



4 April 2025

Tēnā koe

Official Information Act request

Thank you for your email dated 10 February 2025 to the Ministry of Disabled People – Whaikaha (Whaikaha) in which you requested the Explore Specialist Advice 6-monthly report for July to December 2024. On 11 February 2025, Whaikaha transferred your request to the Ministry of Social Development (the Ministry).

I have considered your request under the Official Information Act 1982 (the Act).

Please find attached the Explore – Whaikaha Six Monthly Report for the period 1 July 2024 to 31 December 2024.

Item 11.5 of the report, titled 'Issues/concerns', notes that "the recent decrease in referrals since October has coincided with anecdotal reports from families and other agencies that budget constraints are impacting referrals being made."

Disability Support Services (DSS) would like to clarify that Explore is funded centrally, and referrals are not funded out of Needs Assessment and Service Co-ordination (NASC) budgets. Therefore, NASC decisions around prioritisation of support allocations to remain within their respective budgets should not impact the volume of Explore referrals. Following receipt of the report, DSS has since clarified this with Explore and NASC's.

I will be publishing this decision letter, with your personal details deleted, on the Ministry's website in due course.

If you wish to discuss this response with us, please feel free to contact OIA_Requests@msd.govt.nz.

If you are not satisfied with my decision on your request, you have the right to seek an investigation and review by the Ombudsman. Information about how to make a complaint is available at www.ombudsman.parliament.nz or 0800 802 602.

Ngā mihi nui

pp.

Anna Graham

**General Manager
Ministerial and Executive Services**



Whaikaha 6 Monthly Report

Reporting period

1 July 2024 to 31 December 2024

Kai Whakaute:
We act with Care, Respect and Empathy.

Kai Huhuatanga:
We strive for Excellence and Quality.

Kai Whānaungatanga:
We act in Partnership.

Date: June 2024

Form #

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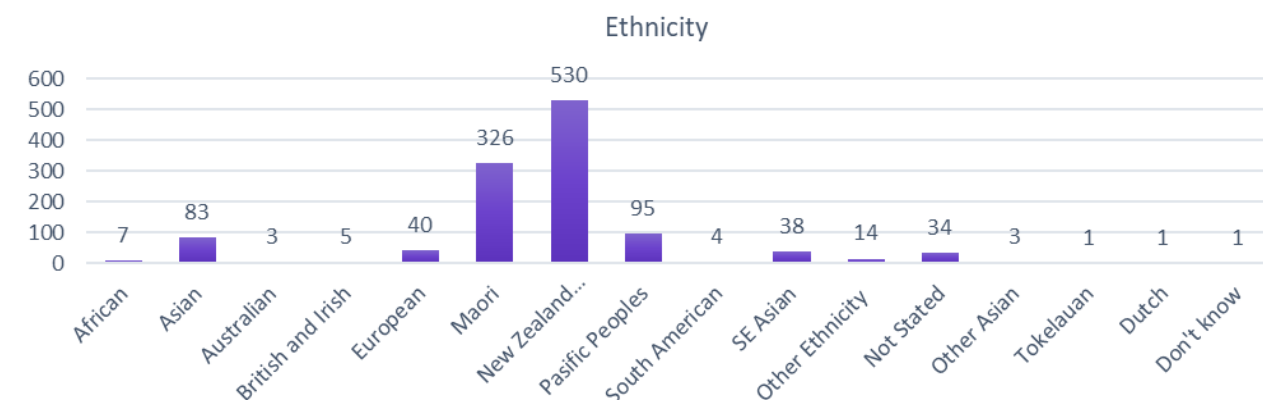
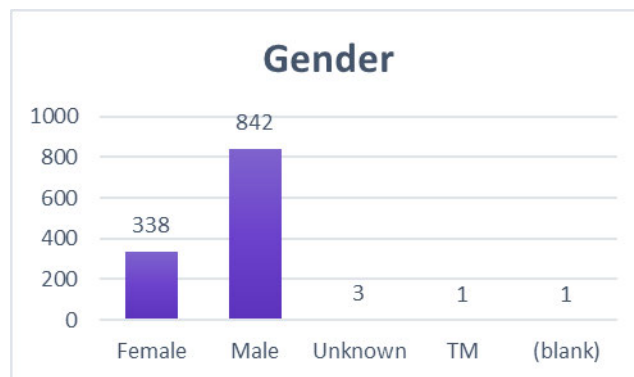
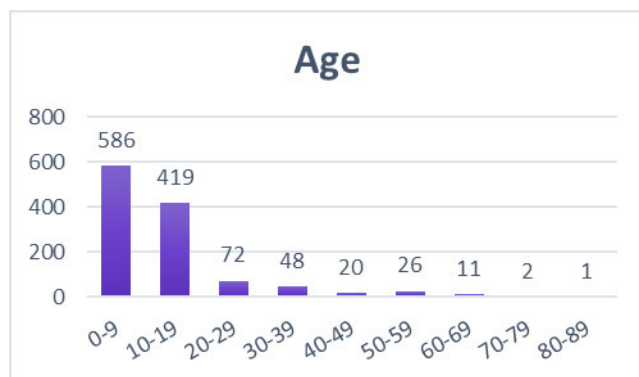
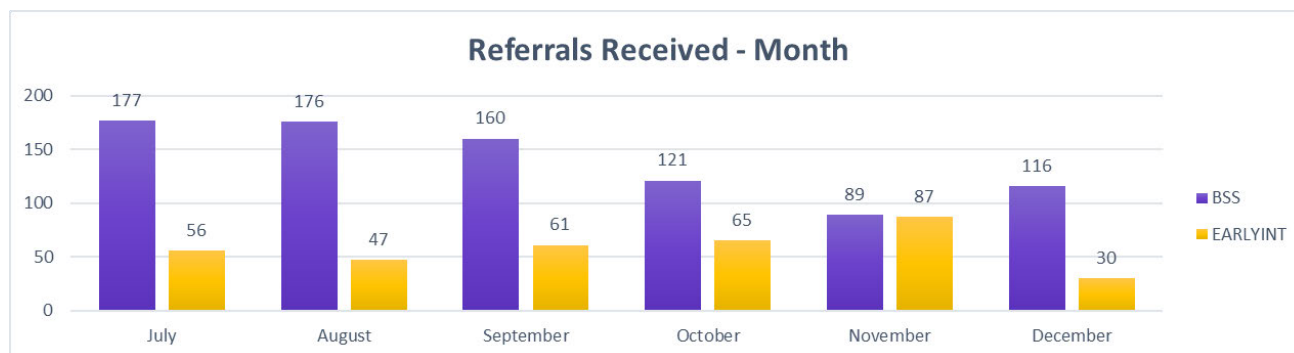
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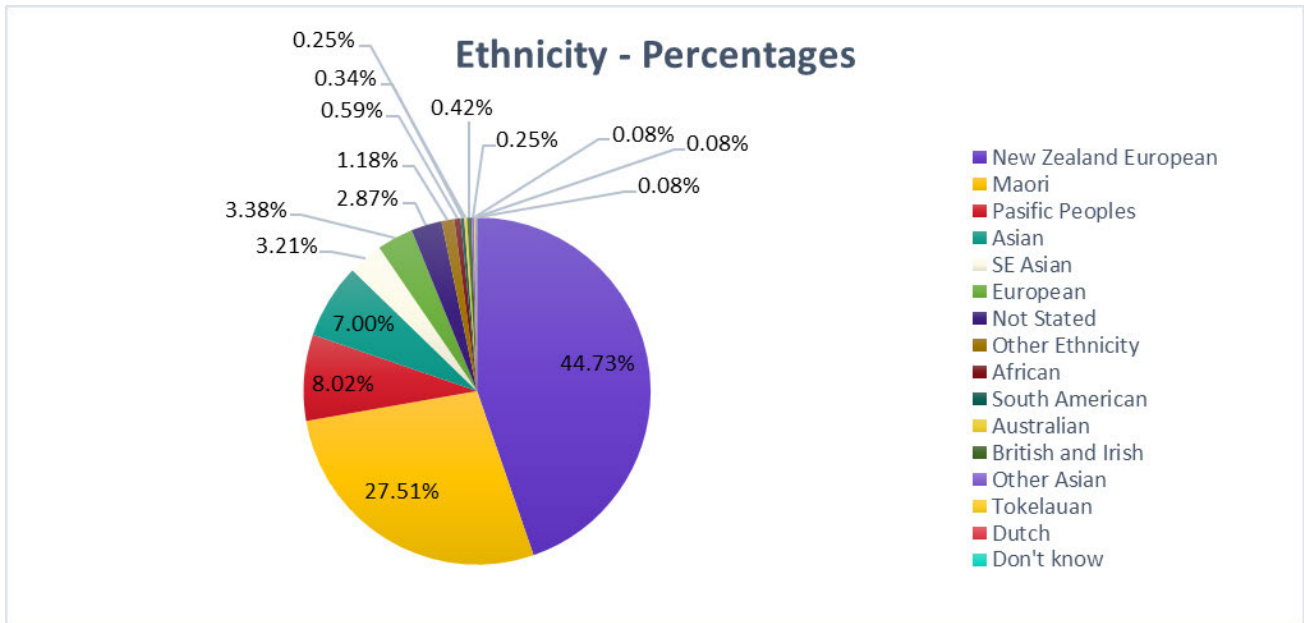
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1. Referrals

1.1.BSS referrals received

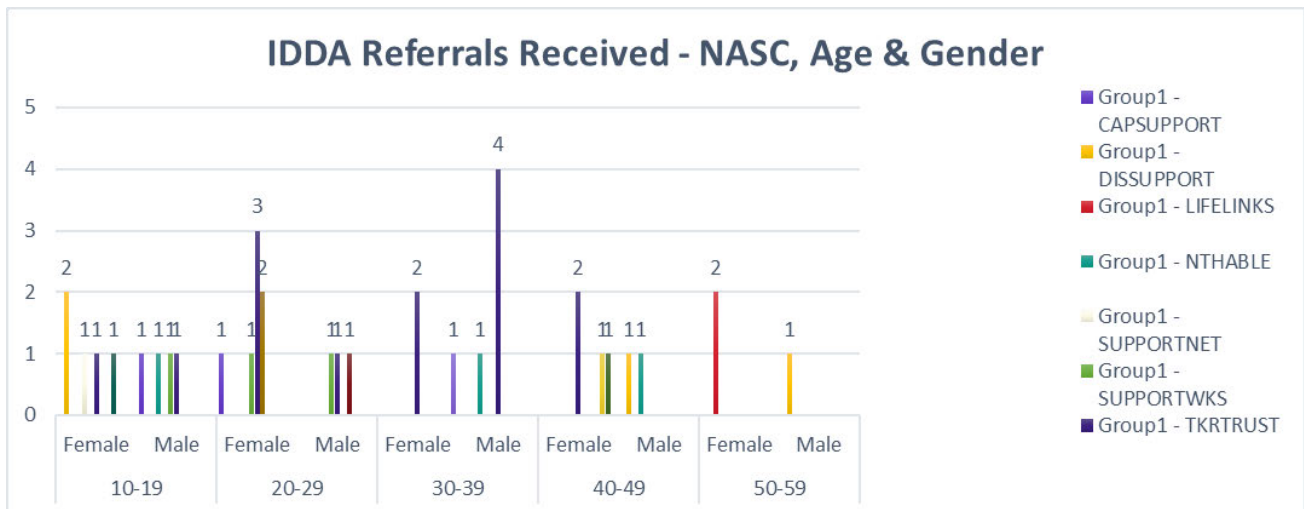
The following graphs show a breakdown of referrals received and accepted during the reporting period by month, age, gender, and ethnicity. A total of **1185** referrals were received and accepted for the six-month period. This compares to 1265 for the same reporting period in 2023. Decline in the number of referrals for tamariki aged 0-9 years is -13%, rangatahi aged 10-19 years is -7%. Indications are that this decline is not in relation to a decline in need or diagnosis, and is in direct contrast to increases in economic and social challenges for many families. This trend has been evident for the past three months and has been escalated to our Senior Portfolio manager and the Northern Regional Manager at MSD DSS.





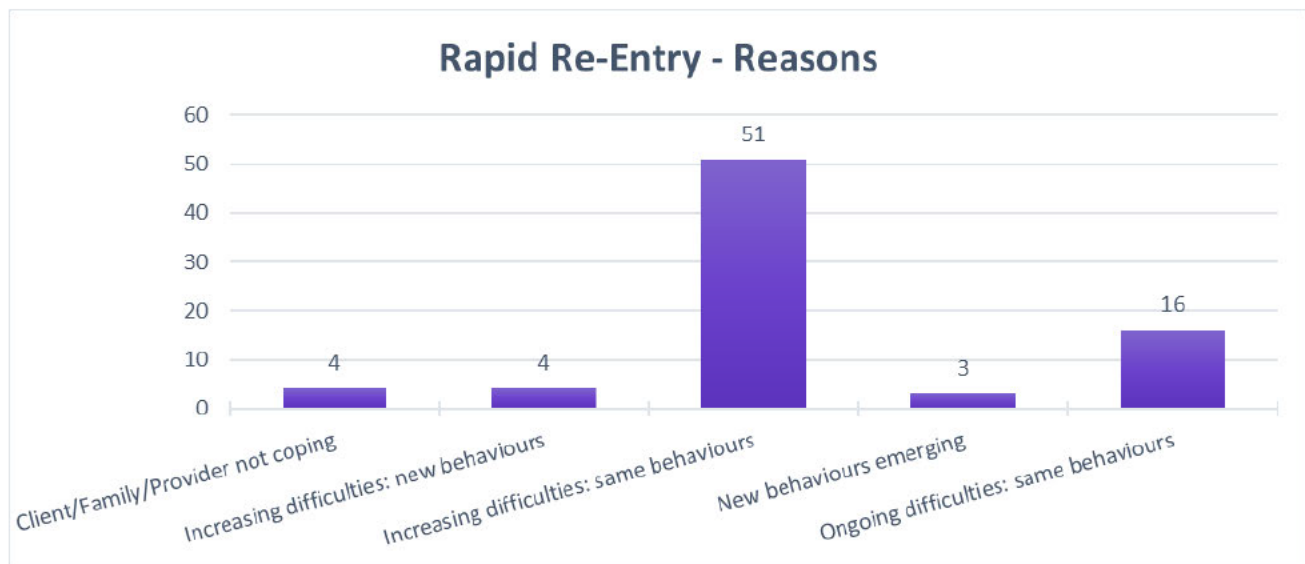
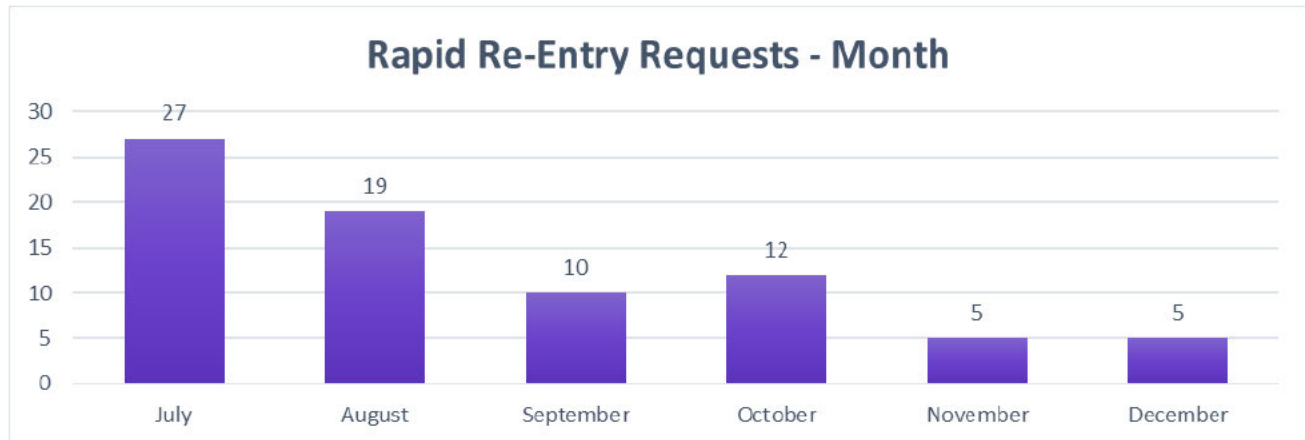
1.2. IDDA referrals received

The following graph shows a breakdown of 36 IDDA referrals received and accepted during the reporting period for completion of IDDA by NASC, age, gender.



1.3. Rapid Re-Entry (RRE)

The following graphs show 78 RRE requests received during the reporting period by month and reason.



1.4. Re-Referrals

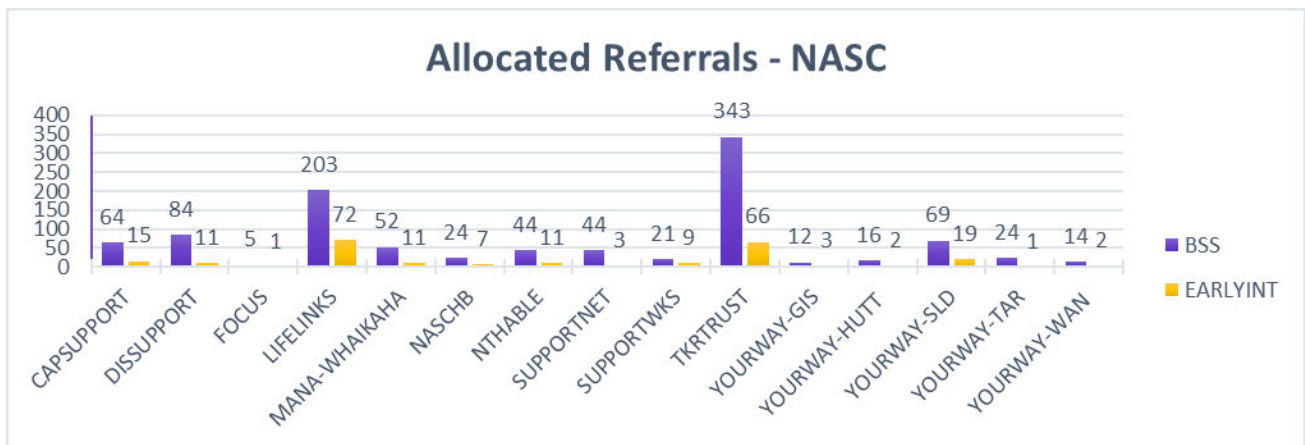
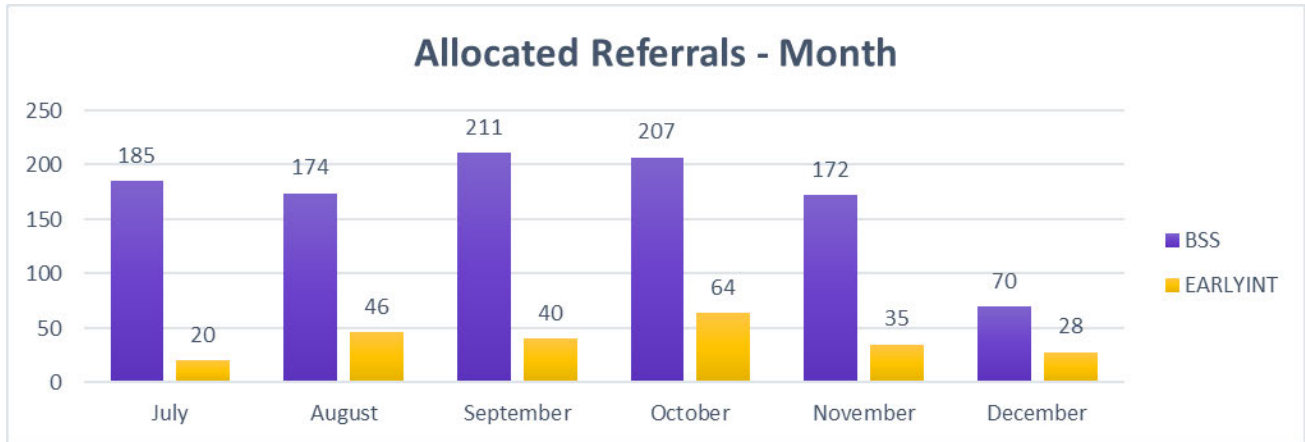
The following table shows the percentage of re-referrals received during the reporting period by type.

Type	Number Received	% of Received
NEW-REF	830	70.04%
RR-NEW	239	20.17%
RR-SAME	116	9.79%
Grand Total	1185	100.00%

2. Allocated Referrals

2.1. Allocated referrals

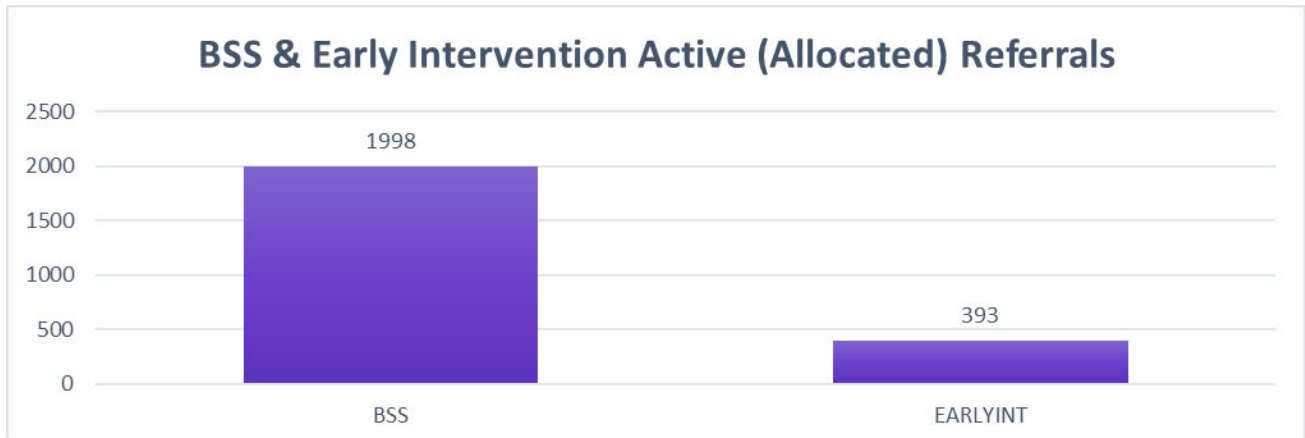
The following graph shows **1252** referrals allocated in the reporting period for BSS and Early Intervention



3. Active Clients

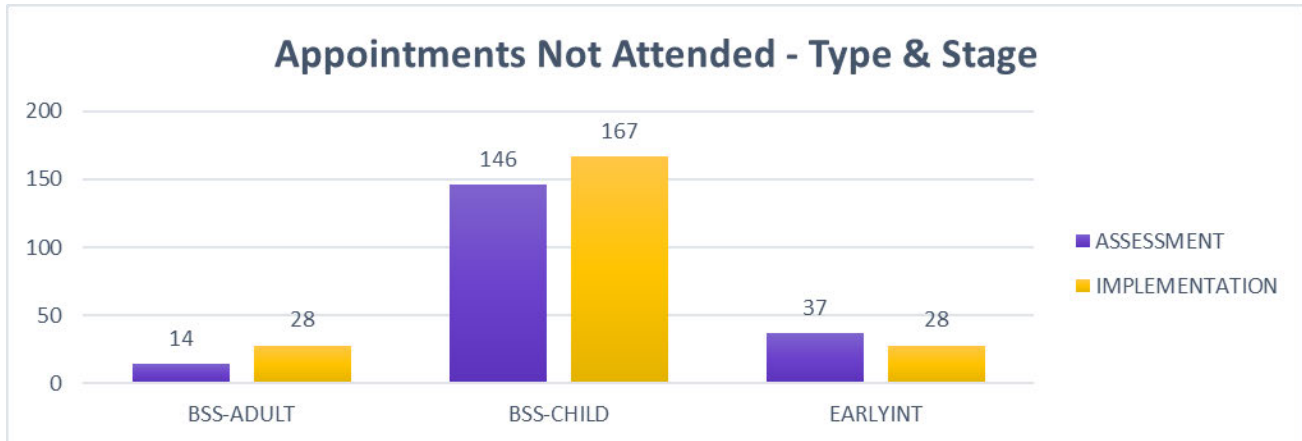
3.1. Active referrals

The following graph shows **2391** BSS and Early Intervention referrals that were active in the reporting period.



3.2. Appointments not attended

The following graph shows **420** appointments that were not attended by clients, either by not showing or providing less than 4 hours notice. There is a concerning pattern of 'non-commitment' to planned appointments. Whilst there is greater than 4 hours notice is given the level of disruption to a behaviour support journey and timely support is significant. This concern involves both families and residential services.

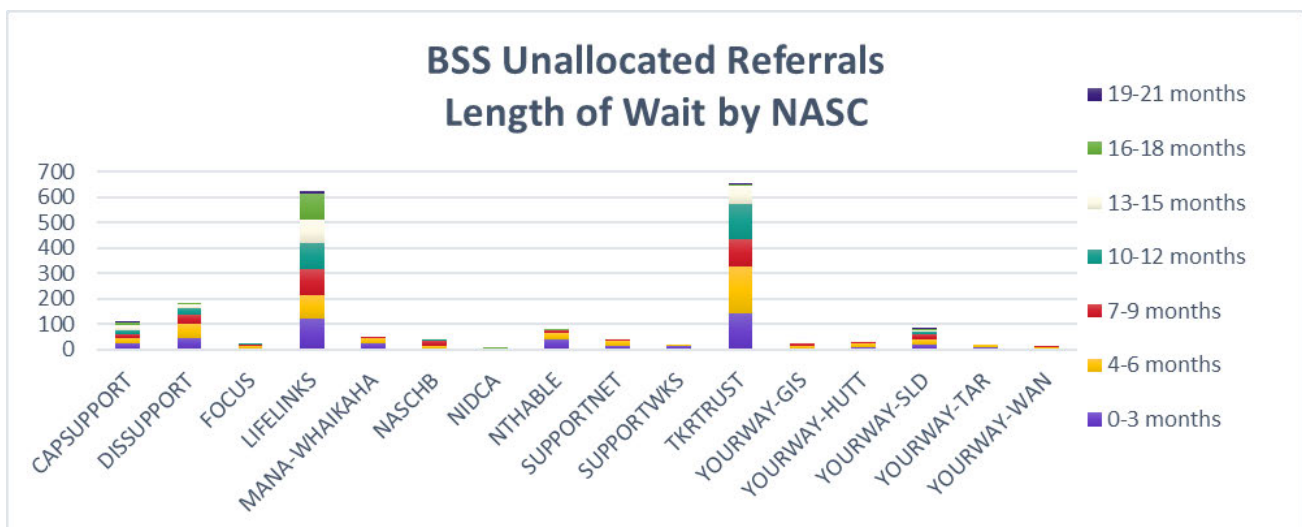


4. Wait List

4.1. Length of wait by NASC and national wait time

We recognize the impact of the wait time and have discussed a proposal with Whaikaha to pilot early response to people/whānau on the waitlist, to 1) provide support at an early stage following acceptance of referral 2) to enhance engagement and progress once a Specialist is allocated to support the full behaviour support journey.

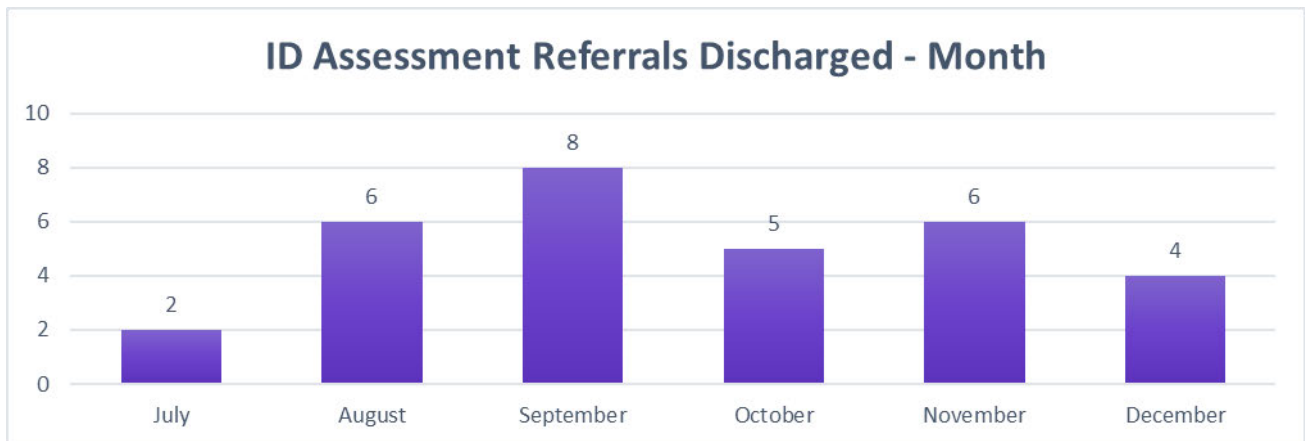
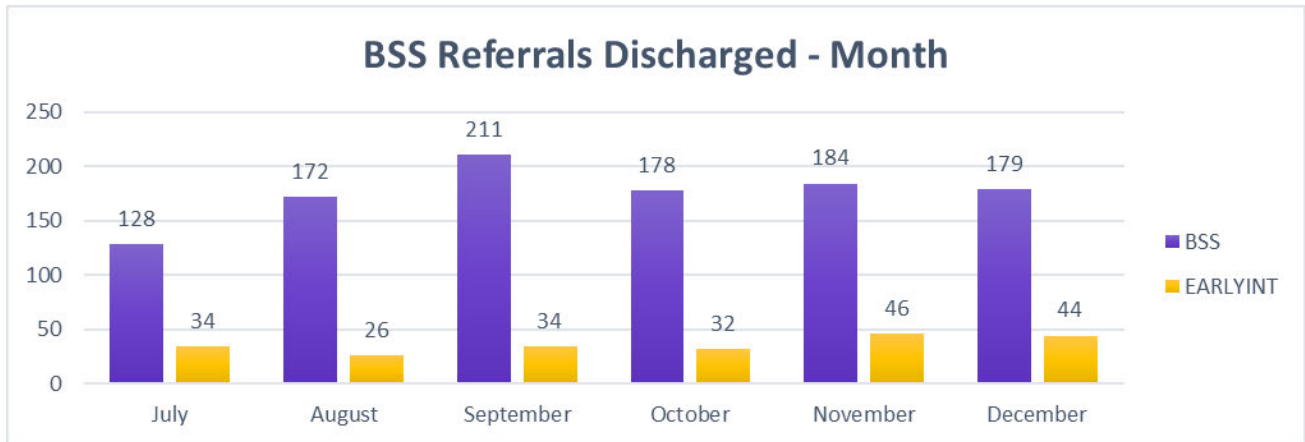
The following graph shows the length of time in months for **1995** unallocated referrals.



5. Discharges

5.1. Total Discharges

The following graphs show the number of referrals discharged per month for the reporting period, **1268** BSS and **31** ID Assessments.



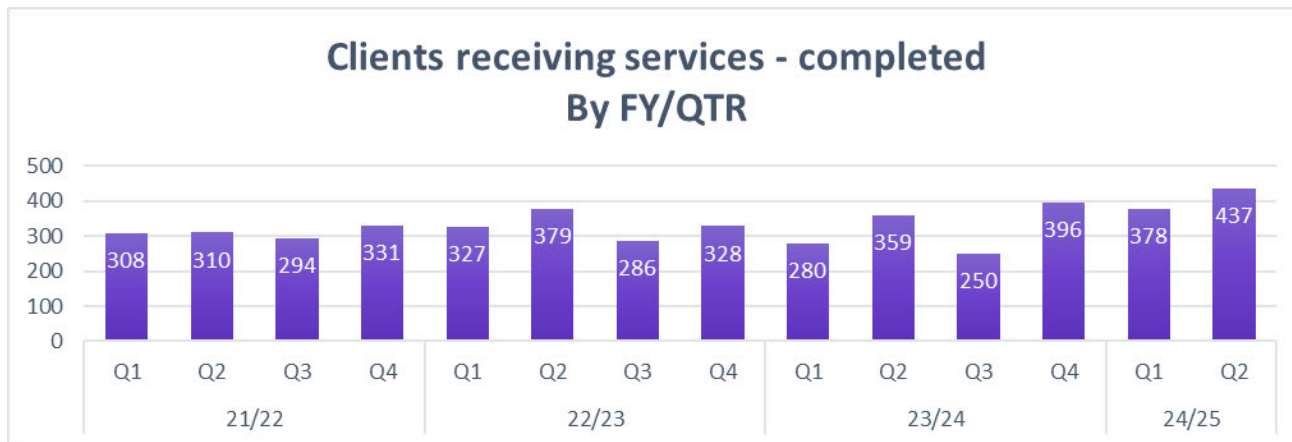
5.2. Minimum First Contact – Over Time

The following graph shows **1168** clients that received services in the reporting period with a minimum of first contact



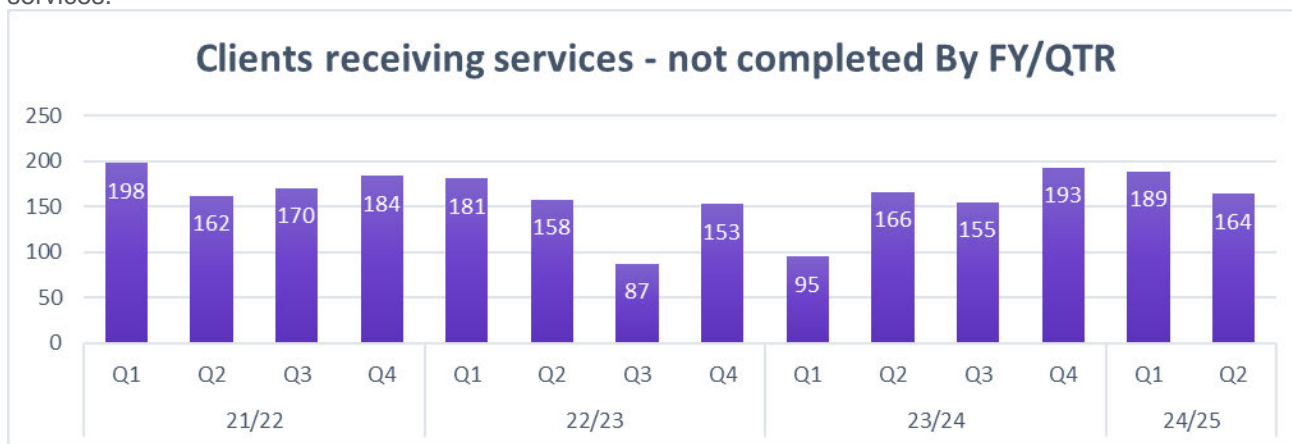
5.3. Received Services: Completed – Over Time

The following graph shows **815** clients that completed services in the reporting period.



5.4. Received Services: Not Completed – Over Time

The following graph shows **353** clients that received services in the reporting period but did not fully complete services.



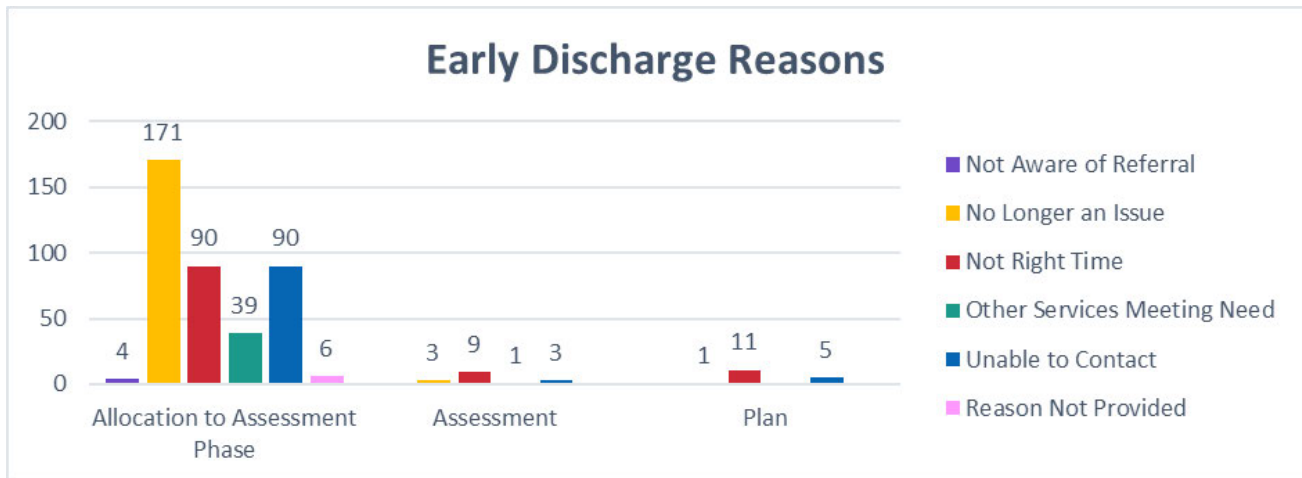
5.5. Waitlist: Did Not Start – Over Time

The following graph shows **82** clients that were on the waitlist in the reporting period and did not start services.



5.6. Early Discharges

The following graph shows **433** Early Discharges and the phase at which Explore exited – after first contact, after assessment, after plan complete.



6. Goals and Outcomes

6.1. Goal achievement

The following graph shows a breakdown of the number/percentage of goals a person has achieved as set in their behaviour support plan in the reporting period.



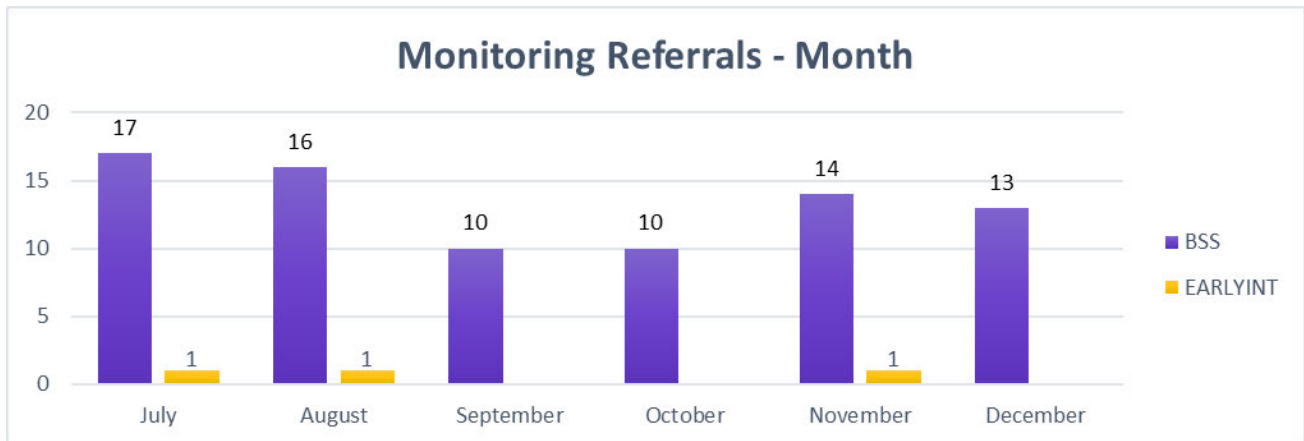
6.2. Quality of plans

BSP's are submitted for review to clinical supervisors before going out to families and providers. Managers review all work for the first year and ongoing as required. These steps ensure that plans receive internal critique and support is provided for the Specialist to grow their skill and confidence while ensuring the quality of plans are maintained at a level the organization expects. Ongoing investment in supervision of all Specialists by Senior Clinicians is another mechanism for maintaining the high-quality plans and support to people and whānau.

7. Monitoring

7.1. Total number of Monitoring referrals

The following graph shows **83** people who were moved to monitoring following discharge from BS and Early Intervention referrals.



8. Specialist Assessments

8.1. Number of specialist assessments completed

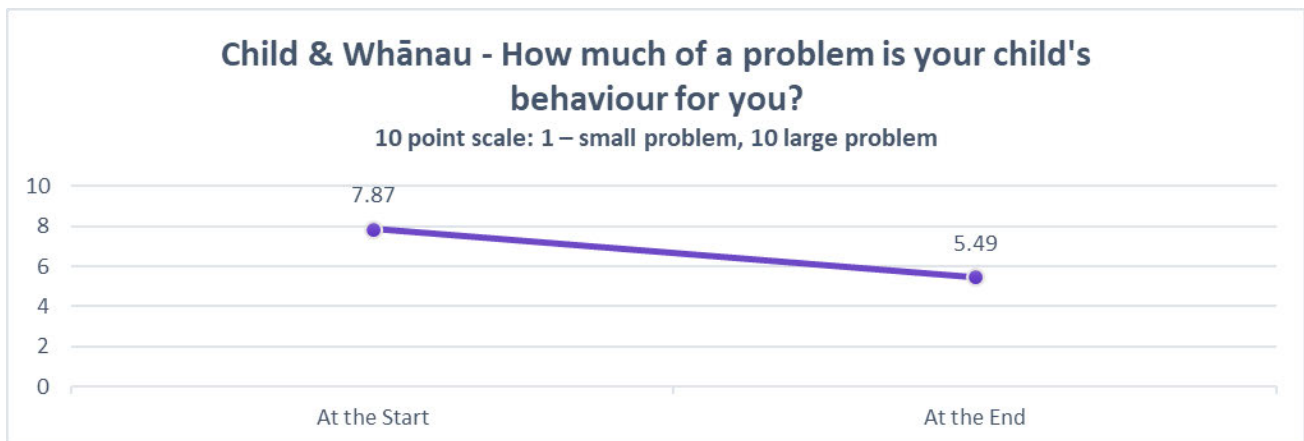
There were no internal or external requests for specialist assessments recorded in the last 6 months.

9. Satisfaction Surveys

9.1. Post discharge satisfaction

The following graphs provide information on satisfaction post explore involvement from both families and provider breakdown in the reporting period.

Child & Whānau



Child & Whānau - How Confident are you in managing this behaviour?

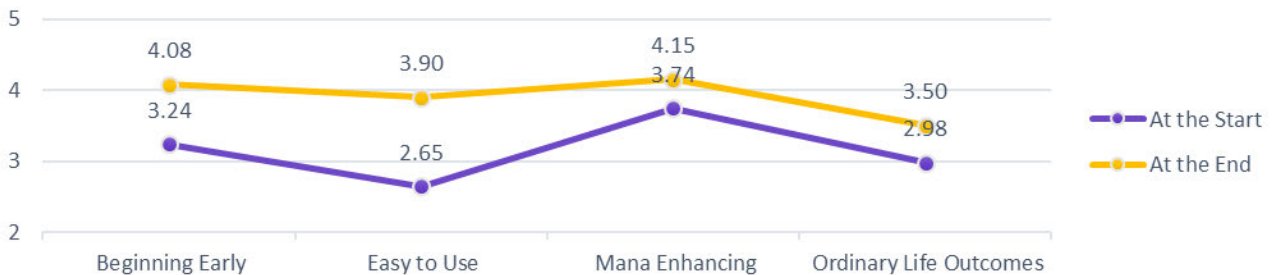
10 point scale: 1 - not confident, 10 - extremely confident



Child & Whānau - Before & After Ratings

Questions aggregated into Enabling Good Lives principles

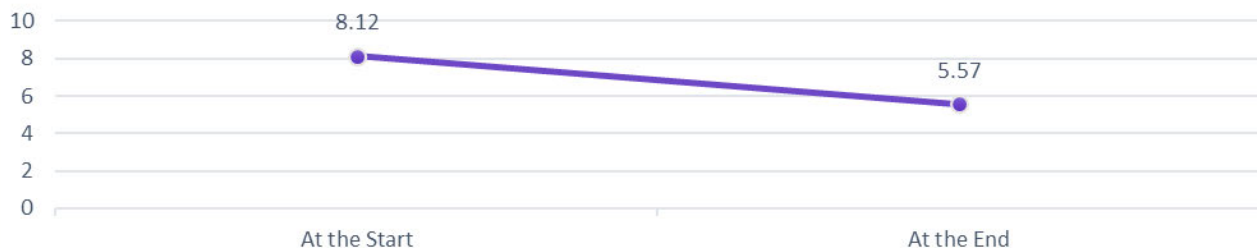
5 point scale: 1 - strongly disagree, 5 - strongly agree



Adult

Adult - How much of a problem is this behaviour for you and/or those around others?

10 point scale: 1 - small problem, 10 - large problem



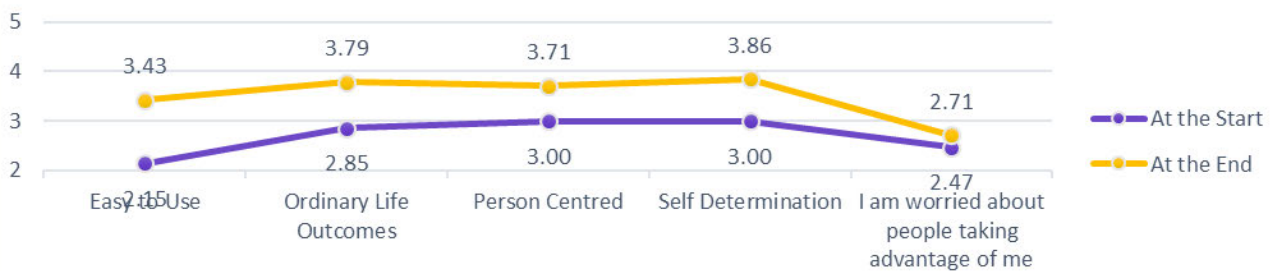
Adult - How confident are you in managing your own behaviour?

10 point scale: 1 - not confident, 10 - extremely confident



Adult - Before & After Ratings

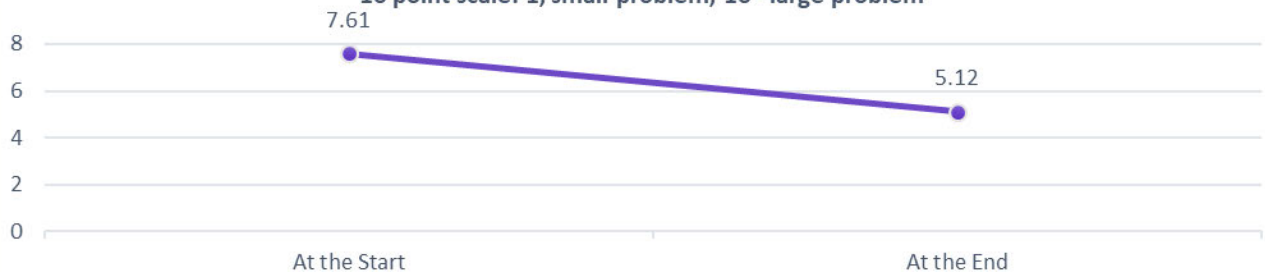
Questions aggregated into Enabling Good Lives principles
5 point scale: 1 - strongly disagree, 5 - strongly agree



Residential

Residential - How much of a problem is this behaviour for you or the person you support?

10 point scale: 1, small problem, 10 - large problem



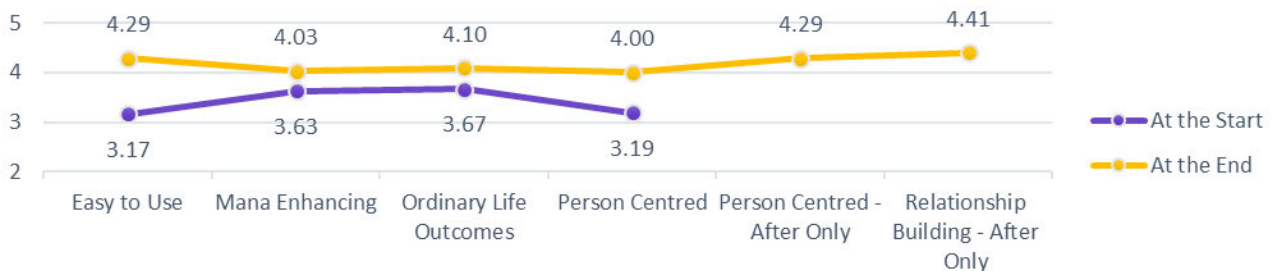
Residential - How confident are you in managing this behaviour?

10 point scale: 1 - not confident, 10 - extremely confident



Residential - Before & After Ratings

Questions aggregated into Enabling Good Lives principles *after survey only
5 point scale: 1 strongly disagree, 5 strongly agree



10. Complaints and Reporting

10.1. Number of complaints received (type)

We have received 2 complaints in the reporting period.

- 2) Parents complained of the specialist overstepping her brief. Investigation found that the specialist had concerns around parental mental health and wellbeing. Parents reported the specialist was focused on what safety planning was in place for them rather than the behaviours of concern of child. Parents were keen to continue to work with Explore but requested a change in specialist. A new specialist was assigned, and the work progressed through to completion and discharge.
- 2) Parent complained that background information in the draft behaviour support plan was incorrect. The information had come from a previous assessment in 2023 and had been shared with the specialist at that time by the other parent of the child. In 2023 a Te Whatu Ora social worker was assigned to the family related to the information that was shared at that time. Reference to this information upset the parent and they expressed their unhappiness as they did not believe it to be accurate. Investigation found the supports put in place in 2023 related to the sensitive information remain in place and are ongoing. Explore's work has continued alongside the family and other support agencies involved.

11. Narrative

11.1. Development work

Review of key documents: has been completed for safety plans, assessment, Positive Behaviour Support plan, review and discharge, involving Explore's Hiwa (Te Roopu Māori) and Lived Experience panel. Alongside each revised document template, a practice guide has been developed to provide updated advice to clarify expectations (e.g., timeliness) and recommend best practice for a person-centered, culturally responsive, and effective approach. Further steps to embed these templates and practice guides over the coming year via training and supervision will strengthen and enhance the consistency of our approach.

Lived Experience Panel:

A designated role for Lived Experience is now established with the aim of bringing forward the voice of disabled people and their whānau within our service. A taskforce has been developed consisting of members of our own staff who either identify as neurodivergent or are parents of neurodivergent children. While this initiative is still in its infancy, we will look to develop this further to progress the lived experience voice into areas such as service design, quality improvement, consumer feedback, and policy development. Incorporating the advice of external consultants with lived experience and the establishment of a parent group will also strengthen the approach.

Strengthening Clinical Governance:

A framework for clinical governance has been progressed and proposes changes to processes and feedback loops to ensure a robust quality improvement process. It is envisaged that a Clinical Quality Group will act as the primary conduit for information from a variety of sources (e.g., consumer satisfaction, clinical audit, cultural responsiveness) that will ensure a strengthened and focus on quality improvement within the service.

Client Management System:

Explore has embarked on a sizable project to replace the existing Client Management System. This 6-month period has seen the development, production and testing of the new Microsoft Dynamics CMS. It is anticipated that transition from existing to a new CMS will take place February 2025, with a high level of due diligence and risk mitigation. There will be no disruption to service delivery, but the potential for minimal disruption (4 working days) to referral loading. Manual processes will be put in place to manage referrals during this 4-day period.

11.2. Relationship/Stakeholder management

Explore maintains relationships with a wide range of sector partners and colleagues from NASC's and residential providers through to allied health professionals such as child development and mental health services, as well as schools and Oranga Tamaki and Kaupapa Māori social service agencies. Explore's Whakaruruhau (cultural support and supervision) relationships continue to strengthen around the country, alongside Noho Marae development, with Noho occurring in Auckland during this reporting period, and other regions with upcoming Noho into 2025.

Explore has recently furthered our working relationship with VisAble (formerly DAPAR – Disability Abuse Prevention and Response) and we are about to begin working together to develop a safeguarding adults policy. An important piece of mahi considering the prevalence of family harm and sexual violence in the disability population.

11.3. NASC's

Waitlist, active, and discharge reports are provided to the NASC monthly, alongside any relevant service and sector updates. Explore Specialist Services Managers maintain regular and frequent meetings with NASC managers to have a coordinated approach to prioritization and discuss and address any issues.

11.4. Trends

While the total number of referrals received in this reporting period has continued to increase from the previous reporting period, there has been a significant decrease of referrals from some NASC regions since October, and a decrease when compared to the same reporting period in 2023. There continues to be an increase in complexity of referrals received, requiring additional co-ordination and supports. The impact to Explore's work often can mean Explore needing to be involved for longer periods of time to gain the desired outcomes and goals. Parental burnout and mental wellness, a need for multiagency co-ordination, housing and cost of living contribute to competing needs for families. Alongside lack of other support agency involvement and staffing issues for residential providers has seen a concerning trend of scheduled appointments not attended increased by over 50% in this reporting period.

11.5. Issues / concerns

The recent decrease in referrals since October has coincided with anecdotal reports from families and other agencies that budget constraints are impacting referrals being made. Explore Managers are working closely with their respective NASC's in understanding referral criteria, especially where there are concerns around risk, and the behaviour support funding stream.

11.6. Positive Stories

Explore has made concerted efforts in some regions to recruit more staff and has nationally focused on reaching as many of our referrals as we can. This has meant that 268 more people received services than the same reporting period last year. While Canterbury and Auckland remain as the areas with the longest waitlist, there has been a significant decrease in those waiting over 18 months, with a reduction from 62 people waiting over 18 months at the start of the reporting period to 4.

We receive feedback from clients who have received services from us through a variety of different ways. Below is a sample and snapshot of some recently received feedback and comments:

Feedback from parent to SW at discharge

I found the "planned activities" training really good, and it worked well for us. We can use it for future high-risk situations. It will be good to continue using the plan as well. I have become more confident in the ways I communicate with my son, e.g., using clear, calm instructions and bending down to his level. I have also learned how to describe exactly what I like when praising him, instead of just saying "good boy".

Feedback from parent to SW's manager

Xxxx was an absolute god send, we were broken before working with him, life is so much better now, thank you.

Written Feedback to SW in card at discharge

I am convinced God sent you to help us at just the right time. I am so thankful for all the study and care you have put into this valuable work that you do! You are a wonderful human and I am so glad we got to meet you and benefit from you. Thank you so much for the wealth of knowledge and the way you instilled a greater sense of confidence in us to continue.

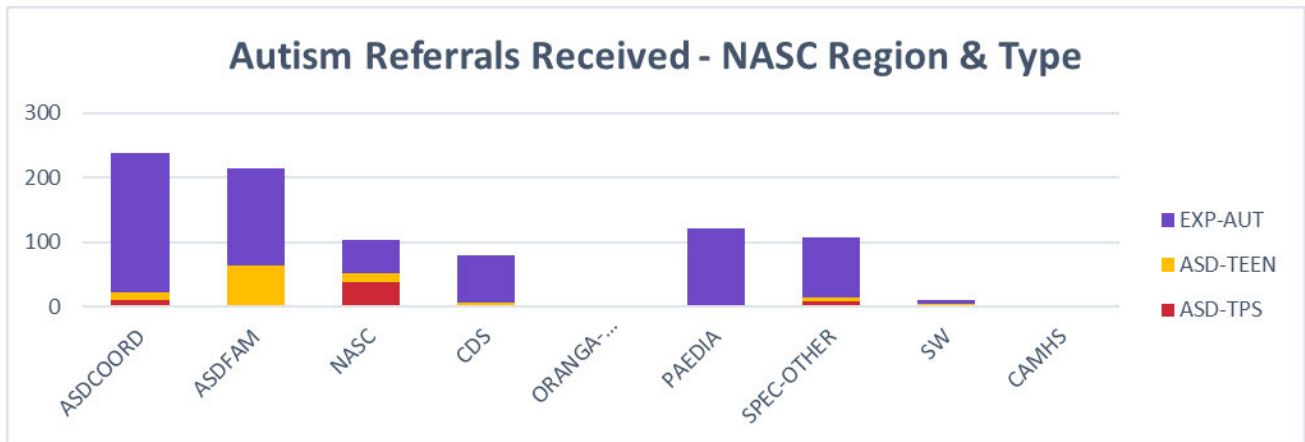
Feedback from a residential team

Thank you so much xxxx. You really have gone over and beyond with providing great resources to help xxx and the team with managing behaviours.

12. Autism Whānau Services

12.1. Referrals received

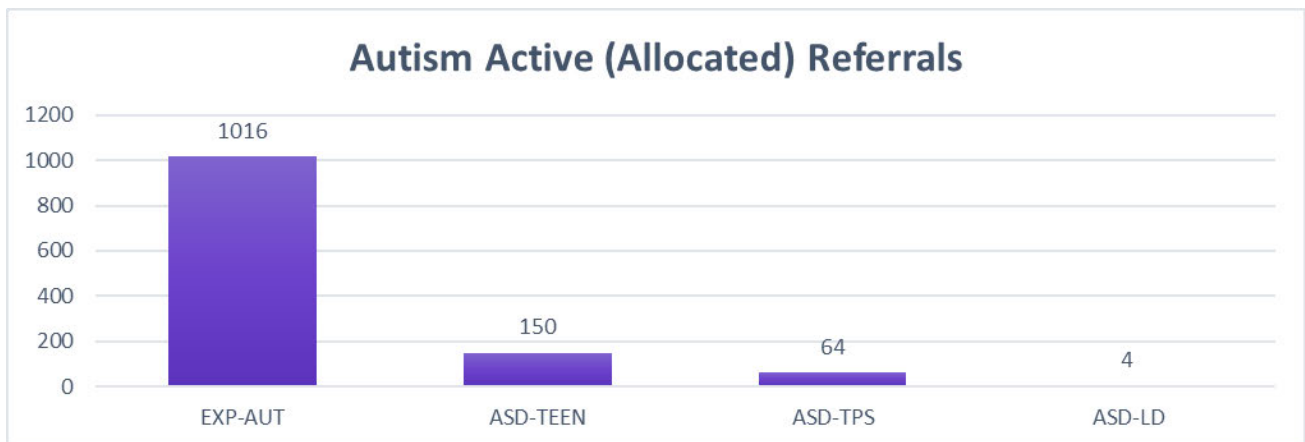
877 referrals received in the reporting period.



Percentage of Autism Referrals Received (Accepted) – All Sources

12.2. Active referrals

The following graph shows **1234** referrals that were active in the reporting period.



12.3. Referral volumes overtime

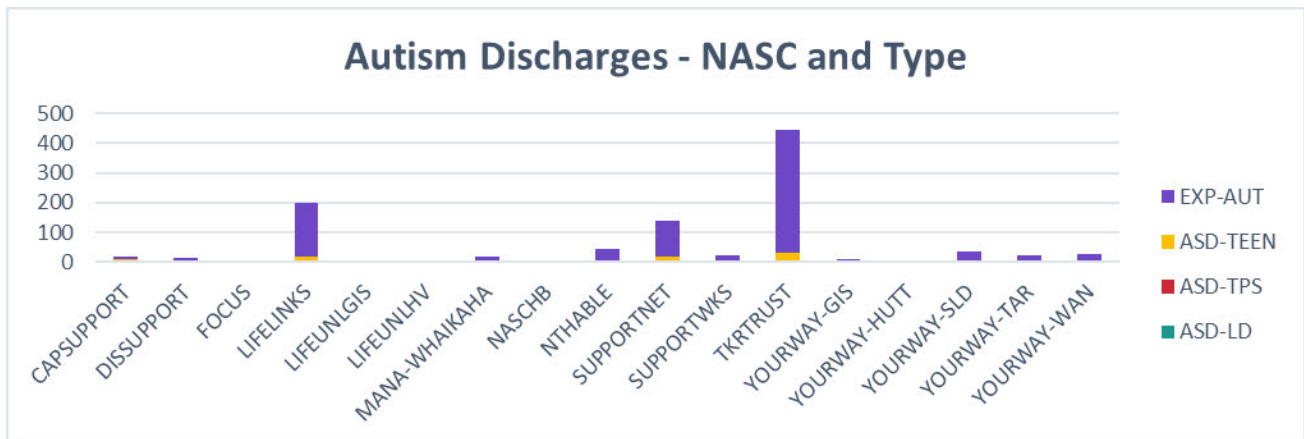


12.4. Waiting time



12.5. Discharges

The following graph shows **1008** referrals discharged in the reporting period, including early discharges.

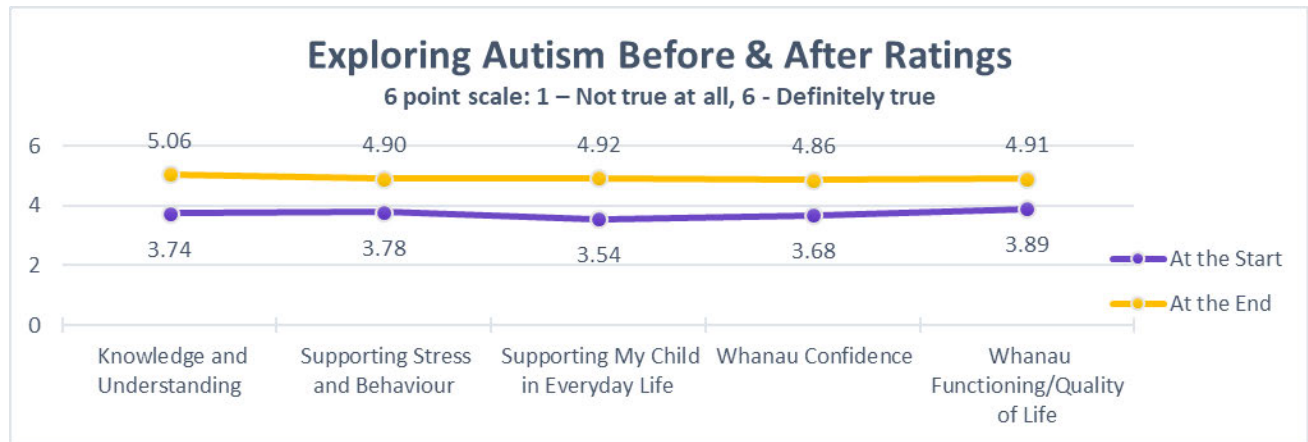


12.6. Programme outcome information

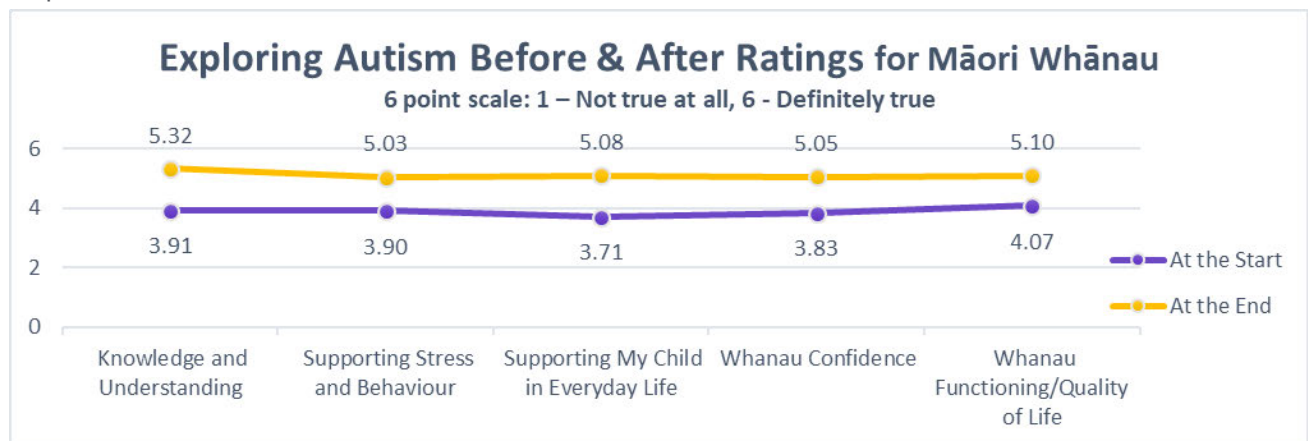
Group delivery

Exploring Autism

Graph showing pre and post survey results by domains (all participants). In the reporting period, there are **393** respondents at the start and **190** at the end.



Graph showing pre and post survey results by domains for Māori whānau. In the reporting period, there are **51** respondents at the start and **24** at the end.



The graph showing pre and post survey results by domains for Māori whānau shows more significant gains in points across all 5 domains than the general population graph.

Programme outcome ratings for Māori are continuing to trend in a positive direction. Increase in return rates of before and after programme parent surveys and outcome measures. In the reporting period, there are 51 respondents at the start and 24 at the end. A significant increase from the previous 6-month reporting period Jan-June 2024 of 21 respondents at the start and 9 at the end.

Sample of participant comments about what they valued about the programme/delivery:

“Online delivery was great and so much easier to do from home. I loved hearing other families share their own experiences with children with ASD. XXX shared to the group that she herself has children with autism, this immediately relieved some anxiety going into the programme because “she gets it.”

Able to talk with other parents about autism and not having a stigma about it. But feeling welcomed and understood.

Doing the course online is great, easy convenient and time-saving regarding gas, travel, traffic \$\$ etc..

The booklet would help so many people when diagnosis is given, I think. Maybe not the questions but the book, helping to understand and finding things to relate too earlier than later would be beneficial for others.

Having an expert talk through the different topics. Real life examples from other parents in person and on the videos.

I enjoyed hearing other people's experiences and the strategies they employed to assist their children.

I also liked the video of the NZ families and hearing about how they equipped themselves for everyday life. I enjoyed hearing other people's experiences and the strategies they employed to assist their children.

I thoroughly enjoyed the material. The book is awesome and it is amazing that we can keep it. The videos from kiwi parents and especially the kids on the spectrum themselves were really good. Last but not least - our awesome tutor, she was awesome in getting us through the heavily packed and informational sessions.

We've completed several of these types of programmes but this was just structured well. The book was an easy read - easy to understand. The videos were just awesome - loaded with tips and advice from not only parents but the kids with autism as well. The videos were also kiwi families which we've never come across in any of the other programmes we've done. Amazing!!

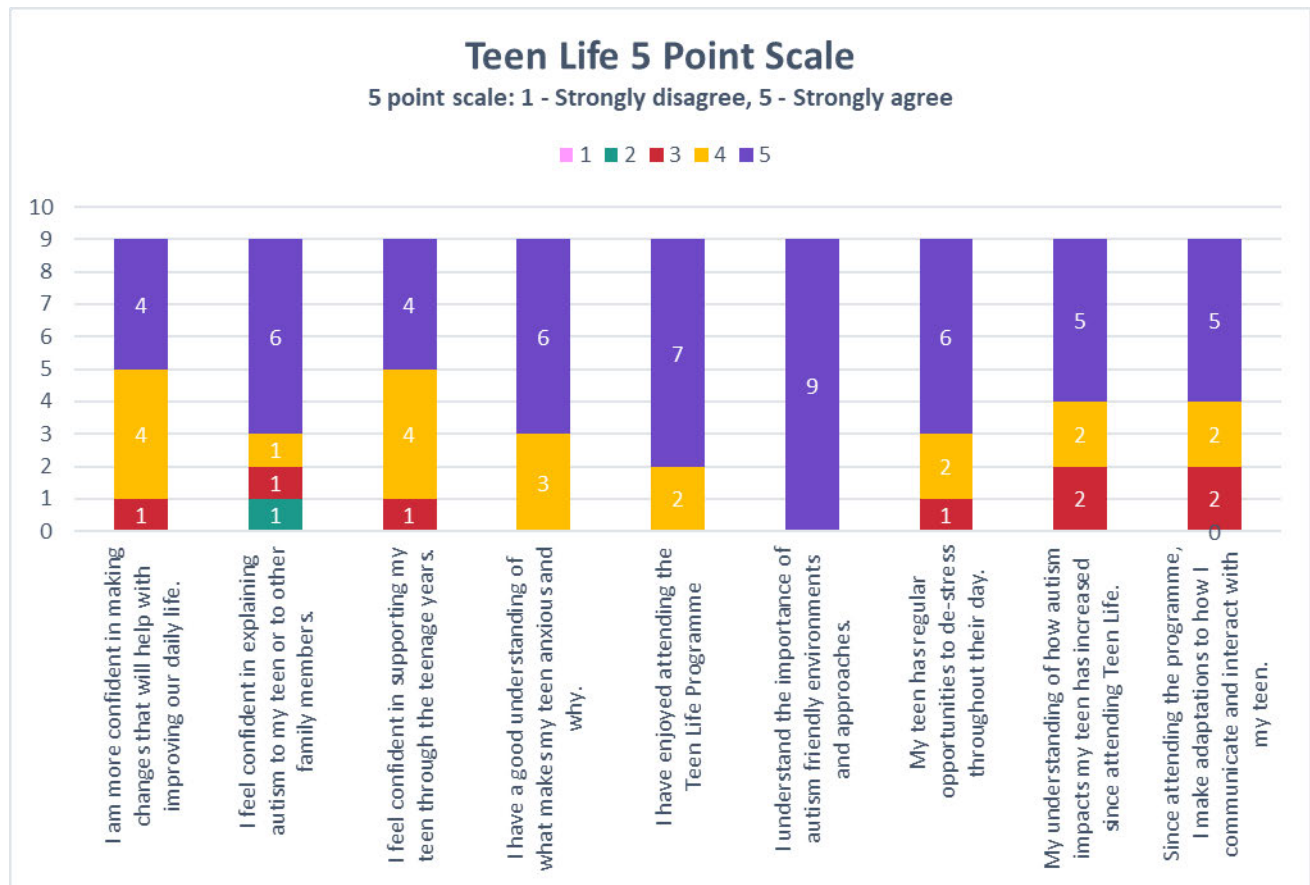
Would recommend it to parents with a new diagnosis or recent diagnosis. I had already done a lot of courses and workshops about autism and a lot of this course was revision.

This course was a true eye-opener for me. I thought I knew enough about ASD, but I learned so much more than I expected. The Explore sessions were incredible—I have come away feeling empowered, with a solid plan for my child and our journey together. It is comforting to have information I can now share with my family, including my child's father and siblings. Knowing where to find support has been a huge relief. As a parent, it is reassuring to realise we're not alone, and that we do have the power to make a real difference in our child's world.

It was great being able to talk to other parents having the same challenges. Plus, I learnt things I had not considered even though I had attended courses covering similar concepts (PACES).

Teen Life

Graph showing post survey results. In the reporting period, there are **9** respondents.



Sample of participant comments about what they valued about the programme/delivery:

The programme coordinator was great, she was so friendly, easy to communicate with and provided a welcoming programme.

I learnt way more than I did giggling. Thank you for a valuable course.

Thank you for the in between moments and parts that made it more personal and relatable xxxx! You are fantastic at what you do!

Maybe pre-teen one and mid teen course would be good.

Summary of observed trends/concerns

General trends identified in previous reports over the past 24 months continue with areas of concern raised by families persisting.

Access to diagnostic services and support services across environments:

- Timely diagnostic services children and youth
- Child and youth mental health services
- Allied specialist supports in schools
- Teacher aide support in schools
- School environment design not accommodating autistic needs

New trends

- Family concerns about NASC funded disability supports ceasing or reducing.
- Families who gave up on waiting for public funded diagnostic services struggling with long wait times for private services.

In the last report we noted a Wellington regional initiative to improve early detection and support for families trained over 300 early childhood workers in the Social Attention and Communication Screening tool (SACS) and the possibility this could increase referral rates in Wellington region for diagnostic assessment and access to support services. Explore have not had any increase in referrals for Autism parent education for pre and primary school aged children yet.

Explore Referral rate trends

Steady increase seen over the past 8 years from 2017 to 2024 from approximately 700 to 2000 in 2024.

In the past 6 months we received 877 new referrals, a reduction from the previous 6-month period when we received 1046.

Autism NZ website cites the incidence of Autism in Aotearoa as 3%. Citing the source as the New Zealand Health Survey. This is consistent with US CDC published rates of 1 in 36 children between age 8 and 12 years. Based on those incidence rate increases we would expect to see continued increases in referral rates over time if diagnosis resource funding keeps up with the increases in demand.

Programme participant feedback trends

The ratio of positive comments to negative comments remains high. The sample of positive comments in the previous section illustrates what families value about the programme content and delivery. Common themes from the smaller volume of negative/critical comments are:

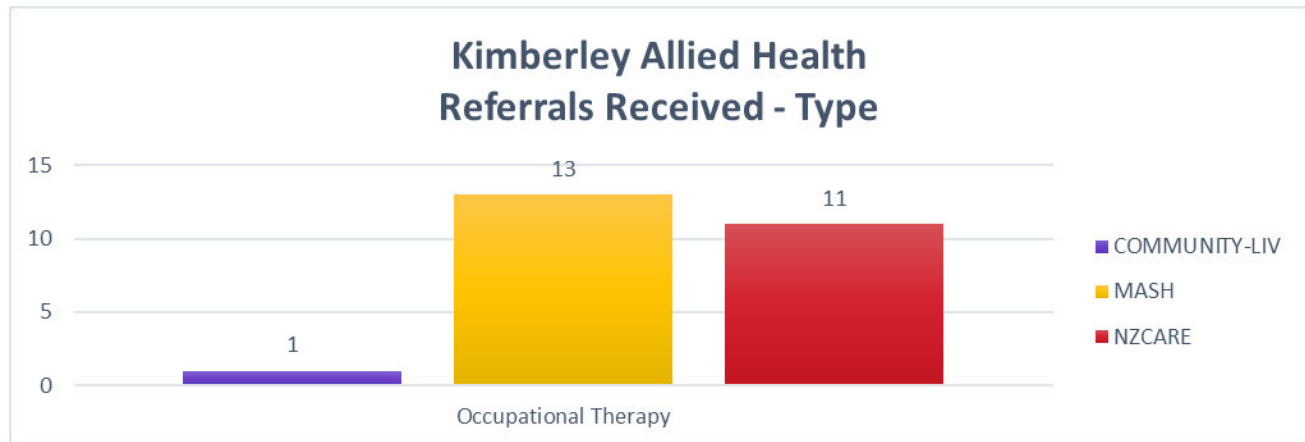
- *Length of wait times to get into a programme*
- *Programme content relevance reducing the longer the period between diagnosis and doing the programme*
- *Programme not being what the referrer described, or family expected e.g. parenting programme for responding to difficult behaviour*
- *Session length considered too long if over 90 minutes*
- *Programme lacking practical advice for children with severe learning difficulties*
- *Parents of children with severe learning difficulties struggling to relate to the experience of parents with children with level 1 Autism*

In conclusion, families get the most from the explore autism support programmes when they can access them within a few months of receiving a diagnosis. Barriers to timely service include access to diagnostic support and funding to deliver programmes not increasing at the same rate as demand for programmes.

13. Kimberley Allied Health

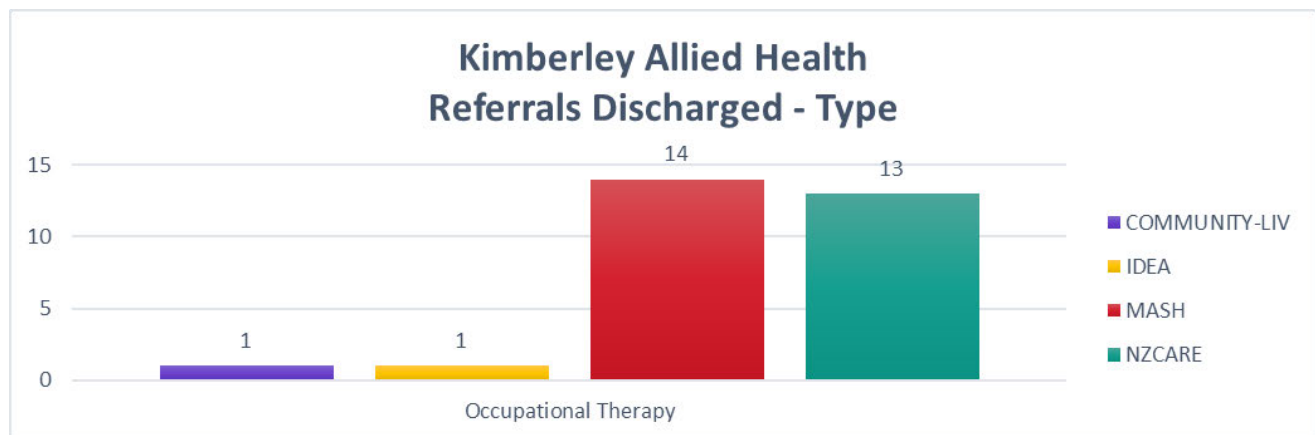
13.1. Referrals received

The following graph shows 25 referrals received in the reporting period.



13.2. Referrals discharged

The following graph shows 29 referrals discharged in the reporting period.



13.3. Processes/concerns/issues

Observations of systems on the client group

Tangata Whaikaha referred can have multiple and complex diagnoses, not limited to their original diagnosis, but can also include aging, additional health needs and new or emergent medical conditions. The extent of a person's disability can mask the true impact of a different condition. In one situation, a kiritaki had a number of neurological events that led to multiple emergency room visits. These were attributed to Transient Ischaemic Attacks for four months with no further investigation until, on the insistence of residential service staff, a CT scan was conducted and a chronic subdural haematoma discovered. Surgical treatment followed and they are recovering well.

On a positive note, we are aware of instances across Te Whatu Ora, where there has been coordination between departments to allow for multiple interventions under a single general anaesthetic e.g. dental and orthopaedic. This is less stressful for the tangata whaikaha, as well as optimising surgery time.

Referrals

The first half of this financial year has seen a steady flow of referrals. The referrals cover both equipment for clients who are declining and replacement equipment. Kimberley kiritaki continue to be impacted by funding constraints and prioritisation systems in place with EMS providers with band 2 and 3 items taking up to 3 months to have funding approved.

There have been a number of instances where short term loan equipment has been needed to facilitate discharge from hospital or to support end-of-life care at home. Colleagues from Te Whatu Ora have been helpful in arranging this on Explore's request.

14. Positive Behaviour Support Training

The cessation of the Disability Workforce Development fund (via Te Pou) will have a significant impact on continuity of delivery of PBS training. Ongoing PBS training supports systemic embedding of PBS in the support of people with disabilities, and the building of capable environments, evidenced by the knowledge and approach of support teams when Explore Specialist Behaviour Support becomes involved.

For the remaining period of the 18-month grant, we delivered 13 programs in the 6-month period across BILD PBS Practitioner, BILD Coaches (Practice Leadership) and Active Support, training staff from 15 providers. We delivered 9 open programs and 4 provider specific. 47% of participants were managers or team leaders, giving confidence provider focus on upskilling to the roles that influence embedding of PBS.

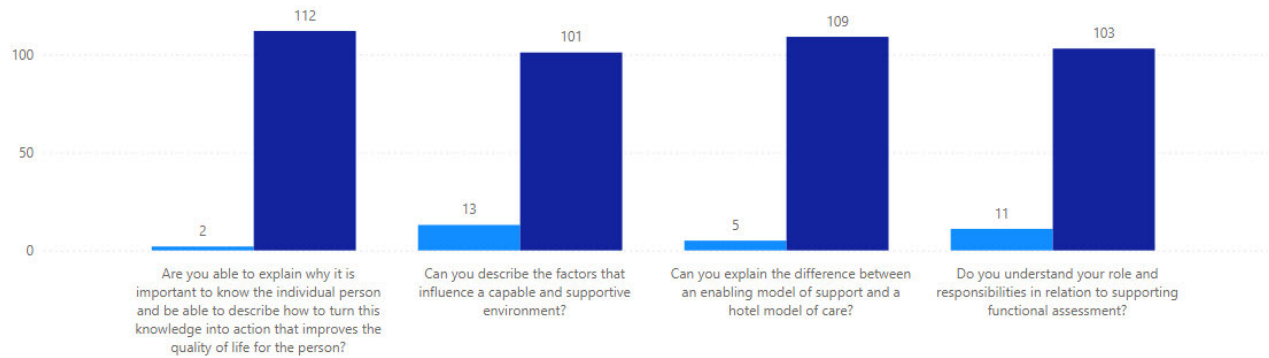
Post survey results from participants (Practitioners program) indicates very good outcomes. Questions 1-8 focus on the values that underpin PBS, the history of disability support, the influence of values, and importantly that Quality of Life is the primary focus in a PBS based intervention. The responses below give a clear picture of confidence and learning in particular aspects of the training and importance of these in providing support.

Count of Post Survey Responses - Part 1, Questions 1-4



Count of Post Survey Responses - Part 1, Questions 5-8

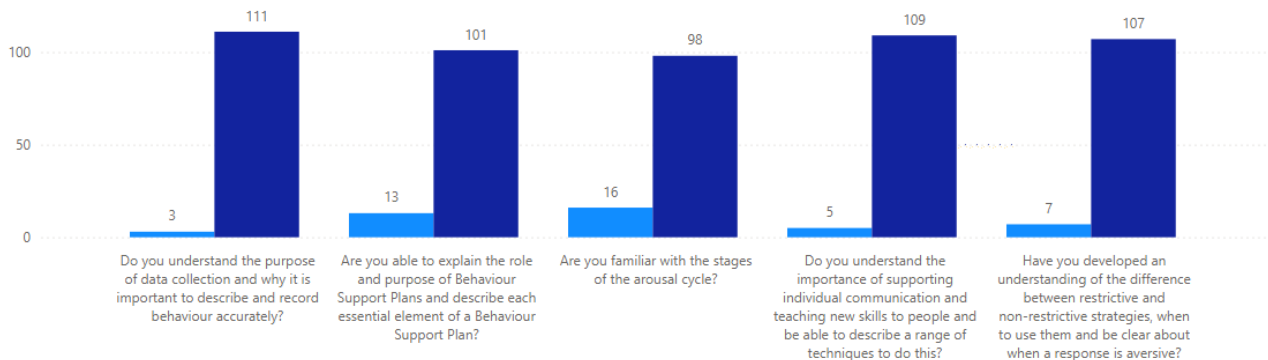
Response ● 2 - Partially ● 3 - Yes



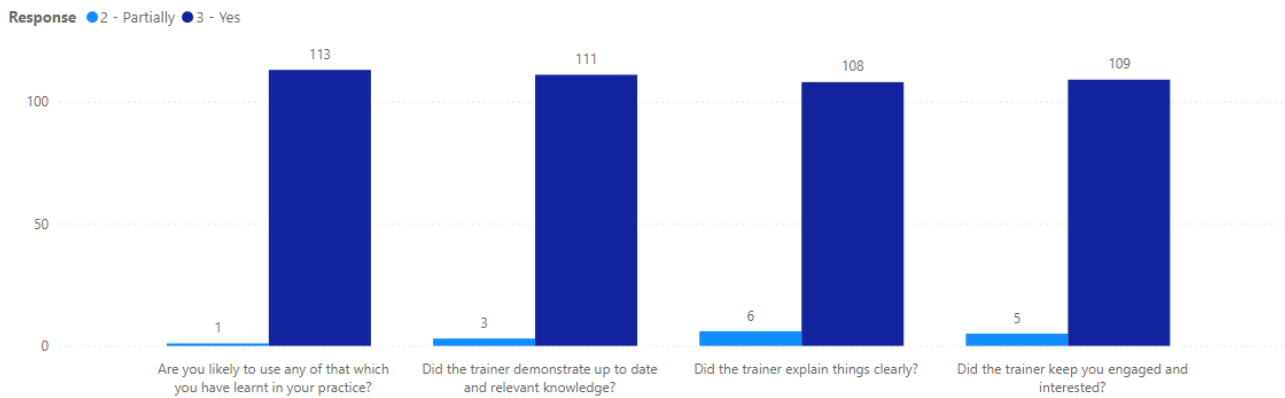
Questions 9-13 are linked to data collection and development of behaviour support plans and skill development. Responses showed some partial understanding in areas of Behaviour Support Plans, the arousal cycle, with improvements from the previous 6 months is understanding restrictive and non-restrictive practice. These results would suggest the value of further engagement with organisations to embed knowledge and practice regarding these key topics.

Count of Post Survey Responses - Part 1, Questions 9-13

Response ● 2 - Partially ● 3 - Yes



Count of Post Survey Responses - Part 2



A full report of PBS training is available.

We look forward to progressing the discussions about how we can facilitate “Early and Targeted interventions” to be considered for providers. This can be individualised to a provider who require their staff to be upskilled in PBS when a person's behaviour is beginning to impact the providers ability to provide a stable and effective support environment. We hope that this will be a valuable option to fill the void created by the cessation of the Te Pou funding, for targeted interventions that the NASC guidelines suggest. Using the PBS BiLD training to include current and specific examples for the participants to learn about and deploy in their PBS led, support approach could very well reduce the need to increase funding by having skilled staff supporting complex people.