Pilot of an Aotearoa-specific early autism support programme.

**Study Protocol**

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**Summary**

This programme of research involves the evaluation of a new programme of support designed specifically for young children who are autistic or showing signs of autism/social communication differences, their whānau/families, and their broader support people in Aotearoa New Zealand. This programme has been developed alongside an autistic advisory rōpū (group), a Māori advisory rōpū, and a professional advisory rōpū. The pilot will involve up to ten whānau/families. The purpose of the pilot is to understand the feasibility, appropriateness, and acceptability of the programme and to identify any barriers, facilitators, and necessary improvements.

**Introduction and Background**

Autism is a form of neurodivergence characterised by differences in sensory and cognitive processing, social interactions, and preferences for routine (Pellicano & den Houting, 2022). Each autistic individual has their own unique profile of strengths, challenges, and areas for support (Taylor et al., 2023). The prevalence of autism is increasing, with current American estimates suggesting that as many as one in 36 children are autistic (Maenner et al., 2023). In Aotearoa New Zealand, 2% of children aged 2-14 are estimated to be diagnosed as autistic (Ministry of Health, 2022).
 Over time our ability to identify and diagnose autistic children has improved. It is now possible to reliably diagnose most children with autism by the age of 2 (Barbaro et al., 2022). Many parents also identify atypical development in their children who will go on to receive an autism diagnosis before the age of 1 (Waddington et al., 2021). The ability to identify and diagnose children earlier enables the provision of early support (this includes “interventions” and support services). Some research suggests that early support can improve a range of social communication and developmental outcomes for children who are, or have a high likelihood of being, autistic and that these improvements may be maintained over time (Pickles et al., 2016; Whitehouse et al., 2021).
 Many early supports have been criticised by proponents of the neurodiversity movement, including autistic self-advocates, who emphasise that autism is a brain-based difference, rather than a deficit or disorder to be ‘fixed’ or ‘cured’ (Kapp et al., 2013; Pellicano & den Houting, 2022). They claim that early supports should not aim to reduce the child’s autism characteristics or make the child appear less autistic (Dawson et al., 2022; Leadbitter et al., 2021). They also condemn certain early supports for using methods which reduce a child’s ability to advocate for their own wants and needs and/or to exhibit choice and control over their own lives (Leadbitter et al., 2021; Leaf et al., 2022)
 While a small number of proponents of the neurodiversity movement argue that there is no need for direct early support, only societal change, most believe that support in the early years can still be beneficial. Such supports should, however, focus on upskilling those around the child and changing the environment and society as a whole to increase the child’s quality of life (Gillespie-Lynch et al., 2017; Pellicano & den Houting, 2022). Supports may also focus on each child’s unique and specific areas of challenge, which could include supporting skills development for everyday tasks, identifying and supporting communication preferences for that individual, and identifying and addressing triggers of aggressive or self-injurious behaviours (Autistic Self Advocacy Network, 2021; Dawson et al., 2022; Kapp ­et al., 2013).
 The results of a recent survey suggests that many New Zealanders and Australians now support and align with the neurodiversity movement. In this survey, most participating parents, autistic adults, and clinical professionals believed in approaches which focus on changing others and the child’s environment as well as, or instead of, changing the child themselves (Waddington et al., 2023). Similarly, these participants were most likely to rate goals related to changing the characteristics of the child as either inappropriate or a low priority. This included goals related to social skills, such as making eye contact, and play skills, such as using a toy for its ‘intended’ purpose.
 Few studies have examined the provision of supports for young autistic children in Aotearoa New Zealand. These limited existing studies have generally evaluated supports developed in other countries, which often target improvements in “neurotypical” social and/or communication skills (McLay et al., 2023; Waddington et al., 2022). While these approaches are considered promising for improving target outcomes, they generally do not examine neurodiversity affirming outcomes such as child quality of life or self-determination (Trembath et al., 2022). Further, these overseas approaches may not be ideally suited to the population of Aotearoa New Zealand, and particularly Māori. A recent scoping review of Māori and autism found that only four studies related to Māori perceptions of general or specific support services and none of these supports were developed specifically for Māori (Tupou et al., 2021).
 It is essential to create and evaluate early supports alongside both autistic people and Māori members of the autistic and autism communities in Aotearoa New Zealand. Autistic people are increasingly included in research through participatory approaches (den Houting et al., 2021). In participatory research power is shared between autistic and non-autistic members of the research team, and autistic people should be included in all phases of the research including commissioning, undertaking, disseminating, evaluating, and utilising the research (den Houting, 2021). This helps to ensure that researchers are conducting meaningful research that is beneficial to, and addresses the priorities and needs of, autistic people themselves. Similarly, there is a lack of Māori-centred and Māori led autism research and very little funding is invested in this area (Emerson et al., 2023a). It is essential to capture the experiences and needs of autistic Māori and their whānau in order to develop supports which are truly culturally responsive. Indeed, Māori participants in a recent research priorities survey indicated a desire for more culturally focussed research (Emerson et al., 2023b). The only way to ensure this is to include Māori in the design of research right from the start.
 This programme of research will involve an evaluation of an Aotearoa-specific autism support programme (as yet unnamed, referred to herein as ‘the programme’). The programme is designed to help and empower family, whānau and other adults, such as teachers, to better support children who are, or may be, autistic. It has been developed alongside three advisory rōpū comprised, respectively, of autistic and neurodivergent individuals, Māori members of the autistic and autism communities, and autism professionals. The evaluation will involve two stages. The first will be a pilot study with up to ten children and their whānau/families. It will consist of a condensed version of this programme, involving 8 home-based sessions.

**Programme Development**

The programme was developed based on ideas and feedback from two key advisory rōpū (groups). The first rōpū was comprised of five autistic and neurodivergent members. This autistic rōpū included employees of relevant government and non-government organisations, a neurodivergent parent, and a part-time user of augmentative and alternative communication. The second rōpū was comprised of five Māori members of the autistic and autism community. This Māori rōpū included whānau members, including parents, of autistic and neurodivergent people, a neurodivergent parent, and educational and clinical professionals, including several individuals involved in Te Kōhanga Reo. A third rōpū was comprised of educators from Autism New Zealand. This professional rōpū was designed to provide feedback on the feasibility, appropriateness, and acceptability of content developed based on the suggestions of the other two rōpū.

 The autistic and Māori rōpū met separately, monthly, online, between February and June 2023 to discuss and plan several aspects of the programme and associated research. The topics discussed in the hui included (a) the delivery of the programme, (b) important outcomes to target in the programme, (c) how adults should support the child, and (d) how the coach should support the adults. The Māori rōpū also developed a set of guiding values (Ngā Tanga) that would underpin the programme. The professional rōpū met once in May and once in June 2023 and provided direct feedback on materials developed based on the ideas of the autistic and Māori rōpū. Members of each rōpū were given $100 in koha (Prezzy vouchers) per meeting in acknowledgement of their contribution.

 Each member of the three rōpū will be given the option to be explicitly named in relation to the development of the programme and their input into the design of the study or to choose for their details to remain confidential. The consent for members of the advisory rōpū to be named in the programme materials (e.g., parent and educator handouts) and research has been included in materials submitted to the committee.

 Based on the input of these rōpū, four members of the research team (Dr. Hannah Waddington, Dr. Jessica Tupou, Lee Patrick, and Carla Wallace-Watkin) developed the programme content. The remaining members of the team and members of the three advisory rōpū provided input and feedback on the content and the programme was adapted accordingly.

**Funding**

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**Pilot Study**

**Aims**

This pilot study aims to understand family and whānau perceptions of feasibility, appropriateness, and acceptability of the early autism support programme. We also aim to identify areas in which the programme could be improved prior to the larger scale randomised controlled trial.

**Registration**

The pilot study is registered on the Australia and New Zealand Clinical Trials Registry (Registration number TBC)

**Hypotheses**

We hypothesise that whānau/families will generally find the programme to be feasible and acceptable based on high session attendance and positive questionnaire and interview responses. We also hypothesise they will also identify clear areas for improvement.

**Design**

This pilot study will use a mixed methods approach involving quantitative questionnaires and a qualitative semi-structured interview. The study will include a pre-assessment, delivery of the programme, and post-assessment

**Participants**

Up to ten whānau/families will be included in the pilot study. Inclusion of eligible whānau/families will be on a first-in-first-served basis. There will be no limit on the number of whānau/family members per child who participate in the programme, but one of the child’s legal guardians will be nominated as the “primary” participant, who will complete all assessment measures. Whānau/family will be eligible to participate in the pilot study of the early autism support programme if:

1. The child is aged between 1 and 5 years 11 months at the start of the programme (week 1 of receiving the support),
2. The child is showing signs of autism/social communication differences on the Social Attention and Communication Surveillance Tool - Revised (SACS-R; Barbaro et al., 2022) or has a clinical diagnosis of Autism Spectrum Disorder,
3. The child does not have a genetic condition which is associated with “autism-like” characteristics (e.g., Rett Syndrome, Fragile X, 22q deletion),
4. Each participating whānau/family member can commit to one, 45-minute to 1-hour long, session per week for 9 weeks, including alternating fortnightly home-based sessions with the child present, and fortnightly sessions without the child present either at home, in a clinic, or via Zoom.
5. The primary whānau/family member speaks sufficient English to understand the requirements of the study and to participate in the coaching sessions.
6. The primary whānau/family member intends to remain in Wellington for the duration of the pilot study (11-weeks)

Whānau/families will not be excluded from the study if their child has physical health conditions or additional diagnoses of neurodevelopmental, mental, or behavioural conditions, as listed in the Diagnostic and Statistical Manual, Fifth Edition (DSM-5, American Psychological Association, 2013). This could include, for example, attention deficit hyperactivity disorder, global developmental delay, or separation anxiety.

Any coach who delivers the support as part of the pilot study will also be given the opportunity to participate in an interview. All coaches who will implement this programme will have experience in supporting young children, and most will have experience in supporting young children who are autistic or showing signs of autism/social communication differences.

**Recruitment**

 The pilot study will be advertised on the Victoria University of Wellington Autism Clinic database. This database includes consenting families of children who are autistic or showing signs of autism/social communication differences who have accessed, or expressed interest in, the Autism Clinic services. The advertisement will also be shared by other relevant organisations in the Wellington region include Te Whatu Ora Wellington, Coast and Hutt Valley; the Wellington Early Intervention Trust; the local branches of the Wellington Ministry of Education Learning Support Team; and Spectrum Playgroup. An advertisement will also be shared on the Facebook pages of local autism community organisations (such as Autism New Zealand and the Autism Intervention Trust). The coaches who deliver the support will be existing employees of the Victoria University of Wellington Autism Clinic. Individual education and health-care providers may also inform relevant whānau/families about the research by directly sharing the study advertisement.

**Materials and Settings**

The programme will generally be delivered in the child’s home in the Wellington region. The study area is limited to the Kāpiti Coast (up to and including Waikanae) and Upper Hutt (up to and including Te Mārua). If the family live outside the study area or if it is otherwise not possible to deliver the programme in their home, the programme will be delivered in another location with which the child is familiar and comfortable, for example, the home of another whānau/family member.

 The programme involves the coach and family and whānau members playing and interacting with the child. These interactions will involve use of toys and materials that exist within the family home (e.g., bubbles, blocks, and books). On occasion, the coach may bring along an inexpensive toy to demonstrate a particular strategy, which may be left with the whānau/family as a koha. The preference, however, will be to use the materials available to the family on a daily basis.

 Some of the play and interactions between the child and the coach and/or whānau/family member will be filmed to enable reflection and discussion. The devices used to film sessions could include an iPad, iPhone, or video recorder. Videos will then be viewed on a computer or laptop.

**Measures**

The primary participant will complete all measures. Other participating whānau/family members can choose whether or not they want to participate in the semi-structured interview.

***Demographic Survey***The whānau/family will complete a demographic survey which will include the following information: (a) who referred them for participation in the study, (b) age of the child, (c) child ethnicity, (d) whether or not the child is diagnosed with autism, (e) who first identified signs of autism/social communication differences in their child, (f) co-occurring diagnoses, (g) amount of spoken language and communication preferences, (f) family members living at home, including those with autism diagnoses, (i) languages spoken at home, (j) access to existing supports, and (h) whānau education, occupation, and income.

Participating coaches will also complete a demographic survey which will include the following information: (a) age, (b) years of experience supporting autistic children, (c) type of experience supporting autistic children, (d) relevant qualifications, and (e) ethnicity.

***Acceptability, Appropriateness and Feasibility Measure***

The Acceptability of Intervention Measure (AIM), Intervention Appropriateness Measure (IAM), and Feasibility of Intervention Measure (FIM; Weiner et al., 2017) are four-item measures of stakeholder perceptions of implementation success (Proctor et al., 2011).Each of the 12 total items is rated on a five-point Likert scale (1 = completely disagree to 5 = completely agree). The FIM has been demonstrated to have strong reliability (Weiner et al., 2017).

***Neurodiversity Affirming Outcomes Survey***

This measure was developed based on the essential neurodiversity-affirming programme outcomes identified by the autistic and Māori advisory rōpū. It has two subscales, one related to outcomes for the child, and one related to outcomes for the parent or other whānau/family members. The child subscale has 19 items related to a range of programme outcomes including communication, connection and interaction with others, quality of life, and formal and informal supports. The whānau/family outcomes subscale has 10 items related to connection and interaction with the child, communication with the child, neurodiversity affirming framing, quality of life, and formal and informal supports. This measure was created because there were no existing measures for the majority of programme outcomes identified by the rōpū. It is not yet validated but we intend to conduct psychometric validation over the course of this programme of research. This measure will take up to 15 minutes to complete.

***Semi-structured Interview***

The semi-structured interview was developed by the researchers for the purpose of this research. It includes prompts regarding family and whānau perceptions of: (a) experiences of delivering the programme, (b) potential facilitators and challenges, and (c) programme improvements. The use of general topics rather than specific questions allows for flexibility during the interview and openness to emerging ideas that may not have been anticipated prior to the interview. All primary participating whānau/family members and coaches will take part in the interview, while other participating whānau/family members can choose whether or not they want to take part in the interview, or just complete questionnaires. These interviews generally take 30 minutes but could take up to 1 hour.

***Attendance***

The coach will collect data on the number of sessions the whānau/family attends and the date of any missed or catch-up sessions. This will be used to determine the percentage of the programme that each whānau/family receives.

***Access to Other Services***
Researchers will work with whānau/families to complete a monthly diary regarding the number of ‘contact hours’ they have with clinical professionals. Hours for each type of service (e.g., counselling, speech language therapy) will be summed into a continuous measure.

***Use of Strategies*** Family and whānau will also complete a weekly log of the number of hours that they use strategies with the child

**Procedures**

***Prior to the Programme***

A member of the study team will conduct eligibility screening with whānau/families who express an interest in participating in the programme. Those whānau/families who are eligible will then meet with a member of the team, either in-person, online, or over the phone, to complete the consent form and answer any questions they may have about the study. Each consenting whānau/family member will complete a demographic survey and the programme-specific measure either digitally or on paper.

***The Programme***

**Programme Structure.** Due to time constraints, the pilot will involve delivery of a condensed version of the programme involving one session per week for 8-weeks. If they desire, whānau/families will also be able to pose additional questions over email between sessions. Weekly sessions will alternate between discussion and practical sessions.

 The fortnightly discussion sessions will involve the coach and whānau/family members discussing strategies and, aside from Week 1, reflecting on the most recent practical session. The child will not be present for these sessions, which will take place in the following locations, depending on whānau/family preferences: (a) the home provided that the child can be reliably entertained by an adult who is not participating in the research, (b) in person without the child in the Autism Clinic in Petone, Wellington, or (c) online via a platform such as Zoom without the child present. These sessions will involve: (a) the coach offering information about strategy use in a variety of formats (e.g., written, illustrations, videos), (b) reflecting on videos of the whānau/family member or coach interacting with the child, (c) selecting manageable goals for the whānau/family to focus on each week, (d) the coach supporting the whānau/family to reframe their understanding of the child in a neurodiversity affirming way, (e) the coach listening to and validating whānau/family experiences, (f) the coach encouraging family and whānau to also focus on themselves and their own hauora (health/wellbeing), and (g) the coach providing support with plans for referrals to other supports and agencies.

 In the fortnightly practical sessions, the coach and the whānau members will play and interact with the child in the home. These sessions will last up to 40 minutes and the coach will support the whānau/family members by (a) checking in at the beginning of each session, (b) interacting with and getting to know the child, (c) modelling appreciation of the child’s differences (e.g., “that play idea is so creative”), (d) modelling use of strategies with the child, (e) videoing interactions between the child and the coach and/or whānau/family members for later reflection, and (f) providing in-the-moment tips and support.

 The primary participant must be able to attend all sessions. Every effort will be made to reschedule missed sessions within the 8-week timeframe but there will also be one week following the programme to catch-up further sessions. It is anticipated that some whānau/families will not receive all 8 possible sessions across the 9-week period. Whānau/family will be deemed to have “received” the support if the primary participant takes part in at least 5 sessions (63% of the programme).

**Underpinning Values (Ngā Tanga).** Five key Māori values (Ngā Tanga) underpin the programme. These values will be used to inform the coaches’ practice including the way in which they support the child and their family and whānau. Coaches will also support the family and whānau to embed ngā tanga with their child. The definitions of ngā tanga in relation to the programme are presented in Table 1 and were informed by discussions with the Māori rōpū and various other resources (e.g., Pihama & Lee-Morgan, 2022; Stewart, 2020):

Table 1.

*Definitions of ngā tanga, the guiding Māori values of the programme.*

|  |  |
| --- | --- |
| **Whanaungatanga** | The literal translation is kinship or relationship, it’s a value that can be used to guide our interactions with others (and the world around us). It’s guided by the concept of whakapapa – the idea that everything is connected. It also covers the idea of collective and reciprocal responsibility for the wellbeing of everyone in the whānau. When our interactions are guided by whanaungatanga, we treat others as if they are our whānau. |
| **Tuakiritanga** | Tuakiri relates to personality and identity or ‘inner being.’ Tuakiritanga is about knowing who you are and where you come from and feeling good about it. It promotes mauri ora and helps tamariki to move forward with self-confidence and pride in their identity. It can be supported by helping tamariki to connect with the language and cultural practices of their whānau and ancestors.  |
| **Manaakitanga** | Thinking and acting in ways that uphold the mana of others and our own mana. This can be done through showing caring, thoughtfulness, generosity, and hospitality. The process of manaaki enhances relationships. It also relates to inclusion and treating all children with care and respect. It involves recognising that all tamariki are born with mana from their parents and tīpuna which needs to be upheld and nurtured. |
| **Kaitiakitanga** | Active guardianship, caring, looking after, or protecting. Kaitiakitanga is also related to roles and responsibilities because it involves recognising that we all have a responsibility to care for and protect the people and the world around us. |
| **Kotahitanga**  | Unity, togetherness, and collaboration. Working together with a common purpose/direction. |

**Programme Content.** An introductory discussion session in Week 1 will involve the coach getting to know the whānau/family and the child including the child’s personality, likes, dislikes, and interests. The coach will also ask about the whānau/family’s goals and aspirations for their child, as well as their understanding of their child’s neurodivergence or autism if the child has an official diagnosis. In this first session there will be a particular focus on whanaungatanga including the coach taking the time to get to know the whānau/family and their context on their own terms and the coach sharing information about themselves as a person, as well as explaining the service and their own expertise and training. If the whānau/family prefers, this phase of getting to know each other can continue after the first week. During this session, the coach will ask the family/whānau to set one priority goal for themselves and one priority goal for their child in relation to this programme and will check progress towards these goals in Week 8 using the Clinical Global Impression Scale – Improvements (CGIS – I; Kadouri et al., 2007).

 The programme covers a range of content related to supporting the child and whānau/family. The coach and whānau/family will discuss possible strategies and content in the discussion sessions and then attempt these in the practical sessions (see **Programme Structure**). The programme has 9 modules and family and whānau can generally decide which content is relevant to the child, and the order in which to discuss this content. The content in many modules will only be relevant to some whānau/families, and each will move through the programme at their own pace. Within this condensed pilot, coaches and whānau/families will only focus on the most relevant content. The only two modules that are compulsory and will be delivered to all whānau/families are “understanding your child” and “respecting your child’s interests and preferences.” “Understanding your child” will generally be presented first. Table 2 covers the programme content, in a possible order in which it might be presented.

 Appendix 1 details the relationship between programme outcomes, overarching approaches to supporting children and adults within the programme, and ngā tanga which underpin each of these outcomes and approaches.

Table 2:

*Programme content.*

|  |  |
| --- | --- |
| Module | Content covered in the module |
| **Understanding your child** | * Autism and neurodivergence including:
	+ Autism as a form of neurodivergence
	+ Other common co-occurring forms of neurodivergence (e.g., ADHD, dyspraxia)
	+ Each child’s unique autistic characteristics
* Explaining autism, neurodivergence, and/or the child’s autistic characteristics to the child and/or others
* Understanding and respecting the child’s unique ways of:
	+ Communicating including spoken and non-spoken language, AAC (Augmentative and Alternative Communication), body language, and tone of voice
	+ Interacting and playing
	+ Showing interest and engagement
	+ Expressing emotions
* Understanding the child’s strengths and building on these
 |
| **Looking after yourself and finding support (may be presented first depending on whānau/family need)** | * Building time to focus on themselves and their own wellbeing
* Finding fulfilment and enjoyment in their interactions and connection with their child
* Taking the pressure off if feeling overwhelmed
* Understanding that it is not possible to implement strategies “perfectly” or all the time.
* Understanding who the important people are in the child, and whānau/family’s life
* Seeking support from formal and informal connections
* Strategies drawn from approaches such as acceptance and commitment therapy, cognitive behavioural therapy, and mindful self-compassion such as:
	+ Detaching from unpleasant thoughts/feelings
	+ Mindfulness, breathing, and grounding exercises
	+ Practicing being the ‘observing self’
	+ Tuning in to inner wisdom
 |
| **Respecting your child’s interests and preferences** | * Use of warm, responsive interaction style
* Showing genuine, unconditional, positive regard for the child
* Respecting personal space and need for alone time
* Making time for “fun” that doesn’t involve demands or learning
* Reducing the frequency of questions, instructions, and demands
* Providing choices for play and activities and choices within activities
* Copying the child’s actions and play ideas and modelling them at later times
* Engaging in parallel play and sharing space without intensively interacting
* Allow the child to change activity when they are no longer interested or have indicated interest in another activity.
 |
| **Creating a safe and comfortable environment** | * Arranging the environment in a way that helps the child to feel comfortable, safe, and regulated
* Reducing distractions
* Provide easy access to sensory tools and experiment with which of these tools work for the child
* Adjust energy levels and volume of voice, and pace
* Using co-regulation strategies to reduce child distress
 |
| **Supporting communication** | * Respecting the child’s preferred and non-preferred forms of communication
* Believing and validating the child’s communication
* Positioning oneself so that the child can easily process communication
* Modelling and creating opportunities for different forms and types of communication
* Matching and building on the child’s communication
* Allowing exploration when learning to communicate
* Use consistent, simplified communication
* Giving the child time and space to process communication
* Using visuals to support understanding
 |
| **Supporting success** | * Assuming competence and believing that the child can succeed
* Supporting the child to explore and learn new things
* Giving the child the amount of help they need
* Encouraging the child when they achieve their own goals
* Identifying when a child is in a good space for learning and when they are not
* Interspersing difficult tasks with easier tasks
 |
| **Navigating everyday life and routines** | * Structuring the environment to make “expectations” clear to the child
* Co-creating familiar, consistent, and motivating routines across a range of activities
* Giving a choice of order and timing of routines
* Supporting with participation in unavoidable routines by using humour, redirection, and distraction
* Communicate transitions in a way that is helpful for the child
* Using favourite toys and activities to support a child with unexpected changes in routines or non-preferred activities
 |
| **Understanding behaviours that cause harm** | This module is focussed exclusively on behaviours which objectively cause harm to the child, others, or property.* Understanding whether the behaviour is an expression of distress or is happening for another reason
* Reducing or removing the environmental factors which are causing the child distress
* Support the child to achieve their goal or express their needs in another, safe way
* Practicing the new, safe way of communicating before the child needs to use the harmful behaviour
 |
| **Tips for the tricky stuff** | This module covers a range of basic tips and ideas for common co-occurring challenges faced by autistic children and their family. It also suggests referral avenues for other relevant organisations. The areas covered by these tip sheets are:* Sleep issues
* Feeding issues
* Running away
* Toileting
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***Autistic and Māori Consultation***Lee Patrick is autistic and will serve as a consultant for the duration of this programme. Each week coaches will have an opportunity to meet with Lee online to ask questions and problem solve in relation to the whānau/families they are supporting. Lee will also respond to questions over email. If whānau/families would like to speak to Lee directly, she will also endeavour to join one of their online discussion sessions. Lee is based in Christchurch, so will not be able to come to sessions in person.

 We intend for at least one of the coaches to be Māori, to have knowledge of te ao Māori with basic skills in te reo and tikanga Māori. Whānau Māori will be given the option of working specifically with this coach/one of these coaches if they desire. These coaches along with Dr. Tupou who helped to develop this programme will also support each other and the remaining coaches to implement culturally responsive support. Dr. Hiria McRae will also be a cultural support person for whānau Māori who take part in this study.

***After the Programme***

After the 9-weeks of the programme (including the week for catch-up sessions) the primary participating whānau/family member and any other relevant participating whānau/family members will be given a printed or digital version of the Acceptability, Appropriateness, and Feasibility measure and the Neurodiversity Affirming Outcomes Survey to complete. Whānau/family and coaches will also be invited to complete the semi-structured interview at a time and place of their choosing, including in-person, over the phone, or online via a platform such as Zoom. They will be sent a list of the topics ahead of time. These interviews will be conducted by a research assistant who is not trained in the programme or familiar with the whānau/families, although they are likely to know some of the coaches. The interviews will be audio recorded and are likely to take around 30 minutes.

**Training and Fidelity of Implementation**

The researchers who develop the programme will train the coaches during several online or in-person workshops. These workshops will include written training materials, PowerPoint presentations, role plays, reflection, and discussion.

 Each coach will be required to implement the practical and discussion sessions in line with the fidelity criteria outlined in Appendix 2. A second coach will observe one practical and one discussion session (25% of sessions) and score the session in line with the criteria. The coaches’ fidelity will be calculated using the formula: (percentage of items implemented correctly/total number of items) × 100.

 As this is a pilot study, and the first time the support has been used or evaluated, the coaching team will have weekly peer supervision meetings to discuss and problem-solve any issues that arise. They will also reflect on each other’s fidelity and identify areas for adjustment and improvement.

**Data Analysis**

Results of the Acceptability, Appropriateness, and Feasibility measure, Neurodiversity Affirming Outcomes Survey, and attendance data will be presented descriptively, in tables. The semi-structured interviews with the whānau/families and the coaches will be transcribed and analysed using conventional content analysis (Hsieh & Shannon, 2005). A predominantly deductive approach to data analysis will be used, with researchers coding strengths of the programme, challenges, and suggestions for improvement. In line with this approach, researchers will complete the following steps: (a) reading and familiarising themselves with the data, (b) going through the data word-by-word to develop preliminary codes, (c) making notes of initial impressions, thoughts, and ideas for analyses, (d) confirming codes and sorting them into sub-categories and categories based on how they are related, and (e) defining each category, sub-category, and code and providing examples.

**Study Timeline**

The timeline for this pilot study is presented in Table 3

Table 3.

*Timeline for pilot study*

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | Sep-23 | Oct-23 | Nov-23 | Dec-23 | Jan-24 | Feb-24 | Mar-24 |
| Obtain ethical approval |  |  |  |  |  |  |  |
| Train coaches |  |  |  |  |  |  |  |
| Recruit families/whānau |  |  |  |  |  |  |  |
| Eligibility screening |  |  |  |  |  |  |  |
| Collect demographic data  |  |  |  |  |  |  |  |
| Schedule programme |  |  |  |  |  |  |  |
| Deliver programme |  |  |  |  |  |  |  |
| Semi-structured interview |  |  |  |  |  |  |  |
| Data analysis |  |  |  |  |  |  |  |
| Report and publish data |  |  |  |  |  |  |  |

**Ethical Considerations**

**Safety**

The research team has procedures in place for ensuring the wellbeing of staff, child, and whānau/family both within the workplace (the Autism Clinic) and in the community. The procedures for ensuring staff safety in whānau/family homes and when driving to and from these homes are outlined in Appendix 3. The child and whānau/family safety plan is included as Appendix 4. It covers various situations that may arise in relation to child and whānau/family wellbeing, for example, the child engaging in behaviours which harm themselves and others, or concerns around the family/whānau mental wellbeing. It then provides actions that the researcher might take, and external organisations who can be contacted.
 Special consideration will be given to the vulnerable nature of participating children and care will be taken to consult carefully with whānau/families and keep them fully informed throughout the research process. Prior to the study commencing, the researchers will meet individually with the whānau/families of potential participants to explain the project and answer any questions that arise. The researchers will ensure that families are aware that they are free to withdraw from the study at any time. Whānau/families will also be invited to decide on the focus of most sessions. Finally, all whānau/families will be given the primary investigator and project manager’s contact details and invited to contact them with any questions or concerns at any stage of the research process.

 **Adverse events.** It is possible that adverse events could occur across the duration of the research. This could include, for example, instances in which the child, whānau/family member, or coach are physically injured or experience significant mental distress. All adverse events will be recorded under the participant’s identification number along with all actions taken to reduce the likelihood that such events will happen in the future. Adverse events directly related to the study will also be confidentially reported in any relevant study publications. All adverse events will be reported to both the Primary Investigator (Hannah Waddington) and the Project Manager (Phoebe Jordan).

**Equity**

Several considerations have been made to reduce potential barriers whānau/families may encounter during participation in either the pilot study. Whānau/families will be offered $20 koha (e.g., petrol, bus, train) as a contribution towards the costs of travelling to the Autism Resource Centre for study assessments. Barriers related to location and transport will be further reduced given the programme will generally be delivered within the whānau/family’s home. Careful thought has been given to the time commitment whānau/families will be making to participate in the pilot. Programme sessions will likely run for a maximum of one hour and will occur once per week. Flexibility has been built into the programme, with families having the choice of session times for both the practice and discussion sessions, and of location for the discussion sessions.

**Equity of participation across cultural groups**. The programme has been developed in conjunction with a Māori rōpū and is underpinned by five key Māori values. This ensures the programme is well suited to the unique context and bicultural underpinnings of Aotearoa New Zealand. The research team intends for at least one of the coaches to be Māori, with knowledge of Te Reo and mātauranga Māori. Māori and Pacific organisations (e.g., the Pasifika Autism Support Group) will be consulted in conjunction with cultural advisors to ensure these communities are aware of the research and to address any concerns that they may have. This is to ensure Māori and Pacific peoples have an equal opportunity to participate.

**Informed Consent**

Whānau/families and additional support people who are interested in participating in the proposed research will be given a detailed information sheet and consent forms (PIS/CF). Each PIS/CF will introduce the investigators and explain: (a) the voluntary nature of the study, (b) the purpose of the study, (c) the study design, (d) who can take part in the study, (e) what participation will involve, (f) the possible risks, (g) the possible benefits, (h) cost reimbursement, (i) procedures for if something goes wrong, (j) what will happen to their information, (k) what happens after the study or if they change their mind, (l) how results from the study will be provided, (m) who is funding the study, (n) who has approved the study, and (o) who to contact for more information or if they have concerns.
 If individuals agree to participate in the study, they will be provided with a consent form but will also be informed that they can withdraw from the study at any time without negative consequences.

**Child Assent**

Due to the age of the children participating in this study, and potential delays in receptive and expressive language and cognition, it will not be possible for them to give informed consent to participate. The protocol for determining child assent is as follows:

1. Behaviours that are indicative of a lack of assent are likely to vary for each child. Prior to meeting the child for the first time, a researcher will have a conversation with the whānau/family to understand what a lack of assent, as well as active assent and interest would look like for the child.
2. The child’s unique ways of showing lack of assent, assent and interest will be recorded and the coach will be expected to familiarise themselves with, and observe the child for, these behaviours.
3. In consultation with family/whānau members, sessions will be terminated if the child is demonstrating a lack of assent. Additionally, if the family/whānau member feels the child does not assent to the session at any time, it will be stopped.
4. Behaviours that indicate a lack of assent could include expressions of distress such as aggressive acts toward others, self-injury, crying, screaming, throwing, or destroying materials, and active opposition and refusal to follow instructions.
5. Behaviours that indicate active assent and engagement could include smiling, laughing, approaching, clapping, focussing intently on the activity, and elevated vocal pitch.
6. If a child indicates that they do not want to do a specific activity but are not showing “signs of distress” as such, the activity will be terminated. If the child appears to assent, the session could continue with the child choosing to engage in another activity or being given some time and space, while the adults continue. New activities can also be overwhelming for some autistic children, so the child may prefer to watch for a while to see what is happening before choosing whether or not to join in.

Every effort will be made to ensure that the child feels comfortable and safe during the practical sessions. Sessions will take place in the home or another location with which the child is familiar. The sessions will be child led and coaches and whānau/families will be explicitly using child-focussed strategies designed to support child quality of life and wellbeing. This includes taking the pressure off by removing all demands on the child and increasing physical distance if the child is indicating that they would not like to interact with the adult in that moment.

**Data Management**

Due to the need to record individualised data for each participant, data collection will not be anonymous. Several steps will be taken to ensure confidentiality is maintained across the data collection and analytic processes. Access to all identifiable data will be restricted to the research team. Participants will be assigned a unique ID upon their entry to the study. Only restricted members of the research team involved with running the research and delivering the programme will have access to a password protected file which pairs each participant (i.e., whānau/family and their child, additional support people) with their unique ID. Research assistants blind to the allocation of whānau/family and the individual responsible for randomisation will only know each whānau/family’s unique ID.

Any handwritten information collected (i.e., pre-, and post- assessment measures, interview notes) will be recorded under each participant’s unique ID. These papers will be stored within a locked draw or cupboard in a secure office at the Victoria University of Wellington. These documents will also be scanned and saved to a password protected cloud-based storage system (i.e., Storage for Learning and Research – SoLAR).

Videos of whānau/family and/or coaches interacting with the child, collected expressly to facilitate reflection, will be recorded on an electronic device (e.g., iPad, iPhone, videorecorder) and viewed on a computer or laptop. These videos will be placed within a password protected file on a secure password protected cloud-based storage system. Videos will only be shared with the whānau/family, their additional support people, their coach, and the research team for purposes of programme/coach supervision. Videos for outcome measurement (i.e., Dyadic Communication Measure for Autism; DCMA) will also be recorded using one of the aforementioned devices, then saved to a password protected cloud-based storage system (i.e., SoLAR) at the study site. These videos will then be permanently deleted from the electronic recording device. Videos will be viewed on the cloud-based storage system for research purposes (i.e., outcome measurement, coach supervision) to ensure the videos cannot be seen by anyone outside the research team.

Audio recordings (i.e., for outcome measurements including interviews) will be captured using an electronic recording device (e.g., iPad, iPhone, audio recorder). Audio files labelled by the participant’s unique ID will be uploaded to the password protected cloud-based storage system (i.e., SoLAR) at the study site as soon as possible (i.e., the same day) before being permanently deleted from the electronic recording device. Transcripts of audio files will also be saved under the participant’s unique ID.

De-identified data collected during this research may be used in future studies related to the programme, if participants consent to this. All source documents will be retained for at least 10 years after the youngest participant in the study has turned 16, then destroyed by permanently deleting all scanned documents from the cloud-based storage system and shredding all paper-based documentation.

**Dissemination**

The results of the pilot study and randomised controlled trial will be submitted for publication in international, peer reviewed journals such as *Autism,* and the *Journal of Autism and Developmental Disabilities*. They will also be presented at international conferences such as the conference for the *Australasian Society for Autism Research.* A community summary will also be shared on the social media pages of relevant organisations (e.g., Autism NZ, Altogether Autism) and on the Autism Clinic website (https://www.wgtn.ac.nz/autism-clinic) and Facebook page.

**Changes based on Peer Review**

Dr. Kandice Varcin, a Research Fellow at Griffith University, reviewed this protocol on the 1st of August 2023 and provided helpful feedback. We made the following changes to the research based upon her feedback:

1. We have now clarified how we will assess acceptability, appropriateness, and feasibility in the hypotheses.
2. We have now included a direct quantitative measure of the acceptability, appropriateness, and feasibility of the support.

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**Appendix 1**

Mapping the relationship between programme outcomes, approaches to supporting the child and adults, and ngā tanga underpinning the programme

|  |  |  |
| --- | --- | --- |
| **Outcome** | **Approaches to supporting the child and adults** | **Ngā tanga**  |
| **Environmental changes** |  |  |
| Improved accessibility of physical and social environments  | **Child focussed**Supporting regulation(Arrange environment in a way that helps the child to feel comfortable and safe; Reduce distractions) | ManaakitangaKaitiakitanga |
| Improved access to sensory tools  | **Child focussed**Supporting regulation(Provide easy access to sensory tools and experiment with which of these tools work for the child) | ManaakitangaKaitiakitangaTuakiritanga |
| Improved access to preferred and meaningful activities, including preferred play | **Adult focussed**Supporting a neurodiversity affirming approach (Help whānau to understand the child)**Child focussed**Understanding the child **(**Understand and respect the child’s unique ways of communicating, interacting, and playing, showing interest and engagement, expressing emotions)Respecting your child’s interests and preferences (all) | WhanaungatangaKotahitangaManaakitangaTuakiritanga |
| **Outcomes for parent and other adults (e.g., whānau, educators)** |  |  |
| Improved physical and mental wellbeing *(e.g., confidence, capacity to manage emotions, access to leisure activities, safety*). | **Adult focussed**Building relationships and connections (all)Supporting whānau wellbeing/hauora (all)Building whānau confidence (all)Supporting a neurodiversity affirming approach (all) | WhanaungatangaManaakitangaKotahitangaKaitiakitanga |
| Improved fulfilment, enjoyment, and confidence in their connection and interactions with the child | **Adult focussed**Supporting whānau wellbeing/hauora (all)Building whānau confidence (all)Supporting a neurodiversity affirming approach (all)**Child focussed**Respecting your child’s interests and preferences(all)Supporting success(all) | WhanaungatangaManaakitangaKotahitanga |
| Improved knowledge of autism as a form of neurodiversity and understanding of their own autistic child | **Adult focussed**Supporting a neurodiversity affirming approach (all)**Child focussed**Understanding the child (Understand autism and neurodivergence) | WhanaungatangaManaakitangaKaitiakitangaTuakiritanga |
| Improved understanding of co-occurring conditions, such as ADHD, dyspraxia, PDA | **Adult focussed**Supporting a neurodiversity affirming approach (help whānau to understand their child)**Child focussed**Understanding the child (Understand autism and neurodivergence) | WhanaungatangaManaakitangaKaitiakitangaTuakiritanga |
| Improved understanding of executive functioning difficulties, and how to modify communication with child based on this | **Adult focussed**Supporting a neurodiversity affirming approach (help whānau to understand their child)**Child focussed**Supporting Communication (Respect the child’s preferred and non-preferred forms of communication; Use visuals to support understanding; give the child time and space to process communication) | WhanaungatangaManaakitangaKaitiakitangaTuakiritanga |
| Improved ability to understand and respond to child needs and communication  | **Adult focussed**Building whānau confidence (all)Supporting a neurodiversity affirming approach (all)**Child focussed**Understanding the child (Understand and respect the child’s unique ways of communicating, interacting, and playing, showing interest and engagement, expressing emotions; believe and validate the child’s communication)Supporting Communication(all) | WhanaungatangaManaakitangaKaitiakitangaTuakiritanga |
| Improved ability to communicate in a way that makes sense to the child and to model different forms and types of communication | **Adult focussed**Supporting a neurodiversity affirming approach (help whānau and others to understand the child)**Child focussed**Supporting Communication(all) | WhanaungatangaManaakitangaKaitiakitangaTuakiritanga |
| Strengthened formal and informal connections with other adults | **Adult focussed**Building relationships and connections (Offer to support the whānau with formal and informal connections) | WhanaungatangaKotahitangaManaakitanga |
| **Outcomes for the child** |  |  |
| Improved ability to understand themselves, including their own skills, wants and needs | **Adult focussed**Supporting a neurodiversity affirming approach (help whānau and others to understand the child)**Child focussed**Understanding the child (Understand and respect the child’s unique ways of communicating, interacting, and playing, showing interest and engagement, expressing emotions; believe and validate the child’s communication; understand autism and neurodivergence)Supporting communication (Model and create opportunities for different types of communication) | WhanaungatangaTuakiratangaManaakitanga |
| Improved ability to advocate for themselves to increase access to their rights, needs and preferences (understanding bodily autonomy for your own and others’ bodies) | **Adult focussed**Supporting a neurodiversity affirming approach (help whānau and others to understand the child)**Child focussed**Understanding the child (Understand and respect the child’s unique ways of communicating, interacting, and playing, showing interest and engagement, expressing emotions; believe and validate the child’s communication)Supporting communication(all) | TuakiratangaManaakitangaKaitiakitanga |
| Improved fulfilment and enjoyment in their connection and interactions with others | **Adult focussed**Supporting whānau wellbeing/hauora (all)Building whānau confidence (all)Supporting a neurodiversity affirming approach (all)**Child focussed**Understanding the child (all)Respecting your child’s interests and preferences (all)Supporting success(all)Navigating everyday routines (all) | WhanangatangaManaakitangaTuakiritanga |
| Feeling more confident and better understood communicating using preferred methods (including through te reo Māori if relevant to the whānau). | **Adult focussed**Supporting a neurodiversity affirming approach (help whānau and others to understand the child)**Child focussed**Understanding the child (Understand and respect the child’s unique ways of communicating, interacting, and playing, showing interest and engagement, expressing emotions; believe and validate the child’s communication)Supporting communication(all) | TuakiratangaManaakitangaKaitiakitanga |
| Improved ability to understand, express, and regulate emotions (but not encouraging masking) | **Adult focussed**Supporting a neurodiversity affirming approach (help whānau and others to understand the child)**Child focussed**Supporting regulation(all)Supporting communication (respect the child’s preferred and non-preferred forms of communication, use consistent communication, simplify communication, give the child time and space to process communication, use visuals to support understanding). | TuakiritangaManaakitangaKaitiakitanga |
| Reduce and replace behaviours which harm themselves or others | **Adult focussed**Supporting a neurodiversity affirming approach (help whānau and others to understand the child)**Child focussed**Understanding behaviours that cause harm(all)Supporting communication (respect the child’s preferred and non-preferred forms of communication, use consistent communication, simplify communication, give the child time and space to process communication, use visuals to support understanding). | ManaakitangaKaitiakitanga |
| Reduce challenges around co-occurring issues such as eating, sleeping etc. | **Adult focussed**Supporting whānau wellbeing/hauora (all)Supporting a neurodiversity affirming approach (help whānau and others to understand the child)**Child focussed**Tips for the tricky stuff(all) | ManaakitangaKaitiakitanga |
| Improved physical wellbeing and safety | **Adult focussed**Supporting a neurodiversity affirming approach (help whānau and others to understand the child)**Child focussed**Understanding behaviours that cause harm(all)Supporting regulation(all)Supporting communication (use consistent communication, simplify communication, give the child time and space to process communication, use visuals to support understanding). | ManaakitangaKaitiakitanga |
| Improved mental wellbeing *(e.g., happiness, self-determination, confidence)* | Each way of supporting autistic children and adults around the child could help the child to feel happier and/or more confident depending on the child and context. | ManaakitangaKaitiakitangaTuakiritanga |
| Developing a sense of personal worth | **Adult focussed**Supporting a neurodiversity affirming approach (help whānau and others to understand the child)**Child focussed**Respecting your child’s interests and preferences (all)Supporting success(all) | ManaakitangaTuakiritanga |
| Developing a sense of cultural identity/belonging | **Adult focussed**Building relationships and connections (Get to know the whānau as people, take the time to understand the whānau’s context; consider the whānau’s culture)Supporting wellbeing/hauora(For whānau Māori, considering incorporating tikanga, encouraging whānau support and involvement, using te reo Māori, etc.)**Child focussed**Supporting communication(Respect the child’s preferred and non-preferred forms of communication, including communication in Te Reo Māori/Te Reo Turi if relevant for the whānau) | WhanaungatangaTuakiritanga |
| Improved ability to care for oneself and to do daily tasks *(e.g., dressing, feeding, toileting)* | **Adult focussed**Supporting a neurodiversity affirming approach (help whānau and others to understand the child)**Child focussed**Navigating everyday routines (all)Support success(all) | ManaakitangaKaitiakitanga |

**Appendix 2**

Coach Fidelity Form - Practical Sessions

This fidelity form is for the practical, in-home sessions where the child is present.

This scale can be used for coaches to self-evaluate their delivery of the programme. It will also be used to examine the coaches’ delivery of the programme of support and to check whether the programme is being delivered as intended.

Score each item as follows:

0 = the coach did not implement this technique
1 = the coach inconsistently implemented this technique or met some but not all of the criteria
2 = the coach generally implemented this technique to an adequate standard

All sessions are underpinned by ngā tanga, a set of guiding values. All coaches are to be aware of, understand, and embed these values across the support they provide. Each fidelity item also correlates with specific ngā tanga, as outlined in the fidelity checklist/session structure. The list of ngā tanga, including definitions for each, are below.

|  |  |  |
| --- | --- | --- |
| **Ngā tanga**  | **Definition**  | **Example from Practical Session**  |
| **Whanaungatanga**  | The literal translation is kinship or relationship, it’s a value that can be used to guide our interactions with others (and the world around us). It’s guided by the concept of whakapapa – the idea that everything is connected. It also covers the idea of collective and reciprocal responsibility for the wellbeing of everyone in the whānau. When our interactions are guided by whanaungatanga, we treat others as if they are our whānau.  | The coach takes the time to greet each whānau/family member and hear about their week, shows genuine interest and does not rush them.  |
| **Tuakiritanga**  | Tuakiri relates to personality and identity or ‘inner being’. Tuakiritanga is about knowing who you are and where you come from and feeling good about it. It promotes mauri ora and helps tamariki to move forward with self-confidence and pride in their identity. It can be supported by helping tamariki to connect with the language and cultural practices of their whānau and ancestors.   | The coach follows the child’s interests in play, commenting to the family/whānau about positive aspects of that play.  |
| **Manaakitanga**   | Thinking and acting in ways that uphold the mana of others and our own mana. This can be done through showing caring, thoughtfulness, generosity, and hospitality. The process of manaaki enhances relationships. It also relates to inclusion and treating all children with care and respect. It involves recognising that all tamariki are born with mana from their parents and tīpuna which needs to be upheld and nurtured.  | The coach adapts the session according to the preferences of the whānau/family. For example, if the child is not enjoying the activity, the coach supports the whānau/family to find another activity or give the child space if they prefer.  |
| **Kaitiakitanga**  | Active guardianship, caring, looking after, or protecting. Kaitiakitanga is also related to roles and responsibilities because it involves recognising that we all have a responsibility to care for and protect the people and the world around us.  | The coach ensures that the environment is comfortable for the child and whānau/family. For example, reducing any distractions and making sure the child is seated comfortably.  |
| **Kotahitanga**  | Unity, togetherness, and collaboration. Working together with a common purpose/direction.  | The coach tied the new concept (creating opportunities for communication) back to one of the goals that the whānau had said were important to them (understanding what their child wants) and checked that this was still important to them.  |

|  |  |  |
| --- | --- | --- |
| **Session structure**  | Ngā tanga  | Score  |
| 1. The coach begins the session by warmly greeting all whānau/family members (including greeting the child in their preferred way), sharing, and listening to any stories from the week, answering questions and areas of clarification, and discussing progress towards the goals identified during the previous discussion
 | Whanaungatanga Manaakitanga Tuakiritanga Kotahitanga  |   |
| 1. The coach settles into play and interaction with the child. This includes but is not limited to:
* respecting and following the child’s interests and preferences,
* arranging the environment so that the child feels comfortable and safe,
* allowing for space and alone time if needed, and
* responding appropriately to child all communication.
 | Whanaungatanga Manaakitanga Tuakiritanga Kaitiakitanga  |   |
| 1. If the child settles into play and interaction, the coach models strategies with the child. These strategies should be relevant to the content covered in recent discussion sessions. The coach also seeks feedback from the whānau/family regarding what is going well with the interaction, anything to change, and identifying child communication that may have been missed.
 | Manaakitanga Kotahitanga  |   |
| 1. The coach provides necessary support to the family/whānau to use relevant strategies. For example, pointing out what is going well in the interaction, identifying child communication that may have been missed, directly helping the whānau/family member if requested or agreed to.
 | Manaakitanga Kotahitanga  |   |
| 1. The coach ends the session by addressing any unanswered questions or areas for clarification, reminding about the session time for the following week, and warmly farewelling all whānau/family members (including farewelling the child in their preferred way).
 | Whanaungatanga Manaakitanga Tuakiritanga  |   |
| 1. The coach manages the session so that, if possible, all necessary components (i.e., 1-5) take place within the allocated session time. The order of components may vary depending on whānau/family need. For example, whether the coach or whānau/family members practice with the child first with the child interaction happens first. If all necessary components do not take place within the allocated session time, there is clear justification for this (for example, the whānau/family is not yet ready to play with the child a receive feedback).
 | Whanaungatanga Kotahitanga  |   |
| **OVERARCHING COACHING TECHNIQUES**  |   |   |
| **Unconditional positive regard –** The session is underpinned by the coach’s positive view of all whānau/family members including the child. This includes, but is not limited to: * listening attentively,
* showing empathy,
* refraining from negative or critical comments,
* responding to and validating whānau/family ideas/opinions/actions in a non-judgmental way, and
* focusing on successes and strengths.
 | Whanaungatanga Manaakitanga  |   |
| **Neurodiversity-affirming** – The coach takes a neurodiversity affirming approach to the content and their discussions with the whānau/family member. This includes, but is not limited to: * framing observations in a neurodiversity affirming way (e.g., stimming might help your child to regulate) and supporting whānau/families to do the same,
* modelling appreciation of the child’s unique way of being (e.g., the coach commenting ‘that play idea is so creative’)
* respecting and understanding the child’s unique way of being in all direct interactions
* supporting the whānau to respect and understand the child’s unique ways of being
 | Tuakiritanga Manaakitanga  |   |
| **Respectful –** The coach adapts the session as needed to suit each whānau/family’s communication and interaction preferences, culture, and neurodivergence (if relevant). This could include, for example: * awareness and acknowledgement of negative experiences of previous services,
* use of Te Reo Māori or the whānau/family’s first language and preferred terms, avoiding jargon,
* incorporating tikanga or other cultural practices,
* being generous with time and support (e.g., flexibility in rescheduling sessions, responding to emails between sessions), and
* avoiding things that might cause offense.
 | Whanaungatanga Tuakiritanga  |   |
| **Confidence-building.** The coach empowers whānau/family members as experts in their own child. This could include, but is not limited to: * emphasizing that the whānau/family member know the child best,
* acknowledging all the things that the whānau/family are already doing well,
* allowing whānau/family members to choose the content, strategies, and goals that they would like to focus on, and
* collaboratively sharing and building upon each other’s knowledge.
 | Kotahitanga  |   |
| **Ngā tanga (scored in discussion with the coach)–** The coach provides evidence of integration of ngā tanga (see table above). The coach chooses one tānga to specifically focus on throughout the session and is able to explain how they embedded this tanga, with specific examples.  | Whanaungatanga Manaakitanga Tuakiritanga Kaitiakitanga Kotahitanga  |   |
| **Total**  | /22  |

Coach Fidelity Form – Discussion Sessions

This fidelity form is for the discussion sessions, without the child is present. These sessions may take place in the whānau/family home (provided the child is entertained), in the clinic, or online via a platform such as Zoom.

This scale can be used for coaches to self-evaluate their delivery of the programme. It will also be used to examine the coaches delivery of the programme of support, to check whether the programme is being delivered as intended.

Score each item as follows:

0 = the coach did not implement this technique
1 = the coach inconsistently implemented this technique or met some but not all of the criteria
2 = the coach generally implemented this technique to an adequate standard

All sessions are underpinned by ngā tanga, a set of guiding values. All coaches are to be aware of, understand, and embed these values across the support they provide. Each fidelity item also correlates with specific ngā tanga, as outlined in the fidelity checklist/session structure. The list of ngā tanga, including definitions for each, are below.

|  |  |  |
| --- | --- | --- |
| **Ngā tanga**  | **Definition**  | **Example from Practical Session**  |
| **Whanaungatanga**  | The literal translation is kinship or relationship, it’s a value that can be used to guide our interactions with others (and the world around us). It’s guided by the concept of whakapapa – the idea that everything is connected. It also covers the idea of collective and reciprocal responsibility for the wellbeing of everyone in the whānau. When our interactions are guided by whanaungatanga, we treat others as if they are our whānau.  | The coach takes the time to greet each whānau/family member and hear about their week, shows genuine interest, and does not rush them.  |
| **Tuakiritanga**  | Tuakiri relates to personality and identity or ‘inner being.’ Tuakiritanga is about knowing who you are and where you come from and feeling good about it. It promotes mauri ora and helps tamariki to move forward with self-confidence and pride in their identity. It can be supported by helping tamariki to connect with the language and cultural practices of their whānau and ancestors.   | The coach identifies positive aspects of the child and their engagement/play during the observations. For example, emphasising how much the child knows about their area of interest and how useful this is.  |
| **Manaakitanga**   | Thinking and acting in ways that uphold the mana of others and our own mana. This can be done through showing caring, thoughtfulness, generosity, and hospitality. The process of manaaki enhances relationships. It also relates to inclusion and treating all children with care and respect. It involves recognising that all tamariki are born with mana from their parents and tīpuna which needs to be upheld and nurtured.  | The coach adapts the session according to the preferences of the whānau/family. For example, discussing the content that they are interested in, and being guided by them in the choice of video clip.  |
| **Kaitiakitanga**  | Active guardianship, caring, looking after, or protecting. Kaitiakitanga is also related to roles and responsibilities because it involves recognising that we all have a responsibility to care for and protect the people and the world around us.  | The coach ensures that the environment is comfortable for the child and whānau/family. For example, if they are in a clinic room, ensuring that the parent is comfortable, and that there are minimal distractions.  |
| **Kotahitanga**  | Unity, togetherness, and collaboration. Working together with a common purpose/direction.  | The coach tied the new concept (creating opportunities for communication) back to one of the goals that the whānau had said were important to them (understanding what their child wants) and checked that this was still important to them.  |

|  |  |  |
| --- | --- | --- |
| **Session structure**  | Ngā tanga  | Score  |
| 1. The coach begins the session by warmly greeting all whānau/family members, sharing, and listening to any stories from the week, answering questions and areas of clarification, and discussing progress towards the goals identified during the previous discussion
 | Whanaungatanga Manaakitanga Kotahitanga  |   |
| 1. The coach helps the whānau/family members to choose the content they would like to cover in this session. This includes whether they would like to learn new content, or to continue to discuss previous content.
 | Kotahitanga  |   |
| 1. The coach shares information about the whānau/family members chosen content using their preferred format(s). This includes verbal explanations, written materials, illustrations, and videos.
 | Manaakitanga Kotahitanga  |   |
| 1. The coach gain whānau/family members feedback on the content, including how the content specifically relates to their child, any adaptations that might be needed, and areas for clarification.
 | Kotahitanga  |   |
| 1. The whānau/family choose video excerpts to watch of themselves and/or other family/whānau members interacting with the child during a previous practical session. These video excerpts should be directly relevant to the content that whānau/family has chosen to discuss. If no video is available, the coach and family/whānau mutually identify aspect(s) of the previous practical session to discuss.
 | Kotahitanga  |   |
| 1. The coach and whānau/family members reflect on interactions identified from the previous practical session. These reflections include observations of what went well, what could be done differently, and interpretations of child communication and emotional expression.
 | Manaakitanga Kotahitanga  |   |
| 1. The coach checks in about the whānau/family’s existing informal and formal supports and, where relevant and desired, assists in making plans for referral or contact with other appropriate services.
 | Whanaungatanga  |   |
| 1. The coach works with the family/whānau to select a manageable goal or goals for the next fortnight. Goals should relate to something the family/whānau want to focus on for themselves (e.g., we will give our child more opportunities for choice), rather than a goal for the child (e.g., our child will say more words).  *Note: Goals should generally be tied to the content discussed within the session. However, at any time whānau/family members can choose to ‘take the pressure off’ by focussing, for example, on their own wellbeing or on finding positives in their existing interactions with their child.*
 | Whanaungatanga Manaakitanga Kotahitanga  |   |
| 1. The coach ends the session by addressing any unanswered questions or areas for clarification, reminding about the session time for the following week, and warmly farewelling all whānau/family members.
 | Whanaungatanga Manaakitanga  |   |
| 1. The coach manages the session so that, if possible, all necessary components (i.e., 1-9) take place within the allocated session time. The order of components may vary depending on whānau/family need. For example, some whānau/families may prefer to reflect on the previous session before discussing new content. If all necessary components do not take place within the allocated session time, there is clear justification for this.
 | Whanaungatanga Kotahitanga  |   |
| **OVERARCHING COACHING TECHNIQUES**  |   |   |
| **Unconditional positive regard –** The session is underpinned by the coach’s positive view of all whānau/family members including the child. This includes, but is not limited to: * listening attentively,
* showing empathy,
* refraining from negative or critical comments,
* responding to and validating whānau/family ideas/opinions/actions in a non-judgmental way, and
* focusing on successes and strengths.
 | Whanaungatanga Manaakitanga  |   |
| **Neurodiversity-affirming** – The coach takes a neurodiversity affirming approach to the content and their discussions with the whānau/family member. This includes, but is not limited to: * framing observations in a neurodiversity affirming way (e.g., stimming might help your child to regulate) and supporting whānau/families to do the same,
* using neurodiversity affirming examples when discussing content (e.g., children communicating effectively in their own unique ways),
* modelling appreciation of the child’s unique way of being (e.g., the coach commenting ‘that play idea is so creative’),
* taking the time to understand the reasons why whānau/family members may want to focus on goals that do not align with the programme (e.g., wanting to focus on eye contact to know that their child is listening to them), and
* supporting the whānau to respect and understand the child’s unique ways of being.
 | Tuakiritanga Manaakitanga  |   |
| **Respectful –** The coach adapts the session as needed to suit each whānau/family’s communication and interaction preferences, culture, and neurodivergence (if relevant). This could include, for example: * use of easy read materials,
* awareness and acknowledgement of negative experiences of previous services,
* use of Te Reo Māori or the whānau/family’s first language and preferred terms, avoiding jargon,
* incorporating tikanga or other cultural practices,
* avoiding things that might cause offense.
 | Whanaungatanga Tuakiritanga  |   |
| **Confidence-building.** The coach empowers whānau/family members as experts in their own child. This could include, but is not limited to: * emphasizing that the whānau/family member know the child best
* acknowledging all the things that the whānau/family are already doing well
* allowing whānau/family members to choose the content, strategies, and goals that they would like to focus on
* collaboratively sharing and building upon each other’s knowledge
* checking for shared understanding by asking questions or allowing whānau to summarise in their own words
 | Kotahitanga  |   |
| **Ngā tanga (scored in discussion with the coach)–** The coach provides evidence of integration of ngā tanga (see table above). The coach chooses one tānga to specifically focus on throughout the session and is able to explain how they embedded this tanga, with specific examples.  | Whanaungatanga Manaakitanga Tuakiritanga Kaitiakitanga Kotahitanga  |   |
| **Total**  | /30 |

Appendix 3

In-home safety plan.

**Prior to entering the home**

Prior to entering the family home for the first time, the researcher will call the family to get to know them, and their support needs. If the researcher feels uncomfortable about the risk of conducting an initial home visit on their own, they will consult with the Primary Investigator (Hannah Waddington) or Project Manager (Phoebe Jordan) who will advise as to whether they should (a) take another researcher on the home visit, and/or (b) arrange to meet the family at a public place. The location and time of home visits will be centrally recorded in a password-protected document. All researchers who drive themselves to family homes must have a relevant driver’s license and up-to date vehicle registration and warrant of fitness.

**During and after home visits**

Each researcher will be assigned a “buddy” who will be aware of when and where the first visit will take place as well as any changes in session location or time. The researcher will check in with the buddy within 30 minutes of their visit finishing via text or call. The buddy will attempt to contact the researcher if they do not hear from them within the time-frame. If they cannot reach the researcher, they will contact the Clinic Lead and make a plan.

Researchers will park in a safe, well-lit area and cover any items of interest within their car (e.g., computers). Researchers will ensure that they have personal identification, a motor vehicle licence, a charged mobile phone with funds, pre-programmed emergency numbers, and will keep car keys on their person. When entering the home, they will take note of any entrances and exits and will monitor the family for signs of, for example, hostility, aggression, or excessive alcohol or drug consumption.

If researchers have concerns about their safety, they will withdraw from the house and notify the Primary Investigator or Project Manager. If appropriate, they will use an excuse like getting an item from the car. If researchers have immediate concerns for their safety they will call the police. Any incidents will be recorded and reported to the Primary Investigator and/or Project Manager.

**General considerations**

All home visits will be finished before 8pm. Home visits will not take place when either the researcher, child, or participating family member(s) are sick. The researcher will not drive to sessions during orange/red weather alerts. The researcher will not travel further than Upper Hutt and the Kāpiti Coast for visits.

**Checklist for researchers conducting home visits**

**Prior to entering the home**

☐ I have called the family and determined the level of risk for the first visit

☐ If there is elevated risk have consulted with the Primary Investigator/Project Manager and I have arranged for a second person to accompany me to the visit and/or have arranged for the visit to take place in a public place.

☐ I have recorded the time of the visit, including catchups in the shared, password protected document

☐ I know who my “buddy” is for visits

☐ I have ensured that all session are scheduled to finish before 8pm

☐ I have ensured that the family does not live further away than Upper Hutt or the Kāpiti Coast

☐ If driving myself to the visit, I have ensured that my vehicle registration and warrant of fitness are up-to-date

☐ I have let my buddy know the time and place of the first session, or any changes to session time and place

**During visits**

☐ I have parked in a safe, well-lit area and hidden any valuables

☐ I have the following items with me:

 ☐ Car keys

 ☐ Mobile phone, charged, with funds and pre-programmed emergency numbers

 ☐ ID/driver’s licence

☐ I have noted the entrances and exits in the family home and any behaviour that I find concerning from family members

☐ I have terminated the session if the child or family member(s) are visibly unwell, disclose that they are not well, or I feel unsafe in any way

**After the first visit**

☐ I have checked in with my buddy

**If any incidents occur**

Call the police in an emergency

☐ I have let the Primary Investigator and/or Project Manager know

☐ I have recorded the incident on the study’s “incident register”

Appendix 4

Child and Whānau/Family Safety Plan

All members of the research team who interact directly with families will aim to be vigilant to the needs of tamariki and whānau and will provide support accordingly. With parental consent, they may also support referrals to relevant external organisations.

|  |  |  |
| --- | --- | --- |
| **Concern** | **Action** | **External Organisations** |
| There is an immediate physical health concern or incident related to a child or parent/family member. | * Those therapists who have attended first aide training will implement the appropriate, trained response.
* If the health concern relates to the child, parents will also be present and may be able to assist.
* If it is an emergency, the therapist will dial 111 or instruct another person present to do so.
* If the health incident is not an emergency, but is of concern, the therapist will advise the family to see their GP (General Practitioner).
 | GPEmergency services |
| The child is engaging in behaviours which physically harm themselves or others. | * The therapist will take immediate action to ensure that everyone is kept safe. This could include:
	+ Removing all demands on the child
	+ Removing unsafe objects/hazards
	+ Removing themselves from the situation
	+ Terminating the session
* A safety plan will be created to identify the child’s need that is not being met, and put appropriate supports in place to help them safely meet that need.
* The incident will also be recorded in the incident register and will be reported to both the Primary Investigator and Project Manager.
* If desired by the family, the therapist will assist the family in making a referral to Explore.
 | Explore |
| Interactions with a parent/family member or responses on assessments indicate that the parent is experiencing severe distress or mental health issues (e.g., stress, anxiety, depression). | * The therapist will advise the parent to see a GP and will follow-up to check that the GP was contacted.
* The therapist will provide whānau with a list of appropriate resources/support services and will assist them in deciding on which, if any, would be helpful and in making the referral.
* The therapist will let the whānau know that if the person is in extreme distress, we will need to ethically act upon it.
* If the parent/family member’s participation in programmes through the Autism Clinic is contributing to that distress, then this may be paused until this distress has been reduced.
 | GP |
| Interactions with a parent/family member or responses on assessments indicate that **parent/family member is in imminent danger related to mental health** (e.g., caregiver mentions suicidal ideation) | * The therapist will support the family member to make contact with support agency (e.g., existing counsellor or GP if suicidal ideation) or the local specialist mental health services crisis team (Te Haika in Wellington).
* If the situation may result in serious harm to self or others, the therapist will contact emergency services.
 | GPTe Haika: 0800 745 477Emergency services |
| Interactions with a parent/family member or responses on assessments indicate that **parent/family member is in imminent danger related to their environment** (e.g., concerns around family violence) | * The parent and therapist will support the parent/family member to make contact with support agency (such as Women’s refuge).
* If the situation may result in serious harm to the parent/family member or others, the therapist will contact emergency services.
 | SeveralE.g., Women’s Refuge |
| Interactions with a parent/family member or responses on assessments indicate that **child is in imminent danger related their environment** (e.g., child is at risk from another family member) | If the concerns are not related to the contact family member\** The therapist will support the parent/family member to make contact with support agency (such as Oranga Tamariki).

If concerns relate to the contact family member\** Make a note of your concerns in the incident register
* Consult the Primary Investigator and/or Project Manager as to whether to contact the appropriate statutory agency (e.g., Oranga Tamariki).
* If the situation may result in serious harm to the child, parent/family member or others, the therapist will contact emergency services.
 | Several,E.g., Oranga Tamariki |

\*The family member who brings the child to therapist sessions and/or who is participating in the coaching.