

Randomised controlled trial of Raupī te Raupō: an Aotearoa-specific early support programme

Study Protocol

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Summary

This programme of research involves the evaluation of a new programme of support called Raupī te Raupō: He Poipoi Tamaiti, he Whaipanga te Āpōpō. Raupī te Raupō is 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. Raupī te Raupō has been developed alongside an autistic advisory rōpū (group), a Māori advisory rōpū, and a professional advisory rōpū. This randomised controlled trial will include 60 children, their whānau/families and additional support people. This study aims to determine the effectiveness of Raupī te Raupō for improving child and whānau/family outcomes compared to standard community support.

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.

Alongside the need for co-designed supports, another key issue in Aotearoa New Zealand is the significant delay in identification, diagnosis, and support for autistic children and their whānau/families. Although signs of autism are often present in the first year of life (Waddington et al., 2021), whānau/family members in Aotearoa New Zealand may not know how to recognise these signs and generally do not see a professional about these signs until their child is aged between three and four years old (Eggleston et al., 2021). Whānau/families can then wait ten months or more for an assessment. On average, children in Aotearoa New Zealand are diagnosed at the age of six, later than in many other developed countries (Eggleston et al., 2010). Following diagnosis, whānau/families report dissatisfaction with the provision and coordination of supports. There are often long waiting lists for services and roughly one in five families/whānau of young autistic children may not receive any kind of professional support (Kasilingham et al., 2021). To address these issues, it is paramount to design ‘pre-emptive’ supports, which can be delivered to children and their whānau/families *as soon as* signs of autism or social communication differences are identified (Whitehouse et al., 2023). This enables support to be provided much earlier, rather than waiting for the current lengthy assessment and diagnosis process.

This randomised controlled trial (RCT) will involve an evaluation of Raupī te Raupō an Aotearoa-specific early support programme. Raupī te Raupō 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 RCT will involve 60 whānau/families who will be randomly allocated to a group who receives Raupī te Raupō or a group who will be assisted to access supports in the community.

Only children showing signs of autism/social communication differences who are not yet diagnosed will be included in the RCT. This is because of the importance of providing and examining access to support as soon as a child is identified, rather than waiting for the lengthy assessment and diagnosis process. In the RCT, 20 sessions within Raupī te Raupō will take place in the family home or another environment in which the child is familiar and comfortable. Five sessions in the RCT will take place with second group of important support people either in the same location or a second location. This could include, for example, sessions at kindergarten, with teaching and support staff, or sessions including the father in the family home.

Programme Development

Raupī te Raupō: He Poipoi Tamaiti, he Whaipainga te Āpōpō 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/July 2023 to discuss and plan several aspects of Raupī te Raupō and associated research. The topics discussed in the hui included (a) the delivery of Raupī te Raupō, (b) important outcomes to target in Raupī te Raupō, (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 whanonga pono) that would underpin Raupī te Raupō. 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.

In September 2023, Associate Professor Mere Skerrett (Ngāi Tahu, Ngāti Rakiāmoa, Ngāti Ruahikihiki, Ngāti Māhuta, Ngāti Unu, Ngāti Maniapoto, Ngāti Pīkiao, Ngāti Te Rangiuuora, Ngāti Pūkeko) generously gifted our ingoa (name) based on ideas from the Māori rōpū. Raupī is about nurturing, taking care of, and cherishing. The wetlands where Raupō (bulrush) grow are the lungs of the land and are essential for survival and wellbeing. Raupō had many traditional uses for Māori including as a covering for poi, in weaving, for canoe sails, and as food. As such, our tomorrow will be filled with a sense of wellbeing when we cherish our youngest ones just as we should cherish raupō.

Each member of the three rōpū will be contacted via email and given the option to be explicitly named in relation to the development of Raupī te Raupō and their input into the design of the study or to choose for their details to remain confidential. Responses to these emails will be saved and recorded.

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

content for Raupī te Raupō. The remaining members of the team provided input and feedback on the content and Raupī te Raupō was adapted accordingly.

In Term 4, 2023 this programme was delivered to ten whānau/families by eight newly trained coaches as part of a pilot. Eight of these whānau and six of these coaches participated in research evaluating their perceptions of the acceptability, effectiveness, and feasibility of the programme. The findings of this pilot research have been used to adapt the programme for the RCT. These adaptations have been made by the four members of the research team who created the original content.

Funding

This study is funded in full by a Rutherford Discovery Fellowship awarded to Dr. Hannah Waddington (<https://www.royalsociety.org.nz/what-we-do/funds-and-opportunities/rutherford-discovery-fellowships/rutherford-discovery-fellowship-recipient/hannah-waddington/>). This Fellowship also covers Dr. Waddington's time on the research and a contribution to Dr. Tupou's time. Carla Wallace-Watkin and Lee Patrick were paid for their time developing Raupī te Raupō's resources and materials.

Randomised Controlled Trial

Adaptations

Raupī te Raupō has been adapted in line with the suggestions from participants in the pilot study.

Registration

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

Aims

The primary aim of this randomised controlled trial is to examine whether Raupī te Raupō is effective in improving primary whānau/family member synchronous responses to the child. The secondary aim is to examine whether Raupī te Raupō is effective in improving a wide range of child and family/whānau outcomes directly or indirectly targeted by the programme. This includes changes on the Neuro-Affirming Survey of Outcomes (NASO), a measure developed specifically for this research which was designed to examine essential programme outcomes identified by the autistic and Māori advisory rōpū. Other child related outcomes include spoken and non-spoken communication, , and wellbeing and health-related quality of life. Other whānau/family outcomes include positive comments about the child, stress, sense of competence, quality of life, and satisfaction with support.

Hypotheses

We hypothesise that Raupī te Raupō will be effective in improving primary whānau/family member synchronous responses to the child. We also hypothesise that it will be effective in improving a range of outcomes for the child and family/whānau members, with the greatest improvements seen for outcomes that are proximal to the support including child spoken and non-spoken communication, and whānau/family member positive comments about the child (Sandbank et al., 2020).

Design

This is a single-site (Wellington), single-blind (rater), two-arm ('receiving Raupī te Raupō,' 'community support') randomised controlled trial with two timepoints (pre and post). The Urn minimisation method (Lachin et al., 1988) will be used to randomly allocate participants to the groups, while minimising group differences in chronological age. We will recruit 60 children and their whānau/families who will be randomised to either the group receiving Raupī te Raupō or the community support group (n = 30 per group).

Participants

Up to 60 whānau/families will be included in the RCT. For the group who receive Raupī te Raupō, there will be no limit on the number of whānau/family members per child who participate, but one of the child's legal guardians will need to be nominated as the "primary" participant and will complete all assessment measures. Other whānau/family members will be approached for consent to participate once the child and primary participating whānau/family member have been allocated to the group who will receive Raupī te Raupō. Whānau/family will be eligible to participate in the RCT if:

1. The child is aged between 1 year 0 months and 5 years 0 months at pre-assessment,
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),
3. The child does not have a sibling or twin who is already participating in the study
4. The child does not have a genetic condition which is associated with "autism-like" characteristics (e.g., Rett Syndrome, Fragile X, 22q deletion),
5. Each participating whānau/family member can commit to 20 sessions of up to one-and-a-half hours across 24 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,
6. The primary whānau/family member speaks sufficient English to understand the requirements of the study and to participate in the coaching sessions,
7. The primary whānau/family member intends to remain in Wellington for the duration of the study (13 months including pre-, post-, and potential follow-up assessments), and
8. The whānau/family do not intend to receive more than 10 hours of autism-specific parent/whānau coaching from a single source for the duration of the study.

Children who have a clinical diagnosis of autism will not be eligible for this study because of the focus on the effectiveness of providing access to the support programme as soon as the child is identified.

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.

Whānau/families will have the opportunity to include another “additional support person” or group of “additional support people.” This could include, for example, a second parent, early education teachers/kaiako, education support workers, close family friends, parents participating in a local playgroup, or other extended whānau/family members such as aunts, uncles, and grandparents. They cannot be other clinical professionals (e.g., speech language therapists, occupational therapists) who are already supporting the child. The additional support person/people will need to meet the following criteria:

1. Deemed to be important to include by the primary participating whānau/family member and other relevant whānau/family members,
2. Can commit to the five sessions for additional support people,
3. Speak sufficient English to understand the requirements of the study and to participate in the coaching sessions, and
4. Intend to remain in Wellington for the duration of research (7 months including pre- and post- assessments).

Recruitment

The recruitment period for this study will last for 2 years. The RCT 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 including 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).

At least 400 education and health professionals will be informed about this research when they attend training in identification of early signs of autism (MoSAIC training). In turn, these individual education and health-care providers may also inform relevant whānau/families about the research by directly sharing the study advertisement.

Materials and Settings

In person (practical) Raupī te Raupō sessions 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 Kaitoke). If the family live outside the study area or if it is otherwise not possible to deliver Raupī te Raupō 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. Discussion sessions will generally be delivered online, via a platform such as Zoom.

Whānau/families will have the opportunity to select an additional support person/people to include. These further support sessions will generally be delivered over Zoom

Some aspects of the pre-, post- and follow-up assessments will also take place in the Autism Clinic at 20 Sydney Street, Petone.

Raupī te Raupō 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.

Screening Measures

The SACS-R+PR will be used to determine eligibility to participate in the RCT while the ADOS-2 will be used to more accurately determine the likelihood that the child will go on to receive a formal diagnosis of autism for reporting and analysis purposes. The SACS assessment may have been completed prior to pre-assessment by a professional within the community or the community advisor within the Autism Clinic through which this RCT is hosted.

Social Attention and Communication Surveillance – Revised (SACS-R) and the SACS – Preschool (SACS – PR). The SACS-R+PR are well-validated instruments used for universal developmental surveillance for autism (Barbaro & Dissanayake, 2010; Barbaro et al., 2023). The SACS-R outlines key social attention and communication markers associated with a higher likelihood of an autism diagnosis at the ages of 11-30 months, while the SACS-PR does the same at 31-60 months. A recent study with a large sample found that the SACS-R+PR had high diagnostic accuracy and sensitivity (Barbaro et al., 2023)

The Autism Diagnostic Observation Schedule, Second Edition (ADOS-2). The toddler modules of the ADOS-2 will be used for children under 30 months who have not acquired phrase speech (Luyster et al., 2009). For children under 30 months, with phrase speech, Module 2 will be used. For children over 30 months, three different modules will be used depending on the verbal abilities of the child (Lord et al., 2012). The ADOS-2 modules are used during diagnostic assessments for autism and generally take between 30 and 60 minutes to administer. Children who do not meet the ADOS-2 cut off for autism spectrum on Modules 1-3 or who do not meet the mild-to-moderate range of concern on the Toddler Module will still be eligible to participate in the RCT. Whānau/families will be able to share these results with diagnostic services and researchers will emphasise that scores, in and of themselves, do not represent a formal diagnosis.

Outcome Measures

There will be two primary assessment time-points: pre-assessment and post-assessment, 6 months later. There is also the possibility of a follow-up assessment 6 months after the post-assessment. This is dependent on gaining additional funding. Table 4 presents the outcome measures used to compare groups in the study, the method of administration, the administration location, and whether the measure is primary, secondary, or tertiary. Where possible, the wording of all measures will be adapted to align with the Autism Terminology Guidance from the Autistic Community of Aotearoa New Zealand, for example ‘early

Study Protocol – Autism Support

Table 4.

Summary of the comparative outcome measures used in the randomised controlled trial.

Name of measure	Measure type	Outcome(s) targeted (Primary/Secondary)	People to complete measure	Administration location
Dyadic Communication Measure for Autism	Observational	Parent synchrony (Primary) Child frequency of interaction affirming and negating communication (Secondary).	-Primary whānau/family interacting with child -Other family/whānau -Additional support people	Clinic
Eliciting Language Samples for Analysis – Toddler	Observational	Child frequency of affirming and negating communication (Secondary).	-Research assistants interacting with child	Clinic
Autism-specific Five-Minute Speech Sample	Speech sample	Positive versus critical comments (Secondary).	-Primary family/whānau -Other family/whānau -Additional support people	Various (zoom or phone)
Neuro-Affirming Survey of Outcomes (NASO)	Questionnaire	Child subscale - Priority child outcomes identified by the advisory rōpū (Secondary). Whānau/family subscale – Priority whānau/family outcomes identified by the advisory rōpū (Tertiary).	-Primary family/whānau -Other family/whānau -Additional support people	Various (digital/paper-based)
KIDSCREEN-10	Questionnaire	Child wellbeing and health-related quality of life (Secondary)	-Primary family/whānau (in relation to child)	Various (digital/paper-based)
Autism Parent Stress Index	Questionnaire	Stress related to the core social disability, stress related to difficult-to-manage behaviour, and stress related to physical issues (Tertiary).	-Primary family/whānau	Various (digital/paper-based)
Parent Sense of Competence Scale	Questionnaire	Parenting satisfaction and efficacy (Tertiary).	-Primary family/whānau	Various (digital/paper-based)
World Health Organization Quality of Life Assessment-BREF	Questionnaire	Physical, psychological, social, and environmental quality of life (Tertiary).	-Primary family/whānau	Various (digital/paper-based)
Acceptability, appropriateness, and feasibility measure	Questionnaire	Stakeholder perceptions of the acceptability, appropriateness, and feasibility of the programme (Tertiary).	-Primary family/whānau -Other family/whānau -Additional support people	Various (digital/paper-based)

intervention’ will be replaced with ‘early support,’ and ‘autism spectrum disorder’ will be replaced with ‘autism’ (Monk, 2022).

Child Outcome Measures

Dyadic Communication Measure for Autism (DCMA). The DCMA will be conducted in the Autism Clinic with the child’s home as a second option if the child is not comfortable enough to participate in the clinic environment. The DCMA will be conducted by a trained research assistant. It involves an 8-minute video-recording the parent and child interacting in a natural way (Aldred et al., 2004; Hudry et al., 2010). The interaction is then coded from videotape for the child’s frequency of interaction-affirming communication (i.e., requesting, directing attention, and acknowledging) and interaction-negating communication. The DCMA is a proximal measure used in large scale evaluations of supports for autistic children and has been shown to be sensitive to the effects of support (Green et al., 2010; Green et al., 2017; Pickles et al., 2016).

Eliciting Language Samples for Analysis – Toddler (ELSA-T). This measure will be completed in person by a trained research assistant in the Autism Clinic. The ELSA-T is a standardised and play-based expressive language and communication measure (Barokova et al., 2020). It is suitable for children as young as 12 months and also sensitive for children with little to no spoken language. The average duration varies from 15 to 30 minutes. It involves eight activities – including pretend play, gross motor games, craft time, snack time, and storybook time – designed to elicit natural language samples. It will be coded in the same way as the DCMA measure above.

Neuro-Affirming Survey of Outcomes (NASO; child subscale). This measure was developed based on the essential neuro-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. 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.

KIDSCREEN-10. This is a parent reported measure of child wellbeing and health-related quality of life (Ravens-Sieberer et al., 2010). It is a shortened version of the KIDSCREEN-27 and -52 instruments. The KIDSCREEN-10 has 10 items each scored on a 5-point likert scale (1 = not at all to 5 = extremely). This measure has been found to be correlated with overall scores on the longer versions of the measures, to have high internal consistency, and reasonable test-retest reliability (Ravens-Sieberer et al., 2010).

Primary Participating Whānau/Family Member Outcome Measures

Dyadic Communication Measure for Autism (DCMA). The same home-based interaction for the child DCMA variables will also be coded for the frequency of parental synchronous compared to asynchronous communication acts (Aldred et al., 2004; Hudry et al., 2010). This is the primary outcome measure.

Autism-specific Five-Minute Speech Sample (AFMSS). The AFMSS is designed to measure the family expressed emotion towards autistic children (Benson et al., 2011). This measure will be conducted by a trained research assistant in the Autism Clinic, over phone, or online via a platform such as Zoom, without the child present or while the child is distracted/entertained. To obtain the sample, the whānau/family member/support person is asked to speak for five minutes about the child. The AFMSS consists of four global scales, which involve an overall impression of the five-minute sample. The initial statement and relationship scales are scored as positive, neutral, or negative, while the warmth and over involvement scales are scored as high, moderate, or low. The sample is also coded for the frequency of critical comments and positive comments. The AFMSS has adequate internal consistency, and predictive utility as it is associated with child “behaviour problems” in autistic preschoolers (Benson et al., 2011; Smith et al., 2021).

Autism Parent Stress Index (APSI). The APSI is a parent-report measure of the self-perceived stress of parents/caregivers of young autistic children (Silva & Schalock, 2012). There are three stress domains: stress related to the core social disability, stress related to difficult-to-manage behaviour, and stress related to physical issues. Items are rated on a 5-point Likert scale (1 = not stressful, 5 = so stressful that sometimes we feel we cannot cope). This measure will be completed on paper or digitally.

Parent Sense of Competence Scale (PSOC). The PSOC is a parent/caregiver-completed measure of parental sense of competence across two primary dimensions: satisfaction and efficacy (Johnston & Mash, 1989). The 16 items are rated on a 6-point Likert scale (1 = strongly agree, 6 = strongly disagree). This measure will be completed on paper or digitally.

World Health Organization Quality of Life Assessment-BREF (WHOQOL-BREF). The WHOQOL-BREF is a survey designed to assess an individual’s perceptions of their quality of life in the context of their own culture (WHOQOL group, 1998). It is a shorter version of the WHOQOL-100. For this study we will be using the New Zealand-specific version of this tool, which has been validated for use in this country (Krägeloh et al., 2013). This survey has a total of 26 generic questions pertaining to physical, psychological, social, and environmental quality of life, as well as five New Zealand specific questions. This measure will be completed on paper or digitally.

NASO (whānau/family subscale). The whānau/family outcomes NASO subscale subscale has 10 items related to connection and interaction with the child, communication with the child, neuro-affirming framing, quality of life, and formal and informal supports.

Acceptability, Appropriateness and Feasibility Measure. This includes adapted versions of the Acceptability of Intervention Measure (AIM), Intervention Appropriateness Measure (IAM), and Feasibility of Intervention Measure (FIM; Weiner et al., 2017) each of which includes two items measuring stakeholder perceptions of implementation success (Proctor et al., 2011). It also has one question about whether participants would recommend the programme to others. Each of the 7 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).

Other Measures

Demographic survey. The primary participating whānau/family member will complete a demographic survey on behalf of themselves and their child. The survey 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.

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 receiving Raupī te Raupō, (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.

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 who are in the group receiving Raupī te Raupō will also complete a weekly log of the number of hours that they use strategies with the child.

Attendance. Researchers will keep track of who attends each session across both groups and the time and date of any missed and rescheduled sessions.

Other Participating Whānau/Family Members and Additional Support People

Other participating whānau/family members and additional support people in the group receiving Raupī te Raupō will complete a demographic survey. The demographic survey for other participating whānau/family members will be identical to that described above, while the demographic survey for additional support people will contain questions about their: (a) age, (b) role/relationship with the child, (c) years of experience in the role – if relevant, (d) experience with autistic children, and (e) length of time knowing the child.

These participants will also complete an adapted version of the Neurodiversity Affirming Outcomes Survey measure before and after having received support and an adapted version of the Acceptability, Appropriateness, and Feasibility measure after having received support either digitally or on paper. If they want, they will also complete the AFMSS with research assistant in the Autism Clinic, over the phone, or online via a platform such as Zoom before and after having received support. Similarly, they may consent to completing the DCMA with the child, in an environment in which the child is comfortable, such as their own home or a kindergarten setting. Data will also be collected on their attendance at sessions, including missed and make-up sessions.

Procedure – Main Whānau and Family

Eligibility Assessment

Initial eligibility assessments will be conducted over the phone by the project manager (Phoebe Jordan). Most whānau/families will already have completed a SACS-R assessment, either with a health or educational professional or with the Autism Clinic administrator. In these circumstances, the project manager will request to see a copy of this SACS-R assessment to confirm that the child is showing signs of autism.

If whānau/families meet all other criteria but have not completed the SACS-R, the project manager will also arrange a time to come to conduct this assessment either over Zoom or in their home.

Pre-Assessment

Once a whānau/family are deemed eligible to take part, and have provided consent to do so, the project manager will enrol them in the study and arrange the pre-assessment, which will be completed within four weeks of the eligibility assessment. The pre-assessment will involve a Zoom/phone call to conduct the AFMSS, a clinic visit with trained research assistants to conduct the observational measures, and the completion of multiple questionnaires. Whānau/families who do not wish to complete the questionnaires online will be given paper copies during the clinic visit. All research assistants will naturally be blind to treatment allocation, as pre-assessment is conducted prior to randomisation.

The clinic visit will be up to 2 hours long and will involve the research assistant conducting the DCMA (Hudry et al., 2010), ELSA-T (Barokova et al., 2021) and the ADOS-2 (Lord et al., 2012) with the child and the whānau/family. It is estimated that families will take up to 2 hours to complete the five online or paper-based questionnaires (NASO, APSI, PSOC, WHO-QOL, KIDSCREEN-10). If needed, the project manager will send follow-up reminders in relation to these questionnaires. The AFMSS will be completed over the phone or Zoom at a time that is convenient to them. The project manager will suggest that whānau/families bring a ‘day-pack’ for their child to the appointment, which could include some snacks, a favourite toy, a comfort item, and any other relevant necessities for the child. The children will also be able to take breaks as and when needed.

Randomisation

Following the pre-assessment, participants will be randomised using the Urn method of random allocation (Lachin et al., 1998) to a group who will receive Raupī te Raupō or a group who will be assisted to access existing supports in the community. Randomisation will be determined by a computer algorithm which will allocate either “Group A” or “Group B.” This randomisation process will be managed by a statistical expert (Matt Hammond) who will be blind to whether Group A or B will receive Raupī te Raupō. The project manager will inform whānau/families of their allocation and the research assistants who conducted the pre-assessment will remain blind to the allocation.

Support Phase

The support phase will last 24 weeks (approximately 6 months). During this phase family and whānau will not be prevented from accessing other supports, aside from a limit of up to 10

hours total of autism-specific parent or family/whānau coaching. Indeed, those in both groups will be assisted to access other relevant supports within the community.

Raupī te Raupō

Programme Structure. Raupī te Raupō will involve 20 sessions for the main participating whānau/family members over 24 weeks. If they desire, whānau/families will also be able to pose additional questions over email between sessions. Week 1 of Raupī te Raupō is an initial session designed for the coach and the family to get to know each other. Prior to the initial session, coaches will send a short video and/or a photo of themselves to their family. Following Week 1, weekly sessions will alternate between discussion and practical sessions.

The fortnightly discussion sessions will involve the coach and whānau/family members discussing strategies and reflecting on the most recent practical session. These sessions will last up to 1.5 hours. The child will not be present for these sessions, which will usually take place online via a platform such as Zoom, without the child present. If the whānau/family are not able to, or comfortable using an online platform, they may take place in the following locations: (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. These sessions will involve: (a) checking in at the beginning of the session and supporting with plans for referrals to other supports and agencies; (b) the coach offering information about strategy use in a variety of formats (e.g., written, illustrations, videos), (c) reflecting on videos of the whānau/family member or coach interacting with the child, and (d) selecting manageable goals for the whānau/family to focus on each week. During one discussion session, whānau/families may choose to have a discussion with an autistic adult. In this session the autistic adult will share their life experiences and will answer any questions that the whānau/family members may have about their child.

In the fortnightly practical sessions, the coach and the whānau members will play and interact with the child in the home or another familiar, comfortable location for the child. These sessions will last up to 45 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 use of strategies with the child, (d) videoing interactions between the child and the coach and/or whānau/family members for later reflection, and (e) 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 24-week timeframe. It is anticipated that some whānau/families will not receive all 20 possible sessions across the 24-week period. Whānau/family will be deemed to have “received” the support if the primary participant takes part in at least 12 sessions (60% of the programme).

Ngā whanonga pono (underlying values). Five key Māori values (Ngā whanonga pono) underpin Raupī te Raupō. 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 whanonga pono with their child. The definitions of ngā whanonga pono in relation to Raupī te Raupō 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 whanonga pono, the guiding Māori values of Raupī te Raupō.

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.

Raupī te Raupō 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 practice these in the practical sessions. Raupī te Raupō 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. However, almost all whānau/families will discuss "understanding your child" and the "following your child's interests and preferences" topic should be covered before the topics on "supporting communication", "supporting learning and growth", and "navigating everyday life and routines." The content in many modules will only be relevant to some whānau/families, and each will move through Raupī te Raupō at their own pace. Table 2 covers Raupī te Raupō's content.

Appendix 1 details the relationship between Raupī te Raupō's outcomes, overarching approaches to supporting children and adults within Raupī te Raupō, and ngā whanonga pono which underpin each of these outcomes and approaches.

Table 2:
Raupī te Raupō content.

Module	Content covered in the module
<p>Understanding your child (compulsory)</p>	<ul style="list-style-type: none"> ● Autism and neurodivergence including: <ul style="list-style-type: none"> ○ 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: <ul style="list-style-type: none"> ○ 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
<p>Looking after yourself and finding support</p>	<ul style="list-style-type: none"> ● 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: <ul style="list-style-type: none"> ○ Detaching from unpleasant thoughts/feelings ○ Mindfulness, breathing, and grounding exercises ○ Practicing being the ‘observing self’ ○ Tuning in to inner wisdom

Study Protocol

<p>Following your child’s interests and preferences</p>	<ul style="list-style-type: none"> ● 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.
<p>Co-regulation</p>	<ul style="list-style-type: none"> ● Supporting the child through overwhelming feelings ● Laying the foundations for regulating emotions
<p>Creating a safe and comfortable environment</p>	<ul style="list-style-type: none"> ● 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
<p>Supporting communication (should cover “Respecting your child’s interests and preferences” first)</p>	<ul style="list-style-type: none"> ● 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
<p>Supporting learning and growth (should cover “Respecting your</p>	<ul style="list-style-type: none"> ● 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

Study Protocol

<p>child’s interests and preferences” first)</p>	<ul style="list-style-type: none"> ● Identifying when a child is in a good space for learning and when they are not ● Interspersing difficult tasks with easier tasks
<p>Navigating everyday life and routines (should cover “Respecting your child’s interests and preferences” first)</p>	<ul style="list-style-type: none"> ● 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
<p>Tips for the tricky stuff</p>	<p>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:</p> <ul style="list-style-type: none"> ● Understanding behaviours that cause harm ● Sleep issues ● Feeding issues ● Running away ● Toileting

Autistic and Māori Consultation

Lee Patrick and Phoebe Jordan are autistic and will serve as consultants for the duration of this programme. Coaches can ask Lee or Phoebe questions over email. If whānau/families would like to speak to Lee or Phoebe directly, each will also endeavour to join one of their online discussion sessions.

Several of the coaches who deliver Raupī te Raupō are Māori, have knowledge of te ao Māori and have 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 Raupī te Raupō 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.

Community Support Group

Whānau/families in the community support only group will receive 30-minute support phone or Zoom calls from the project manager or another consistent researcher once a month. The researcher will listen to parents' thoughts and concerns, give general advice in response to their questions, and assist with referrals if requested. The support calls will not include any content from Raupī te Raupō.

Post-Assessment

The post-assessment will be conducted within two weeks of the end of the support phase by research assistants blind to group allocation. Whānau/family members will be instructed not to share their group allocation with these research assistants. The procedure will be identical to the pre-assessment, except whānau/families will not repeat the demographic questionnaire and will instead complete the Acceptability, Appropriateness, and Feasibility measure (Bailey et al., 2011)

Whānau/families who receive the support will be invited to take part in a semi-structured interview about their perceptions of the benefits and challenges of the approach as well as areas for improvement. 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. These interviews generally take 30 minutes but could take up to 1 hour. The interview will take place in person during the home visit, on the phone or over Zoom, depending on whānau/family preferences.

Follow-up

There is the possibility that we may follow-up with some families 6 months after post-assessment. This is funding and capacity dependent. The follow-up timepoint will involve fewer assessments, and will be restricted to some combination of the AFMSS, the DCMA, and/or a semi-structured interview.

Procedure – Additional Support People

Eligibility

Whānau/families who have been allocated to the group receiving Raupī te Raupō will be invited to select one “additional support person” or a group of “additional support people” to also participate. See **Participants** section for information about the additional support people who could be included. The whānau/family will request consent from these additional support people to share their contact details with the research team. The project manager will get in touch to inform them of the research. If they are willing, the project manager will then meet with the support person/people in person, over the phone, or online to discuss the study information, eligibility criteria, and, if relevant, gain informed consent.

Pre-assessment

All eligible, consenting additional support people will complete a demographic survey, the NASO, and optionally, the AFMSS and DCMA prior to their first session.

Support phase

Additional support people will receive 5 sessions over the course of the 24 weeks. The main whānau/family members will also be able to attend these sessions if they wish. The sessions will resemble the discussion sessions received by the main participating whānau/family and will also generally be delivered over Zoom (see **Raupī te Raupō - Programme Structure**). The first session will also involve the coach and the additional support person/people getting to know each other. The content discussed will be identical but due to the limited number of sessions, fewer topics will be covered. Further, the videos for reflection will be of the coach interacting with child, rather than the additional support people.

If the participating whānau/family do not want to include any additional support people, or if consenting additional support people cannot be found, the family/whānau will instead receive an additional 4 discussion sessions over the course of their participation in the support phase of Raupī te Raupō.

Post-assessment

The post-assessment will be conducted within two weeks of the end of the support phase and will be identical to pre-assessment except that there will be no need to collect demographic information and instead the Acceptability, Appropriateness, and Feasibility measure will be completed (Bailey et al., 2011). They can also choose to complete the AFMSS and the DCMA. Additional support people will be invited to take part in a semi-structured interview about: (a) experiences of receiving Raupī te Raupō, (b) potential facilitators and challenges, and (c) programme improvements. If they want to participate, the interview will take place in person, on the phone or over Zoom, depending on their preferences.

Follow-up

Follow-up procedures for additional support people will be identical to those for main whānau/family members.

Interobserver Agreement

A random 5% of all observational measures (AFMSS, DCMA, and ELSA-T) will also be coded by a second blind research assistant. Interobserver agreement will then be calculated using intraclass correlation coefficients.

Training and Fidelity of Implementation

The researchers who developed Rauipi te Raupo will train all coaches in two half-day in-person or online theoretical workshops prior to implementing the programme. These workshops will include written training materials, PowerPoint presentations, role plays, reflection, and discussion. Most coaches will practice implementing the programme for at least a term with a community family, before implementing it as part of research.

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 with the main family/whānau and one discussion session with the additional support person/people (10-20% 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. The coaching team will have fortnightly 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.

Protection Against Bias

The procedures were developed to protect against bias in several ways. First, participants are randomised to groups, which controls for extraneous variables. Further, the research assistants who conduct the pre- and post-assessments will be blind to group allocation, as will the statistical expert (Matt Hammond) who will manage the random allocation. Second, some data will also be collected by research assistants, who are unfamiliar with the child, in a different setting from the provision of support (the Autism Clinic). This will reduce the effects of boundedness and correlated measurement error (Sandbank et al., 2020). Third, all coaches will be trained to deliver Rauipi te Raupo to a high standard and there will be regular checks on their fidelity of implementation.

Data Analysis

Statistical Analysis

All pre- and post-assessments will be scored by a research assistant who is blind to group allocation. Another researcher who is also blind to the treatment condition will run the statistical analyses. R will be used for all analyses. The primary outcome measure in this study is Parent Synchrony on the DCMA and the remaining child outcomes are secondary, while the whānau/family outcomes are tertiary. We will test changes in each of these outcomes with a 2 (group allocation: receiving Rauipi te Raupo; community support only) × 2 (time: pre and post) repeated measures ANOVA, comparing changes in the group who receives Rauipi te Raupo relative to the group who receives community support.

Power

The proposed study is sufficiently powered to detect changes in the primary outcome measure of parent synchrony on the DCMA accounting for the intensity and duration of the support (1 hour per week for 6 months). We estimated the prior effect size for the impact of Raupī te Raupō on parent synchrony based on the findings of Pickles et al., (2016) who employed a similar approach to support in terms of delivery method and intensity. Specifically, their study involved fortnightly delivery of parent mediated support for six months followed by monthly booster sessions for the following six months and at follow-up found an effect size of 0.61 for the entire treatment period (Cohen's d). We will recruit 60 children, which will provide a two-tailed repeated measures ANOVA with 83% power to detect a 0.61 effect size and will allow for up to 4 whānau/families to drop out retaining a level of power above 80%.

Study Timeline

The timeline for the RCT is presented in Table 5

Table 5.

Timeline for RCT (3-month increments)

	Aug-Sep 23	Oct-Dec 23	Jan-Mar 24	Apr-Jun 24	Aug-Sep 24	Oct-Dec 24	Jan-Mar 25	Apr-Jun 25	Aug-Sep 25	Oct-Dec 25	Jan-Mar 26	Apr-Jun 26	Aug-Sep 26	Oct-Dec 26	Jan-Mar 27	Apr-Jun 27	Aug-Sep 27
Obtain ethical approval	█																
Train coaches		█	█														
Recruit research assistants		█															
Train research assistants			█														
Recruit families/whānau				█	█	█	█	█	█								
Eligibility screening				█	█	█	█	█	█								
Pre-assessment				█	█	█	█	█	█	█	█						
Post-assessment						█	█	█	█	█	█	█	█				
Data analysis														█	█		
Reporting and publishing 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.

None of the children in the RCT will be diagnosed at the time of eligibility screening. Whānau/families may find positive screening results on the SACS-R (Barbaro et al., 2022) to be surprising, overwhelming, or upsetting. The results will be communicated clearly to families/whānau, and they will be informed that it is not an official diagnosis, but merely confirmation that their child is showing signs of autism and/or social communication differences/delays. They will be informed that they can contact their General Practitioner for a referral to the local branch of Te Whatu Ora for further diagnostic assessment. The team will assist the whānau/family in making this referral if needed. They will also ask the whānau/family for permission to share the results of the SACS-R or subsequent ADOS assessment with the child development team. Whānau/families will also be assisted in accessing other support services if they desire.

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

The RCT includes a community support control group. Potentially, whānau/families in the RCT who are allocated to the community support group may feel as though they are disadvantaged in comparison to whānau/families who are allocated to receive Raupī te Raupō. Several elements of the study methodology have been designed to mitigate these

concerns. Whānau/families in the community support group will receive monthly 30-minute phone or zoom support calls during which they may discuss their thoughts, concerns, and any questions they may have with the project manager or another member of the research team. A booklet containing information regarding presently available local community services will be offered to whānau/families in the community support group at the start of the research study. Members of the research team will assist whānau/families by making referrals to such services as and when requested. Those in the community support group will also be eligible to receive Raupī te Raupō delivered in the RCT through the Victoria University of Wellington Autism Clinic upon conclusion of their study participation. The research team have chosen not to collect follow-up data from whānau/families in the community support group to ensure they become eligible to receive Raupī te Raupō within the usual wait time (6 months) for Victoria University of Wellington Autism Clinic services.

Several considerations have been made to reduce potential barriers whānau/families may encounter during participation. Whānau/families will be offered \$30 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 that Raupī te Raupō 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 study. Programme sessions will likely run for a maximum of one hour and will occur once per week. Flexibility has been built into Raupī te Raupō, 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. Raupī te Raupō has been developed in conjunction with a Māori rōpū and is underpinned by five key Māori values. This ensures Raupī te Raupō 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). There will be three separate PIS/CFs, depending on the participants' role as the nature of their involvement will differ. Specifically, there will be a separate information sheet for: (a) the nominated primary whānau/family member participating in the RCT, (b) other whānau/family members participating in all 20 sessions in the RCT, (c) additional support people participating in the RCT.

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 Raupī te Raupō 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., Sharepoint).

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 Raupī te Raupō /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., Sharepoint) 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., Sharepoint) 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 Raupī te Raupō, 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 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.

3. We have now specified that we will use module 1 instead of the toddler module of the ADOS for children <30 months with phrase speech.
4. We have clarified with the developers that the DCMA is indeed appropriate for children under 2,
5. We have now specified that we will focus on parent synchronous responses to the child, rather than “parent synchrony and responsiveness”
6. We have reduced the number of sessions for whānau/families from 24 to 20 in the RCT to account for the high likelihood of missed sessions.
7. We have specified that child will be included if they show signs of autism and/or social communication differences on the SACS-R

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Appendix 1

Mapping the relationship between programme outcomes, approaches to supporting the child and adults, and ngā tanga whanonga pono underpinning Raupī te Raupō

Outcome	Approaches to supporting the child and adults	Ngā whanonga pono
Environmental changes		
Improved accessibility of physical and social environments	Child focussed <u>Supporting regulation</u> (Arrange environment in a way that helps the child to feel comfortable and safe; Reduce distractions)	Manaakitanga Kaitiakitanga
Improved access to sensory tools	Child focussed <u>Supporting regulation</u> (Provide easy access to sensory tools and experiment with which of these tools work for the child)	Manaakitanga Kaitiakitanga Tuakiritanga
Improved access to preferred and meaningful activities, including preferred play	Adult focussed <u>Supporting a neurodiversity affirming approach</u> (Help whānau to understand the child) Child focussed <u>Understanding the child</u> (Understand and respect the child’s unique ways of communicating, interacting, and playing, showing interest and engagement, expressing emotions) <u>Respecting your child’s interests and preferences</u> (all)	Whanaungatanga Kotahitanga Manaakitanga Tuakiritanga
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 <u>Building relationships and connections</u> (all) <u>Supporting whānau wellbeing/hauora</u> (all) <u>Building whānau confidence</u> (all) <u>Supporting a neurodiversity affirming approach</u> (all)	Whanaungatanga Manaakitanga Kotahitanga Kaitiakitanga

<p>Improved fulfilment, enjoyment, and confidence in their connection and interactions with the child</p>	<p>Adult focussed <u>Supporting whānau wellbeing/hauora</u> (all) <u>Building whānau confidence</u> (all) <u>Supporting a neurodiversity affirming approach</u> (all)</p> <p>Child focussed <u>Respecting your child’s interests and preferences</u> (all) <u>Supporting success</u> (all)</p>	<p>Whanaungatanga Manaakitanga Kotahitanga</p>
<p>Improved knowledge of autism as a form of neurodiversity and understanding of their own autistic child</p>	<p>Adult focussed <u>Supporting a neurodiversity affirming approach</u> (all)</p> <p>Child focussed <u>Understanding the child</u> (Understand autism and neurodivergence)</p>	<p>Whanaungatanga Manaakitanga Kaitiakitanga Tuakiritanga</p>
<p>Improved understanding of co-occurring conditions, such as ADHD, dyspraxia, PDA</p>	<p>Adult focussed <u>Supporting a neurodiversity affirming approach</u> (help whānau to understand their child)</p> <p>Child focussed <u>Understanding the child</u> (Understand autism and neurodivergence)</p>	<p>Whanaungatanga Manaakitanga Kaitiakitanga Tuakiritanga</p>
<p>Improved understanding of executive functioning difficulties, and how to modify communication with child based on this</p>	<p>Adult focussed <u>Supporting a neurodiversity affirming approach</u> (help whānau to understand their child)</p> <p>Child focussed <u>Supporting Communication</u> (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)</p>	<p>Whanaungatanga Manaakitanga Kaitiakitanga Tuakiritanga</p>
<p>Improved ability to understand and respond to child needs and communication</p>	<p>Adult focussed <u>Building whānau confidence</u> (all) <u>Supporting a neurodiversity affirming approach</u> (all)</p> <p>Child focussed</p>	<p>Whanaungatanga Manaakitanga Kaitiakitanga Tuakiritanga</p>

	<p><u>Understanding the child</u> (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)</p> <p><u>Supporting Communication</u> (all)</p>	
Improved ability to communicate in a way that makes sense to the child and to model different forms and types of communication	<p>Adult focussed <u>Supporting a neurodiversity affirming approach</u> (help whānau and others to understand the child)</p> <p>Child focussed <u>Supporting Communication</u> (all)</p>	Whanaungatanga Manaakitanga Kaitiakitanga Tuakiritanga
Strengthened formal and informal connections with other adults	<p>Adult focussed <u>Building relationships and connections</u> (Offer to support the whānau with formal and informal connections)</p>	Whanaungatanga Kotahitanga Manaakitanga
Outcomes for the child		
Improved ability to understand themselves, including their own skills, wants and needs	<p>Adult focussed <u>Supporting a neurodiversity affirming approach</u> (help whānau and others to understand the child)</p> <p>Child focussed <u>Understanding the child</u> (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) <u>Supporting communication</u> (Model and create opportunities for different types of communication)</p>	Whanaungatanga Tuakiratanga Manaakitanga
Improved ability to advocate for themselves to increase access to their rights, needs and preferences (understanding bodily autonomy for your own and others’ bodies)	<p>Adult focussed <u>Supporting a neurodiversity affirming approach</u> (help whānau and others to understand the child)</p> <p>Child focussed <u>Understanding the child</u> (Understand and respect the child’s unique ways of communicating, interacting, and playing, showing interest and engagement, expressing</p>	Tuakiratanga Manaakitanga Kaitiakitanga

	emotions; believe and validate the child’s communication) <u>Supporting communication</u> (all)	
Improved fulfilment and enjoyment in their connection and interactions with others	Adult focussed <u>Supporting whānau wellbeing/hauora</u> (all) <u>Building whānau confidence</u> (all) <u>Supporting a neurodiversity affirming approach</u> (all) Child focussed <u>Understanding the child</u> (all) <u>Respecting your child’s interests and preferences</u> (all) <u>Supporting success</u> (all) <u>Navigating everyday routines</u> (all)	Whanangatanga Manaakitanga Tuakiritanga
Feeling more confident and better understood communicating using preferred methods (including through te reo Māori if relevant to the whānau).	Adult focussed <u>Supporting a neurodiversity affirming approach</u> (help whānau and others to understand the child) Child focussed <u>Understanding the child</u> (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) <u>Supporting communication</u> (all)	Tuakiratanga Manaakitanga Kaitiakitanga
Improved ability to understand, express, and regulate emotions (but not encouraging masking)	Adult focussed <u>Supporting a neurodiversity affirming approach</u> (help whānau and others to understand the child) Child focussed <u>Supporting regulation</u> (all) <u>Supporting communication</u> (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).	Tuakiritanga Manaakitanga Kaitiakitanga
Reduce and replace behaviours which harm themselves or others	Adult focussed	Manaakitanga Kaitiakitanga

	<p><u>Supporting a neurodiversity affirming approach</u> (help whānau and others to understand the child)</p> <p>Child focussed <u>Understanding behaviours that cause harm</u> (all) <u>Supporting communication</u> (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).</p>	
Reduce challenges around co-occurring issues such as eating, sleeping etc.	<p>Adult focussed <u>Supporting whānau wellbeing/hauora</u> (all) <u>Supporting a neurodiversity affirming approach</u> (help whānau and others to understand the child)</p> <p>Child focussed <u>Tips for the tricky stuff</u> (all)</p>	Manaakitanga Kaitiakitanga
Improved physical wellbeing and safety	<p>Adult focussed <u>Supporting a neurodiversity affirming approach</u> (help whānau and others to understand the child)</p> <p>Child focussed <u>Understanding behaviours that cause harm</u> (all) <u>Supporting regulation</u> (all) <u>Supporting communication</u> (use consistent communication, simplify communication, give the child time and space to process communication, use visuals to support understanding).</p>	Manaakitanga Kaitiakitanga
Improved mental wellbeing (<i>e.g., happiness, self-determination, confidence</i>)	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.	Manaakitanga Kaitiakitanga Tuakiritanga
Developing a sense of personal worth	<p>Adult focussed <u>Supporting a neurodiversity affirming approach</u> (help whānau and others to understand the child)</p> <p>Child focussed</p>	Manaakitanga Tuakiritanga

	<p><u>Respecting your child’s interests and preferences</u> (all)</p> <p><u>Supporting success</u> (all)</p>	
<p>Developing a sense of cultural identity/belonging</p>	<p>Adult focussed</p> <p><u>Building relationships and connections</u> (Get to know the whānau as people, take the time to understand the whānau’s context; consider the whānau’s culture)</p> <p><u>Supporting wellbeing/hauora</u> (For whānau Māori, considering incorporating tikanga, encouraging whānau support and involvement, using te reo Māori, etc.)</p> <p>Child focussed</p> <p><u>Supporting communication</u> (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)</p>	<p>Whanaungatanga Tuakiritanga</p>
<p>Improved ability to care for oneself and to do daily tasks (<i>e.g., dressing, feeding, toileting</i>)</p>	<p>Adult focussed</p> <p><u>Supporting a neurodiversity affirming approach</u> (help whānau and others to understand the child)</p> <p>Child focussed</p> <p><u>Navigating everyday routines</u> (all)</p> <p><u>Support success</u> (all)</p>	<p>Manaakitanga Kaitiakitanga</p>

Appendix 2

Coach fidelity form – Discussion Sessions

This fidelity form is for the discussion sessions, without the child 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, to check whether it 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 Whanonga Pono, 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 whanonga pono, as outlined in the fidelity checklist/session structure. The list of whanonga pono, including definitions for each, are below.

Ngā whanonga pono	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 whanonga pono	Est. length (mins.)	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	10-15	
2. The coach checks in about the whānau/family's existing formal supports (including access to funding) and, where relevant and desired, assists in making plans for referral or contact with other appropriate services.	Whanaungatanga	5-10	

3. 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		
4. The coach gains 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	15-25	
5. 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	20-30	
6. The coach and whānau/family members reflect on interactions identified from the previous practical session and in the video reflection. This includes reflections specific to the programme content, observations of what went well, child successes, what could be done differently, and interpretations of child communication and emotional expression.	Manaakitanga Kotahitanga		
7. 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). The coach also helps the family to work out the context(s) in which they will target the goal. <i>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.</i>	Whanaungatanga Manaakitanga Kotahitanga	5-10	
8. 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	5-10	
9. The coach manages the session so that, if possible, all necessary components (i.e., 1-8) 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	Whanaungatanga Kotahitanga		

<p>session before discussing new content. If all necessary components do not take place within the allocated session time, there is clear justification for this.</p>			
OVERARCHING COACHING TECHNIQUES			
<p>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:</p> <ul style="list-style-type: none"> • 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. 	<p>Whanaungatanga Manaakitanga</p>		
<p>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:</p> <ul style="list-style-type: none"> • 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). • supporting the whānau to respect and understand the child’s unique ways of being 	<p>Tuakiritanga Manaakitanga</p>		
<p>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:</p> <ul style="list-style-type: none"> • 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 Māori or other cultural practices, • avoiding things that might cause offense. 	<p>Whanaungatanga Tuakiritanga</p>		

<p>Confidence-building. The coach empowers whānau/family members as experts in their own child. This could include, but is not limited to:</p> <ul style="list-style-type: none"> • 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		
Total			/26

Coach fidelity form – practical

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, to check whether it 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 Whanonga Pono, 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 whanonga pono, as outlined in the fidelity checklist/session structure. The list of whanonga pono, including definitions for each, are below.

Ngā whanonga pono	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	The coach adapts the session according to the preferences of the

	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.	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 whanonga pono	Est. length (mins.)	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	5-10	
2. The coach settles into play and interaction with the child. This includes but is not limited to: <ul style="list-style-type: none"> • 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	15-25	

See the “self-reflection strategies with child” document for a full list of strategies.			
3. 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. If necessary, the coach asks the whānau to record five minutes of the interaction.	Manaakitanga Tuakiritanga		
4. The coach provides time for the family/whānau to use relevant strategies with their child. If needed, the coach supports the family/whānau to choose a relevant toy/activity and to settle into the play. If the whānau/family is comfortable, the coach records 5 minutes of the interaction.	Manaakitanga Tuakiritanga	15-25	
5. The coach and family/whānau support each other with play, interaction, and strategy use. This could include, for example, discussing what is going well in the interaction, child successes, areas for improvement, and identifying communication that may have been missed. This may take place in the moment and/or briefly following the interaction depending on the needs of the child and family/whānau preferences. The coach may directly help the whānau/family member during the play/interaction if requested or agreed to. Note: It is not expected that the coach or the parent provide in the moment support while they are also filming.	Manaakitanga Kotahitanga		
6. The coach ends the session by addressing any unanswered questions or areas for clarification, reminding about the session time for the following week, asking whether the family would like to continue the same topic or focus on a new topics, and warmly farewelling all whānau/family members (including farewelling the child in their preferred way).	Whanaungatanga Manaakitanga Tuakiritanga	5-10	
7. The coach manages the session so that, if possible, all necessary components (i.e., 1-6) 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 and receive feedback).	Whanaungatanga Kotahitanga		
OVERARCHING COACHING STRATEGIES			
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: <ul style="list-style-type: none"> • listening attentively, • showing empathy, 	Whanaungatanga Manaakitanga		

<ul style="list-style-type: none"> 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. 			
<p>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:</p> <ul style="list-style-type: none"> 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 	<p>Tuakiritanga Manaakitanga</p>		
<p>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:</p> <ul style="list-style-type: none"> 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. 	<p>Whanaungatanga Tuakiritanga</p>		
<p>Confidence-building. The coach empowers whānau/family members as experts in their own child. This could include, but is not limited to:</p> <ul style="list-style-type: none"> 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, 	<p>Kotahitanga</p>		
<p>Ngā whanonga pono (scored in discussion with the coach)– The coach provides evidence of integration of ngā whanonga pono (see table above). The coach has chosen one whānonga pono to</p>	<p>Whanaungatanga Manaakitanga Tuakiritanga</p>		

Aotearoa Autism Support – Study Protocol

specifically focus on throughout the session and is able to explain how they embedded this tanga, with specific examples.	Kaitiakitanga Kotahitanga		
Tota			/22

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.

Ongoing safety concerns

If a researcher continues to have concerns after the first session, regardless of whether a buddy was present, they will consult with the Primary Investigator (Hannah Waddington) or Project Manager (Phoebe Jordan) about options. These options include: (a) continuing to have a buddy in each session, (b) conducting the research in a community, rather than home locations, or (c) withdrawing the family from the study due to safety concerns which cannot be mitigated. It is possible that a police check may be conducted with the family at this stage.

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 sessions 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.	<ul style="list-style-type: none"> ● 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). 	GP Emergency services
The child is engaging in behaviours which physically harm themselves or others.	<ul style="list-style-type: none"> ● The therapist will take immediate action to ensure that everyone is kept safe. This could include: <ul style="list-style-type: none"> ○ 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	<ul style="list-style-type: none"> ● The therapist will advise the parent to see a GP and will follow-up to check that the GP was contacted. 	GP

<p>indicate that the parent is experiencing severe distress or mental health issues (e.g., stress, anxiety, depression).</p>	<ul style="list-style-type: none"> • 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. 	
<p>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)</p>	<ul style="list-style-type: none"> • 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. 	<p>GP Te Haika: 0800 745 477 Emergency services</p>
<p>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)</p>	<ul style="list-style-type: none"> • 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. 	<p>Several E.g., Women’s Refuge</p>
<p>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)</p>	<p>If the concerns are not related to the contact family member*</p> <ul style="list-style-type: none"> • The therapist will support the parent/family member to make contact with support agency (such as Oranga Tamariki). <p>If concerns relate to the contact family member*</p> <ul style="list-style-type: none"> • 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). 	<p>Several, E.g., Oranga Tamariki</p>

	<ul style="list-style-type: none">• If the situation may result in serious harm to the child, parent/family member or others, the therapist will contact emergency services.	
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*The family member who brings the child to therapist sessions and/or who is participating in the coaching.