provided.
- Other priorities adults mentioned included getting diagnoses for co-occurring conditions; managing their sensory needs; making friends and accessing support around making friends; reducing overload, overwhelm, or burnout; accessing employment support to find an appropriate job; telling their family about their diagnosis; and openly enjoying the positive aspects of being autistic without shame.

What are people’s experiences with support services?

- Autistic adults said that Autism NZ’s Outreach Coordinators helped them to access other supports, and made other supports (specifically the NASC) accessible for them when it would otherwise have been impossible to navigate. Podcasts and the *I Am Autistic* book helped them to identify with other autistic adults, and to talk to others about what being autistic meant.

- Parents' positive feedback focussed on help and guidance in accessing further supports; funding; and providing a deeper understanding of their child. Multiple participants said that Autism NZ's Outreach Coordinators helped them to navigate a confusing system and get support. Capital Support provided necessary funding for occupational therapy (although one participant mentioned that funding changes mean they can no longer access this). FANZ workshops and the *I Am Autistic* book provided a deeper understanding of autism and their children, practical strategies, and ways to talk to extended family members about their child. Some participants named specific people: Autism NZ's Kaiarahi provided invaluable cultural support, and Autism NZ's employment support facilitator was very proactive and helpful. Another participant said that Spectrum playgroup provided community and connection with similar families, free of judgement.
- Negative feedback focussed on waitlists and systems being difficult to navigate. Participants reported that their NASC didn't respond to their initial contact or took a long time to respond; that Child Development Service had a huge waitlist and different branches didn't communicate with each other; that public speech language services had waitlists so long they were forced to use private services instead; and that funding changes mean their children will be pulled out of necessary services.

Conclusion and recommendations

This research supports our understanding of diagnosis as a critical point that can have long term impacts on an individual's life as well as for their family and whānau. Diagnosis can help an individual to understand and explain themselves or their child, and it is seen as an important step towards accessing necessary supports.

Our findings provide evidence to continue implementing our Diagnostic Service and allow us to prioritise future service provisions through Autism NZ, including:

- Seeking funding to continue the Kaiarahi role to provide a culturally responsive pathway for people accessing our services.
- Expansion of our current Diagnostic Service in Wellington to meet demand as well as establishment of diagnostic services in other key centres across Aotearoa.
- Establishment of a post-diagnostic mental health and wellbeing service as indicated in Autism NZ's long-term strategy.
- Professional development for professionals and other organisations involved in autism diagnosis and support focussed on practical approaches to implement strength-based, neurodiversity-affirming and culturally responsive diagnostic and support pathways.
- Government advocacy to increase understanding and the need for diagnosis and post-diagnostic support throughout Aotearoa.

Who did the research

This research was completed by researchers at Autism NZ:

- Dr Larah van der Meer; Research and Advocacy Manager
- Dr Michelle Stevens; Diagnostic Service Lead, SLT
- Chanelle Moriah; Research and Advocacy Advisor
- Lee Patrick; Research and Advocacy Advisor
- Jennifer Loughnan; Intern Psychologist

Acknowledgements

The authors acknowledge the financial support of a Lotteries Community Research Grant.

We would like to thank the Autism NZ Community Advisory Group and Tuia Group for input into the design of the research.

Thank you to the adults, parents, and family/whānau who completed the surveys and interviews and shared their experiences of the autism diagnostic process and post-diagnostic supports.

Terminology in this document reflects currently accepted autism terminology used in Aotearoa.

Where to go for more information

For more information about this research, please email: research@autismnz.org.nz

For more information about the Autism NZ Diagnostic Service, please see:

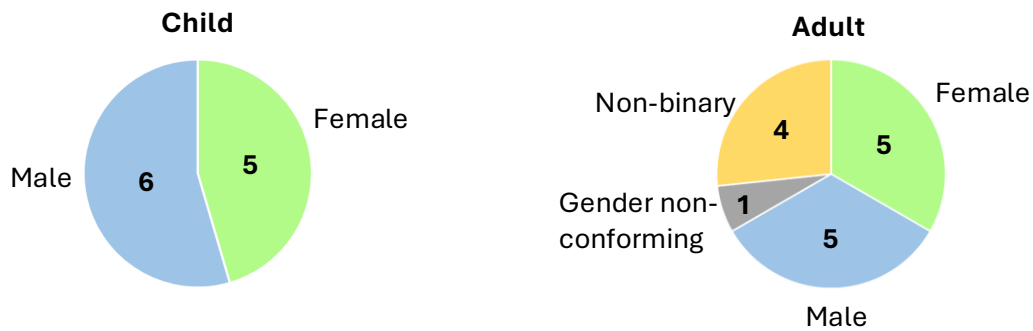
<https://autismnz.org.nz/diagnostic-service/>

Appendix A: Survey results

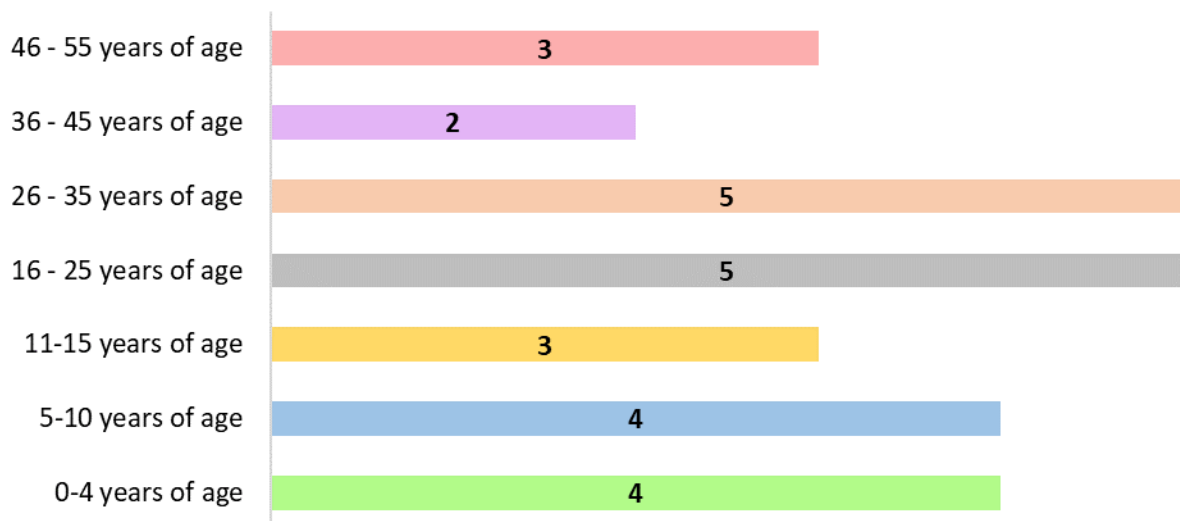
Pre-assessment survey data

The pre-assessment survey was the first survey that participants completed prior to their first appointment with the diagnostic service. 26 participants completed this survey. 11 of these participants were parents of a child who was being assessed, and 15 were adult clients who were being assessed.

Gender of client

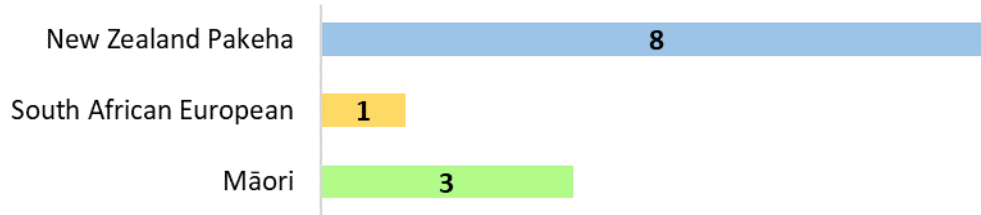


Age of Client

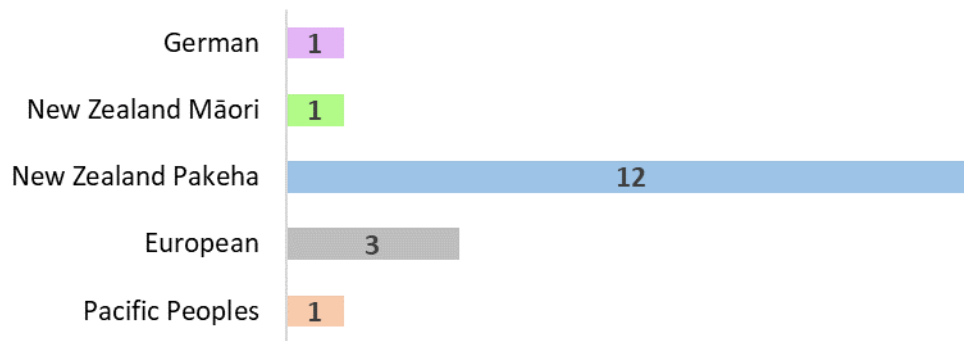


Ethnicity of Client

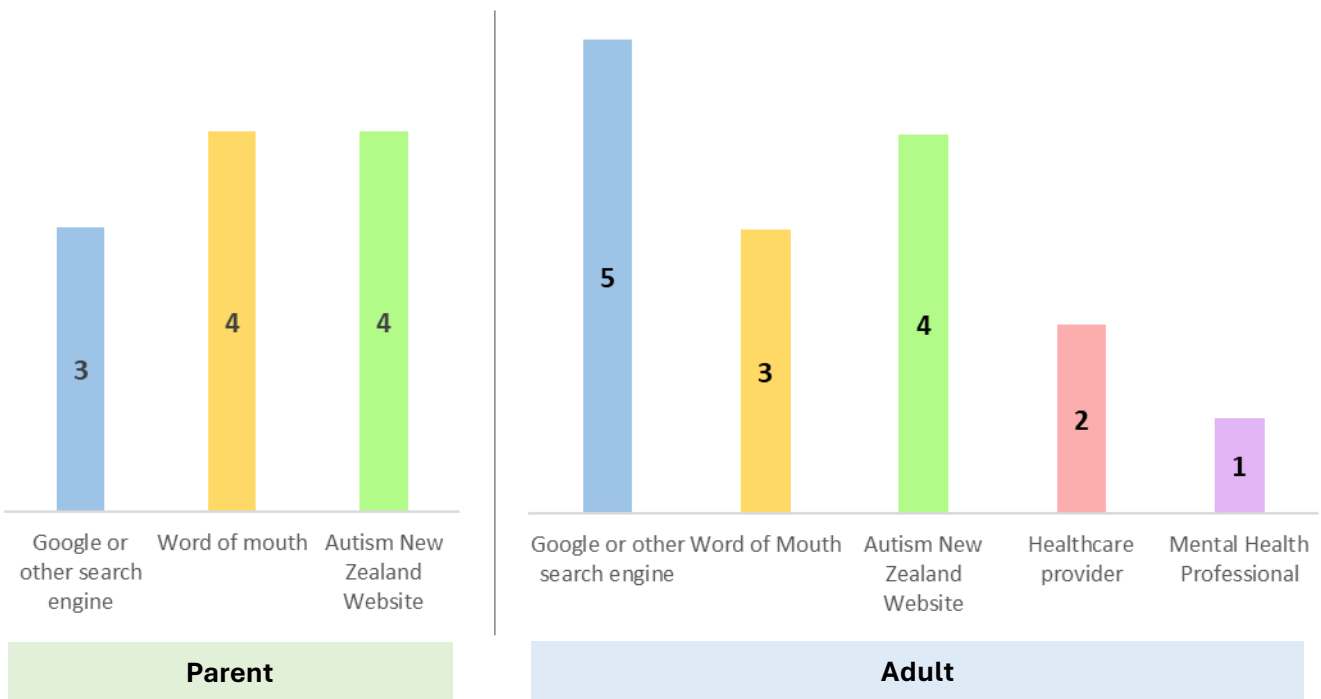
Child



Adult



How participants found out about the service



Why participants chose our service

Parent

Participants commented that they felt our services might be faster than other options, and may be more connected to other networks of support. One commentor felt like it was their only option for an assessment for their child.

Adult

Some clients were seeking validation and support.

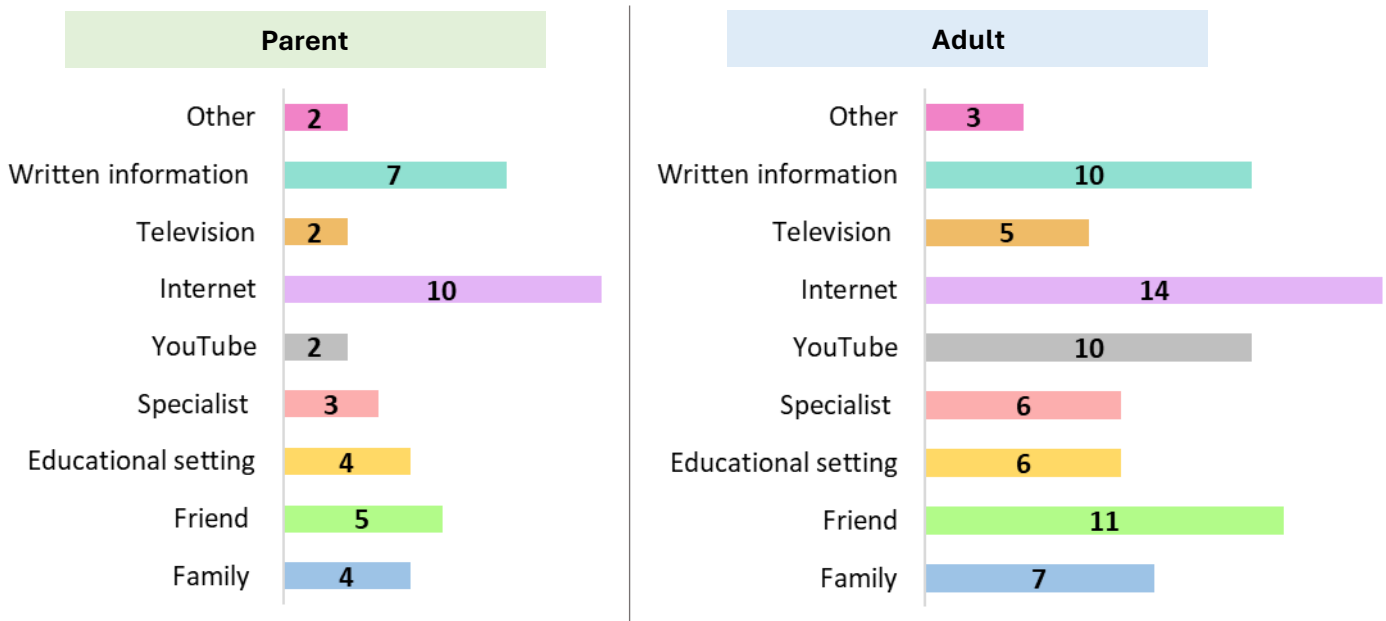
Our services were recommended to the client and were subsidised.

One client noted that they were aware that assessing adults accurately can be difficult and they wanted to be sure they had the best chance of coming to a legitimate conclusion.

Clients couldn't access services through the public system or elsewhere.

They felt that our service had the most comprehensive information about getting an assessment and it was easy to get in contact. The site felt professional, informative, and up front about the costs and timelines involved.

Sources used by participants to find out more about autism



Why participants chose to seek a diagnostic assessment for themselves or their child

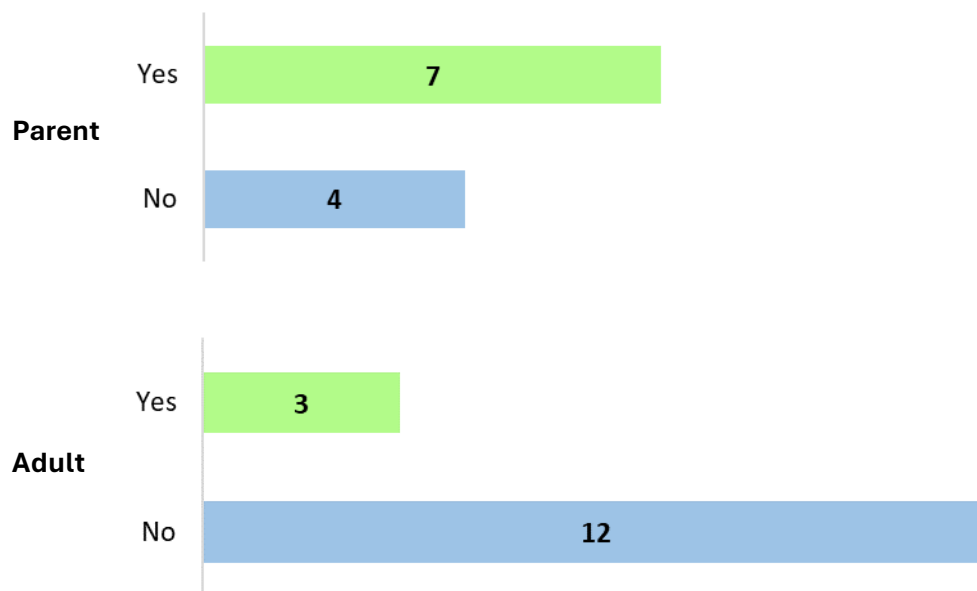
Parent

Parents were mostly seeking an assessment to find, and access help and tools to better support their child and their development as early as possible. Others wanted validation and peace of mind.

Adult

Adult clients expressed a desire to learn more about themselves and understand who they are so they could be more accepting of themselves and find the right tools to reduce struggles they were having. Others just wanted an answer so they could stop questioning whether they were autistic or not. They wanted closure.

Have participants previously tried to access services for themselves or their child?



Comments

Parent

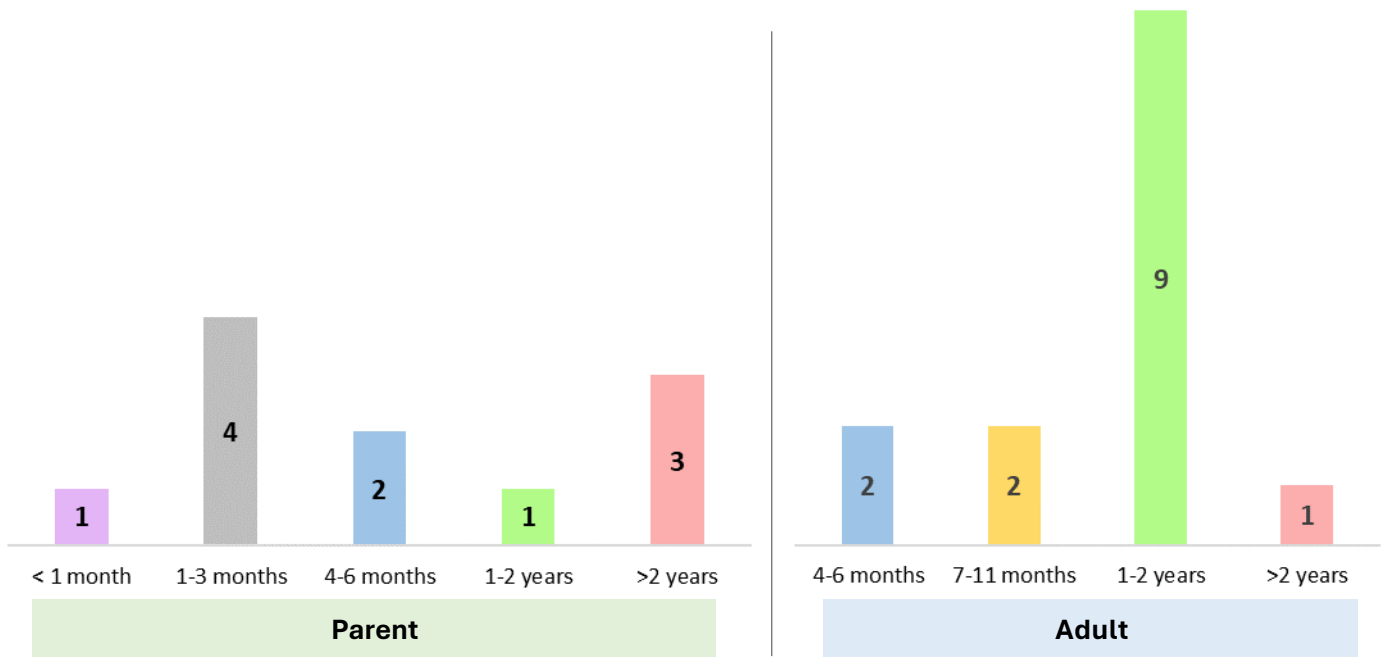
One parent noted that they sought services elsewhere but were told that their child’s behaviour was the result of the parent’s anxiety.

Two parents said they were denied services.

Adult

One client said that they were recommended for an assessment as a child but that their parents did not pursue it.

Length of time trying to access a diagnostic assessment



Services participants accessed in the past related to their concerns

Parent

- Nurture & Thrive Occupational Therapy
- Health/ GP
- Physio
- Barnardos Socialworkers in schools
- Counsellor
- Plunket
- Skylight trust

Adult

- Therapy/ Counselling/ Psychiatrist/ Psychologists, mental health professionals
- Te Haika
- Electoral Commission
- Hutt valley DHB
- GP
- Autism organisations
- Actually Autistic
- Various forms of educational help early in school (Years 1-6ish)
- Teen life

Helpful services

We asked participants which, if any, of the services they had accessed had been particularly helpful to them, their families or their child. They listed the following:

Parent

- Nurture & Thrive
- Health
- Physio
- Barnardos Social Workers in Schools
- Child Development Service - Hutt hospital

Adult

- Therapy/ Counselling/ Psychiatrist/ psychologists
- Teen life
- Hutt valley DHB
- Better help
- Autism organisations
- Psychologist focusing on drug and alcohol
- Twitter
- GP

Unhelpful services

We asked participants which, if any, of the services they had accessed had been particularly difficult or unhelpful to them, their families, or their child. They listed the following:

Parent

- Ministry of Education: Denied the referral for support stating they wouldn't do anything without a formal audiology appointment citing that he is deaf (having never met him - he isn't deaf).

Adult

- GP: Always told it's anxiety related and I don't know if it's correct or not anymore, medical trauma
- GP: For pretty much my whole adult life until this year I have not had a single stable GP, just seeing whoever was available. This didn't really help me make a lot of progress in how I was feeling for a really long time and didn't push me forward to where I am now.
- Counselling: I've had a few counsellors that I really think didn't understand me very well and directed a lot of the blame for my feelings back on me, which was not very helpful for me.
- Counsellor: When I was at University I didn't understand what was wrong with me and going to see a counsellor didn't help very much at that time.
- Te Haika: Only saw a social worker (one training/watching and one qualified). Was a very dismissive and rude interaction. Even poked fun of some of my ideations.
- Mental health: Gaslighting.

Post diagnosis support

We asked participants what supports and services they anticipate they will want to access if they receive a diagnosis of autism following their assessment. They listed the following:

Parent

- Speech language therapy
- Something to help my daughter regulate her emotions/ Counselling/ Therapy
- Parent seminar
- Educational support/ MoE learning support/ School understanding and extra support, extension
- NASC
- Educational opportunities
- Space to drop in
- Something to help with socialising/ communication/ programmes to support interest and social skills
- Some therapy around her sensory challenges
- Transition support for primary to intermediate school
- Outreach coordinators
- Child disability allowance/ financial
- Parent to parent support forums

Parents commented that they weren't sure what supports were available so they weren't sure how to answer and they wanted guidance and advice from the diagnostic team around what supports to pursue or access.

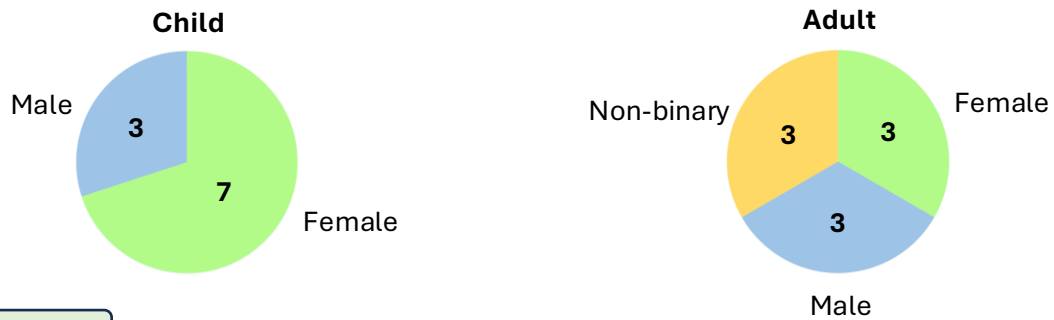
Adult

- Specialised Therapy
- Emotional help/ anger issues
- Maybe something to do with navigating unstructured social situations/ help with interactions with others
- Help with understanding the diagnosis
- Disability support at the University
- Advice on how to manage stress
- Support groups
- Support in management of mental state and interactions with the world
- Information about my rights, options regarding my issues
- Household management
- Maybe financial or professional help
- Support around working/ not working. Financial support
- News, information, article, for example about research or recognition
- Advice on how to manage sensory overload
- Tools and support for the workplace
- Classes or course on autism

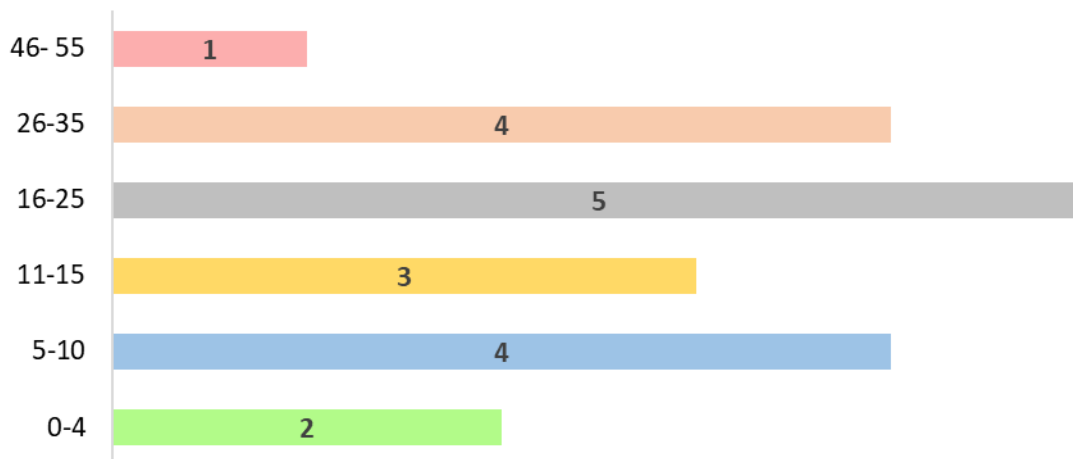
Diagnostic service feedback survey data

Following their assessment, participants were given the opportunity to complete a feedback survey. 19 participants took part in this survey, 10 of whom were parents and 9 of whom were adult clients.

Gender of client

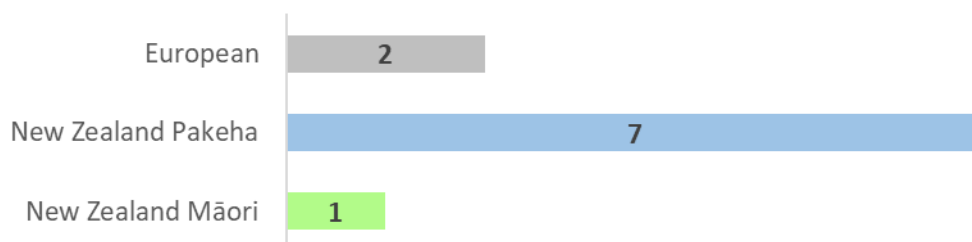


Age of client

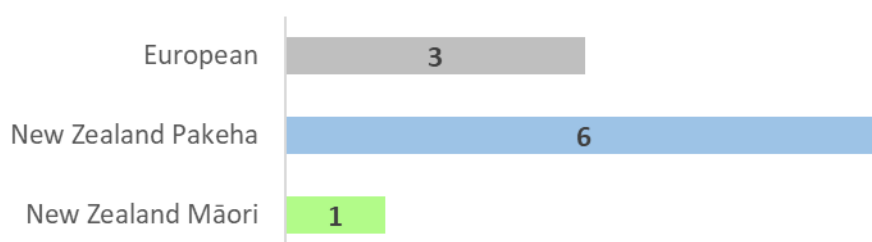


Ethnicity

Child

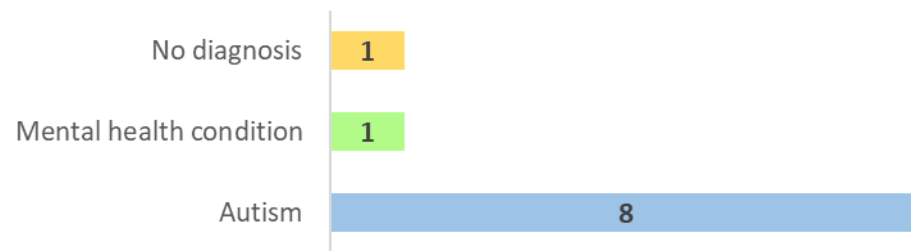


Adult



Diagnostic outcome

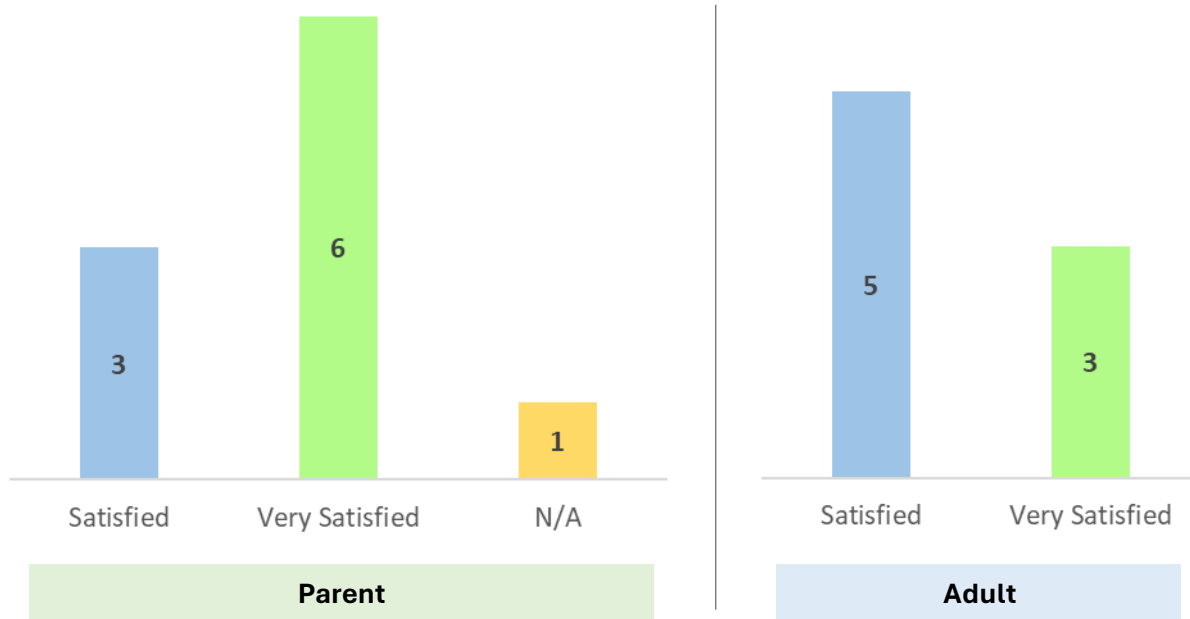
Child



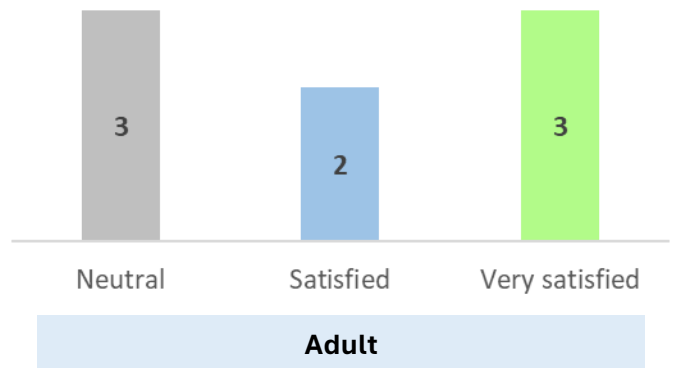
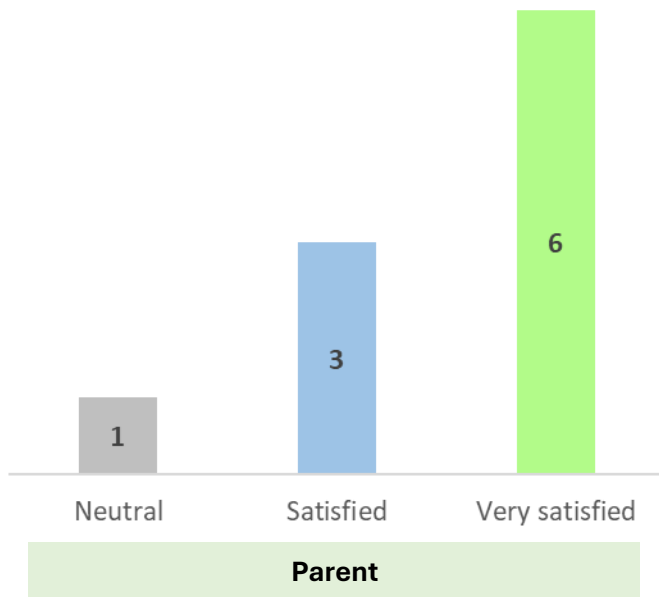
Adult



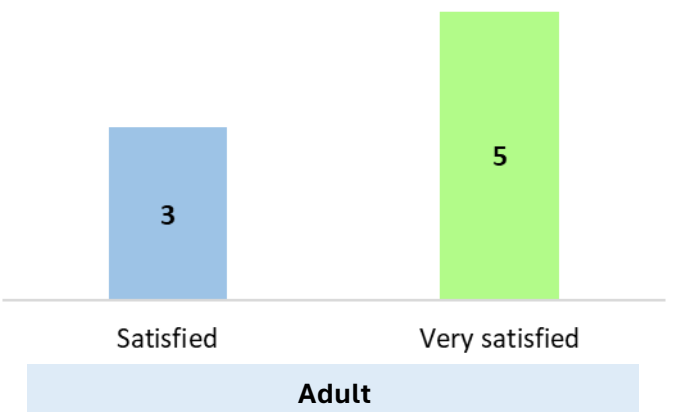
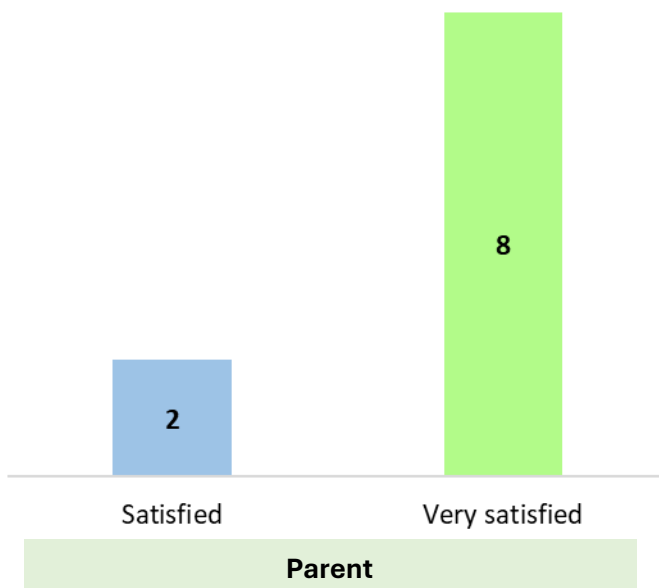
Satisfaction with Registration of Interest



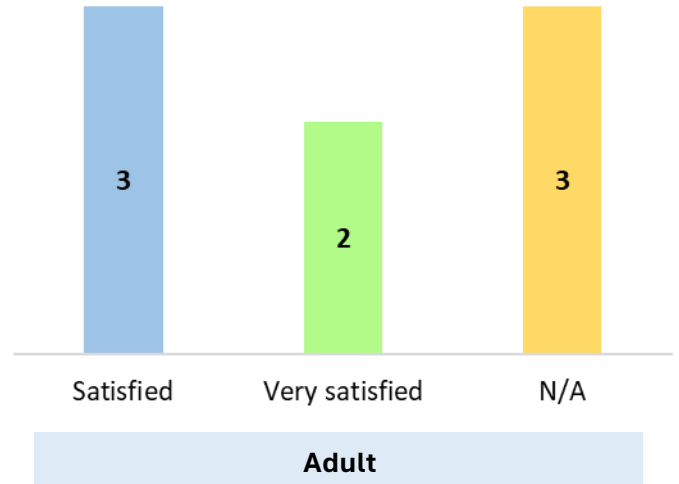
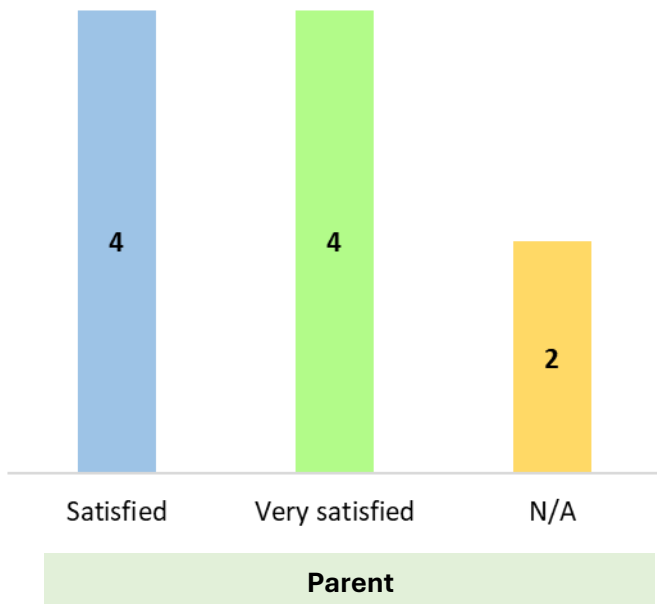
Satisfaction with wait times



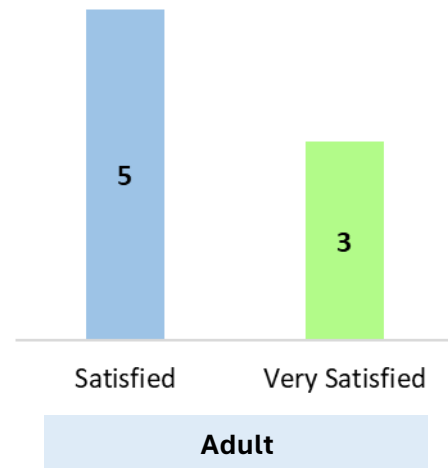
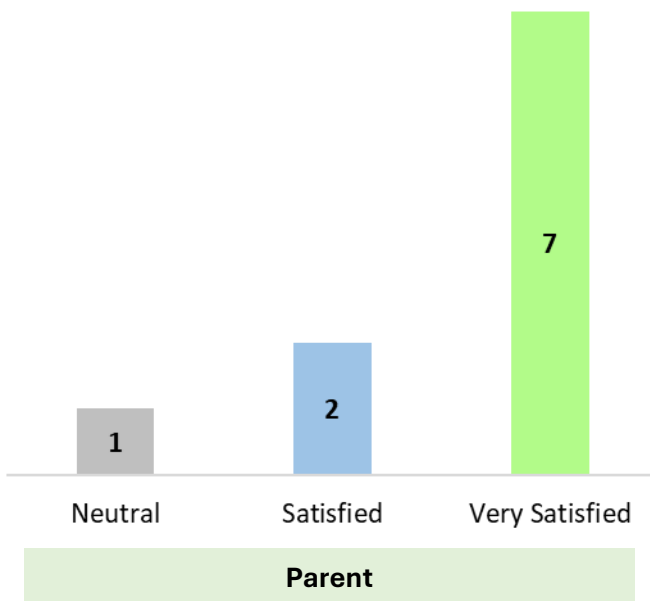
Satisfaction with initial interview



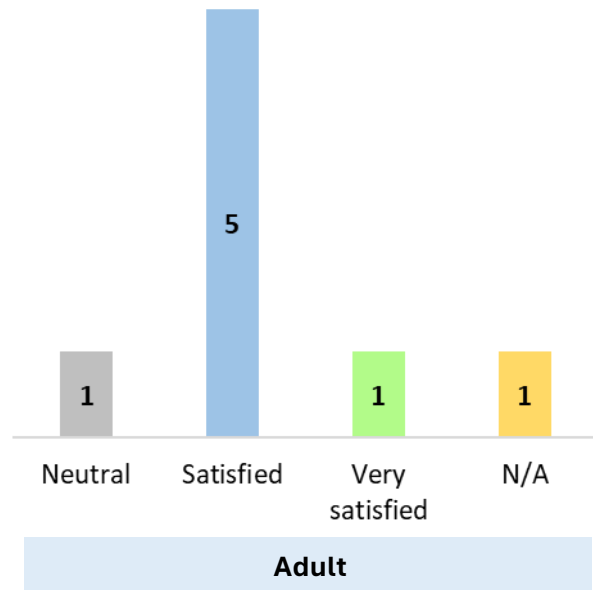
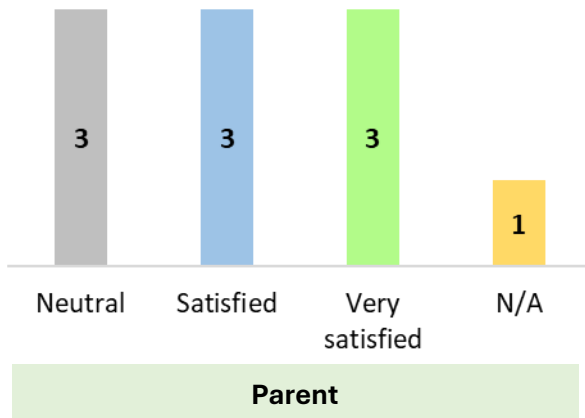
Satisfaction with other assessments



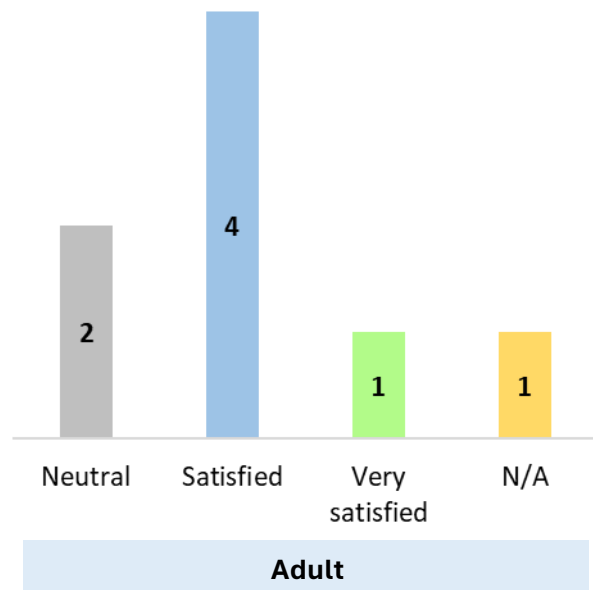
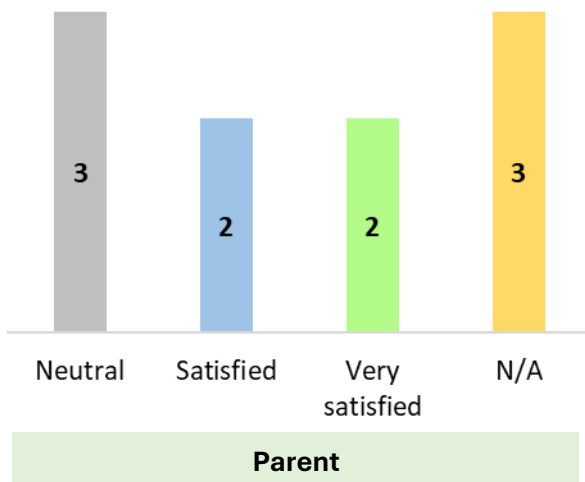
Satisfaction with feedback appointment



Satisfaction with follow-up resources

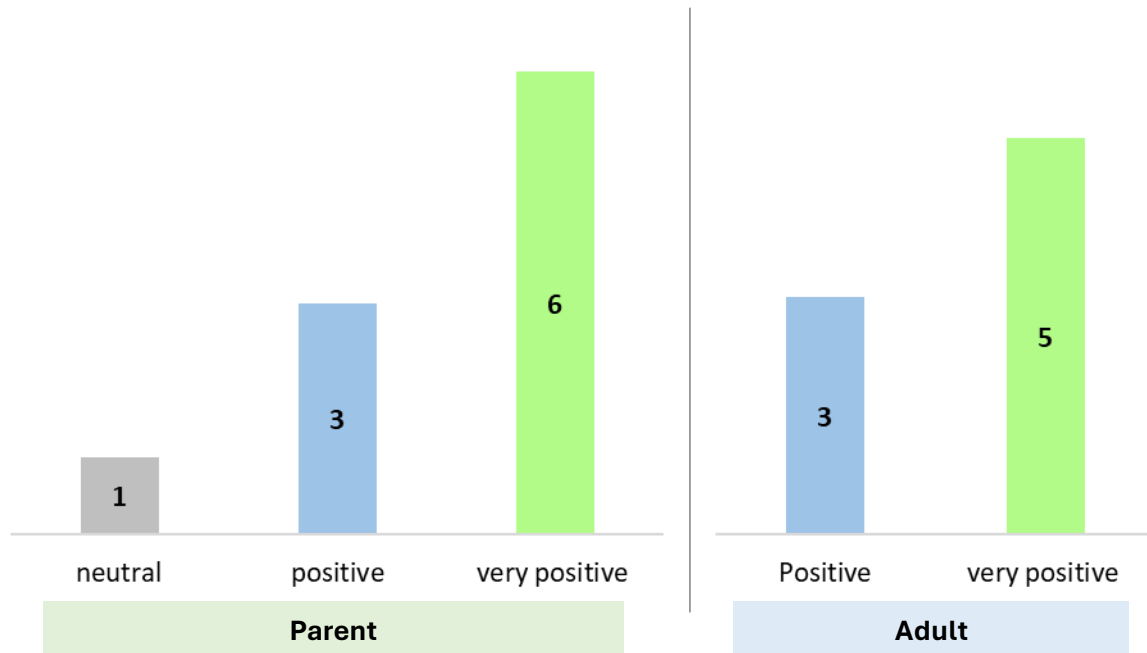


Satisfaction with follow-up support



Overall experience with the Diagnostic Service

Participants were asked to rate how positive or negative their overall experience was with the diagnostic service at Autism New Zealand.



Appendix B: 3- and 6- month survey and interview results

Diagnostic service

Parents

Overall, parents were very positive about the diagnostic service. They felt comfortable, informed about what was happening, and reassured. Parents said that the process was easy; that questions about their child were asked in a sensitive way; and that they felt their children could be themselves without being judged. They were particularly positive about the staff, and talked about the staff's ability to accommodate and engage with their children.

There were a few issues mentioned, like lack of parking, misspelt Māori names in one report, and a child refusing to enter the building because it said 'Autism' on the front. One parent also said that the amount of forms they needed to fill out before their appointment could be prohibitive for other parents with less education or ability.

"Everyone acts here how I wish other people would act."

Adults

Adults were also positive about the process and the staff. They said it felt community-led, neuro-affirming, and mana-enhancing. There were several comments specifically about the service lead, who adults said was available to answer questions leading up to their appointment, was compassionate and understanding during the assessment, and made them feel comfortable and among family by sharing her own neurodivergence. The clinic environment was comfortable, with no expectations of making eye contact or removing sensory aids like sunglasses.

Multiple adults mentioned that they felt the clinical aspects of the report were in the background, and that the focus was on them as a person. They felt seen and celebrated as an autistic person, both in the assessment and when reading the reports. One Māori adult talked about the idea that in Te Ao Māori people are not segmented into different parts (e.g. physical health, emotions, mental health), and that the clinic was the first service they had accessed that treated them as a whole person.

Several adults found the lack of a concrete timeline difficult, both in terms of knowing when their assessment would be in advance, and knowing how long it would take to get the results (one did acknowledge that the staff were transparent about this). Other difficulties adults reported included finding the forms exhausting and time-consuming and having a difficult experience asking their parents about their childhood.

One adult recommended having someone from Autism NZ's Outreach service in the feedback session, to give a direct link to the next step in the process.

"[T]his room... had been unlocked, and... they had sort of plucked me out of this very dark space, and embraced me."

Experience of diagnosis (not specific to the service)

Adults

Adults found getting an autism diagnosis liberating. Some said that it explained a lot about their lives, or that it allowed them to have greater compassion for themselves.

Several adults said that they floundered post-diagnosis; for some the time after they got their diagnosis was a blur, or they forgot which services had been recommended or where they should go next. One said the diagnosis hadn't changed that they were overwhelmed day-to-day.

Parents

Parents reported that their children's diagnosis provided relief and enlightenment. Some reported that they now feel like they have a voice, particularly around issues with school. Parents reported being grateful for the diagnosis.

Summary of services accessed

Adults

Recently diagnosed autistic adults mentioned accessing Autism New Zealand Outreach Coordinators; Taikura Trust NASC; Yellow Ladybugs; the book *I Am Autistic* by Chanelle Moriah; and podcasts by autistic adults.

The services they believed were most helpful were Outreach Coordinators, podcasts by autistic adults, and the *I Am Autistic* book. Least helpful were Taikura Trust and Yellow Ladybugs.

Participants said that Autism New Zealand's Outreach Coordinators helped them to access other supports, and made other supports (specifically the NASC) accessible for them when it would otherwise have been impossible to navigate. Podcasts and the *I Am Autistic* book helped them to identify with other autistic adults, and to talk to others about what being autistic meant.

Negative feedback for Taikura Trust was focussed on lack of contact; participants said they hadn't heard back or had waited months to hear back. One participant also found the Yellow Ladybugs site difficult to navigate and aimed at children rather than adults.

Parents

Parents of recently diagnosed autistic children mentioned accessing NASCs (specifically Kia Roha and Capital Support); CDS; Autism New Zealand services (including Outreach Coordinators, the FANZ workshop, kaiarahi services, and employment support); the book *I Am Autistic* by Chanelle Moriah; the IHC library; private occupational therapists and speech language therapists; CAMHS; WINZ; Facebook groups; and the Spectrum playgroup in Naenae.

The services they believed were most helpful were NASCs (specifically Capital Support); CDS; Autism New Zealand's Outreach Coordinators, employment service, diagnosis service, FANZ workshop, and kaiarahi service; the IHC library; the *I Am Autistic* book; and private occupational therapy.

Those they believed were least helpful were NASCs (specifically Kia Roha) and CDS.

Parents' positive feedback focussed on help and guidance in accessing further supports; funding; and providing a deeper understanding of their child. Multiple participants said that Autism New Zealand's Outreach Coordinators helped them to navigate a confusing system and get support. Capital Support provided necessary funding for occupational therapy (although one participant mentioned that funding changes mean they can no longer access this). FANZ workshops and the *I Am Autistic* book provided a deeper understanding of autism and their children, practical strategies, and ways to talk to extended family members about their child. Some participants named specific people: Autism New Zealand's Kaiarahi provided invaluable cultural support, and Autism New Zealand's employment support facilitator was very proactive and helpful. Another participant said that Spectrum playgroup provided community and connection with similar families, free of judgement.

Negative feedback focussed on waitlists and systems being difficult to navigate. Participants reported that their NASC didn't respond to their initial contact, or took a long time to respond; that CDS had a huge waiting list and different branches didn't communicate with each other; that public speech

language services had waitlists so long they were forced to use private services instead; and that funding changes mean their children will be pulled out of necessary services.

Reasoning behind not accessing other services

Adults

Adults reported being too busy and overwhelmed to access other services. Some said that other life events like family illness or pregnancy got in the way; others were just already overwhelmed and could not add another thing to the pile.

One adult reported that they were too nervous to access services; another said accessing support required phone calls, which was not possible for them.

Some adults said that they did not remember which services had been recommended or what had been talked about post-diagnosis, often because the diagnosis itself was so emotional.

Parents

Parents reported that accessing support for their children was not financially feasible; and that they were unable to navigate the support system.

Other reasons behind not accessing support included being overwhelmed with the amount of information provided; being too busy; being nervous about their child being judged; being blocked by gatekeepers like GPs; still being in the process of getting diagnoses for other family members; support and training programmes requiring full days off work, which was not feasible; and children refusing to engage with support services.

Post-diagnosis priorities (parents)

This list is a combination of what survey respondents said was their top priority, and what interview respondents either specified was their top priority or seemed to put the most emphasis on:

- Learning how to manage child's behaviour
- Reducing meltdowns/high levels of distress
- Accessing respite support
- Better understanding their child
- Getting/continuing speech therapy
- Child starting school – making sure it will work for them
- Finding an educational setting that child will cope with
- Further diagnoses for multiple children
- Children's happiness
- Making sure child isn't ashamed/helping child to accept who they are

This list includes all other priorities parents mentioned:

- Managing child's behaviour
- Keeping themselves, the child, and sibling/s safe
- Accessing respite support
- Transitioning to intermediate school
- Changing the home environment to support the child
- Helping their child feel positive/confident about their autistic identity
- Finding social groups where the child feels comfortable
- Using more visual tools at home
- Putting predictable routines in place
- Figuring out education that works for the child
- Communication
- Being open to learning from the child what they need

- Supporting the child to be their best self
- Sensory toys
- Working out how to have a life that everyone in the family enjoys

Post-diagnosis priorities and goals (adults)

This list is a combination of what survey respondents said was their top priority, and what interview respondents either specified was their top priority, or seemed to put the most emphasis on:

- Clarifying a sense of identity
- Learning more about themselves
- Recontextualising traits/life events in the light of the diagnosis
- Accessing daily living support
- Changing approach to household management
- Gaining compassion for themselves
- Sorting out their life
- Unmasking
- Sorting out benefits

This list includes all other priorities adults mentioned:

- Getting an ADHD diagnosis
- Managing sensory needs, especially around food
- Recontextualising traits in the context of the diagnosis
- Accessing support
- Accessing support for physical health/wellbeing
- Telling family
- Discussing children's diagnoses with them
- Making friends
- Accessing support for making friends
- Reducing overload/overwhelm/burnout
- More deliberate approach to reducing overload
- Dropping unnecessary demands
- Finding a job
- Finding a more appropriate/acceptable job
- Accessing employment support
- Exploring unmasking
- Finding more coping mechanisms
- Setting routines
- Getting out more
- Openly enjoying the positive aspects of autism without shame