

Early Identification and Support for Autistic Children and their Caregivers in Aotearoa New Zealand:

Evaluation of an Early Detection Training and Support Programme Delivered by Autism New Zealand

Authors

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Summary

Autism is a form of neurodivergence characterised by differences in sensory processing, social communication and behaviour. Estimates suggest that 1 in 40 children in Aotearoa New Zealand are Autistic.

While autism can be identified as early as 12 months old, many children and their families face lengthy delays in accessing diagnostic services, as well as post-diagnostic support. This is largely due to increased demand for services and support, systemic and structural barriers to access and a lack of trained professionals.

This report presents the findings from an evaluation of two inter-related programmes delivered by Autism New Zealand: (1) Monitoring of Social Attention Interaction and Communication (MoSAIC) early identification training and (2) Let's Play early support programme.

Study 1: Monitoring of Social Attention, Interaction and Communication Training

Background

The number of education and health professionals trained in early autism identification is greatly exceeded by the number of families seeking diagnostic and support services. As a result, many parents face barriers to accessing a diagnosis and long waitlists for support.

Failure to identify autism early misses a critical window for providing necessary support that can enhance the health and wellbeing outcomes of Autistic children and their caregivers.

Early Childhood Educators have frequent contact with the children in their centre and, with their expert knowledge of typical child development, can help identify children who miss expected milestones.

The Social Attention and Communication Surveillance (SACS) tool is a validated detection tool that is widely used to identify children showing early signs of autism. It can be administered by health and education professionals who have completed the Monitoring of Social Attention, Interaction and Communication (MoSAIC) training, developed by Associate Professor Josephine Barbaro at La Trobe University.

Aims

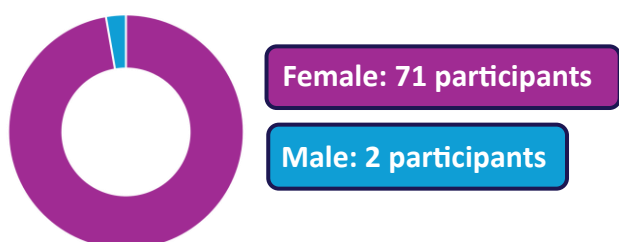
The aims of Study 1 were to:

1. Evaluate the feasibility and acceptability of training Early Childhood Educators to use the SACS tool to aid universal surveillance in Aotearoa New Zealand.
2. Assess Early Childhood Educators' perceptions of whether this tool is culturally-responsive for the Aotearoa New Zealand context.

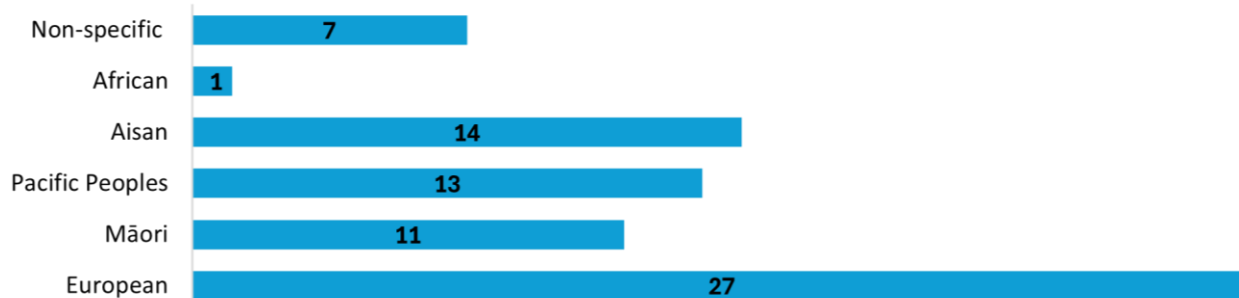
Participants

Participants included 73 Early Childhood Educators working in Auckland.

Gender



Ethnicity

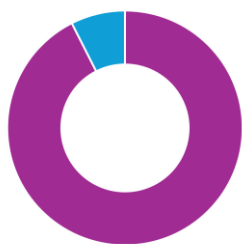


Participation in the study



Of the 67 participants who completed the training:

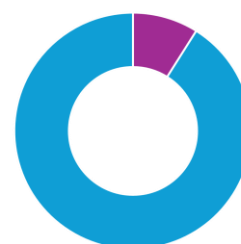
62 completed the post-workshop survey



42 completed the follow-up survey



6 took part in an interview.



Setting

MoSAIC training workshops were delivered in-person at the Autism New Zealand West Auckland community clinic.

Measures

Participants were asked to complete electronic surveys pre- and post-training, and at 12-week follow-up. During follow-up, participants were also invited to take part in a phone interview.

Results

Pre-workshop Survey

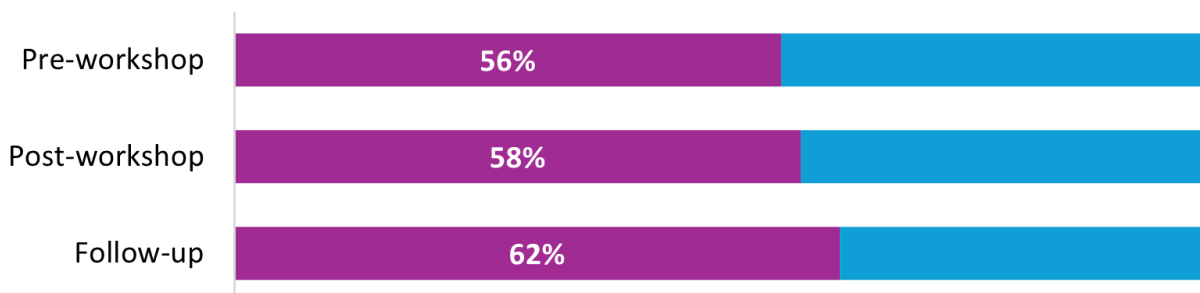
Nearly one third of the participants reported having received autism specific training prior to MoSAIC.

Development and Autism Knowledge

Developmental Milestones

Six multi-choice items asked participants about their knowledge of the social attention and communication development of neurotypical children (e.g., “At what age could you expect a child to respond when someone calls his/her name?”).

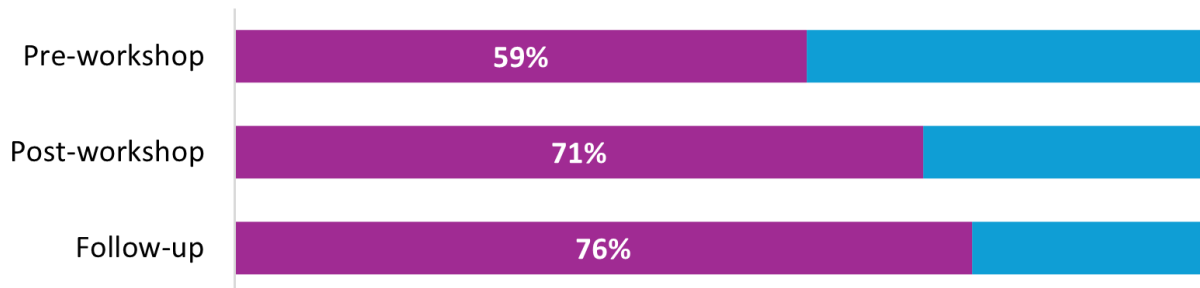
Average percentage of correct responses from participants:



Accuracy of autism beliefs

Participants were also presented with six statements about autism. Half of these statements were false (e.g., “Autism can be cured”), while the other half were true statements.

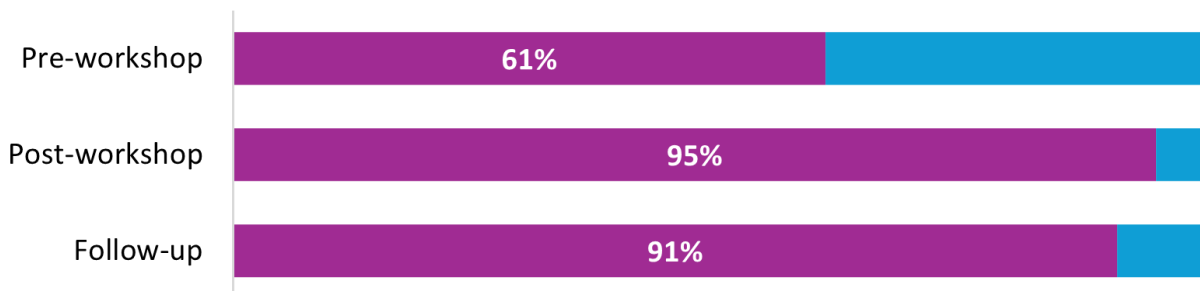
Average percentage of correct responses from participants:



Knowledge of early autism signs

On another item, participants were presented with a list of seven child behaviours and were asked to select the three that they thought were indicative of a high likelihood of autism.

Average percentage of correct responses from participants:



Confidence in Identification of Autism

In all three surveys, participants were asked to rate the same eight items to measure their confidence in identifying and supporting Autistic children. These items were answered on a 6-point Likert scale from 1 ('Strongly Disagree') to 6 ('Strongly Agree').

The eight items rated confidence in:

- Identifying the early signs in 12-, 18-, 24-, 30-, and 36-month-old infants
- Discussing concerns about suspected autism with parents or caregivers
- Knowing who to refer parents or caregivers to
- Knowing what services are available in NZ for families with autistic children or suspected autism

Average confidence ratings from participants (rated out of 6):



Cultural Appropriateness

Participants' average ratings of cultural appropriateness (rated out of 6):



Phone Interviews

There was a collective view that the SACS tool could be implemented by teachers with families of all ethnicities. It also seems evident that the teachers need support to know how to initiate a difficult conversation with parents about a topic that could be devastating for them and potentially life changing.

Conclusions

Study participants rated MoSAIC training highly, endorsed its delivery format and value, saw the potential for it to benefit to their work, and viewed it as highly culturally appropriate.

Findings suggest that the MOSAIC training and use of the SACS tool may provide a viable mechanism for improving early identification of autism in Aotearoa New Zealand.

Study 2: Let's Play Programme Evaluation

Background

Research suggests caregivers of Autistic children experience higher rates of parenting stress and psychological distress than caregivers of non-Autistic children. This may be compounded by insufficient access to appropriate services and supports for Autistic children and their caregivers.

A large body of research highlights the benefits of early autism identification and support for enhancing the health and well-being outcomes of children and their caregivers. In spite of compelling evidence, many Aotearoa New Zealand families face barriers to accessing diagnostic and support services.

'Let's Play', a programme developed by Autism New Zealand, is a caregiver-mediated, Developmental-Relational Intervention that is delivered using a combination of group workshops and 1:1 coaching during home visits. It is developed to bridge the support gap while families await diagnosis and access to support.

Autism New Zealand's Let's Play programme focuses on enhancing: (1) caregivers' play skills, (2) caregivers' communication with their child, and (3) family wellbeing.

Aims

The aims of study 2 were to evaluate:

1. The effects of the Let's Play programme on engagement between caregiver's and young Autistic children.
2. The effects of programme participation on caregivers' parental stress, psychological distress, and sense of competence.
3. The effects of programme participation on children's quality of life, behaviour, and communication.
4. The social acceptability, cultural responsiveness, and feasibility of the Let's Play programme.

Participants

A total of 91 families with an Autistic child (aged 1.8-5.3 years) consented to take part in the study.

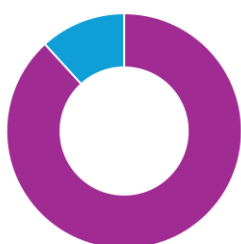
Gender



Child

Female: 15 participants

Male: 69 participants



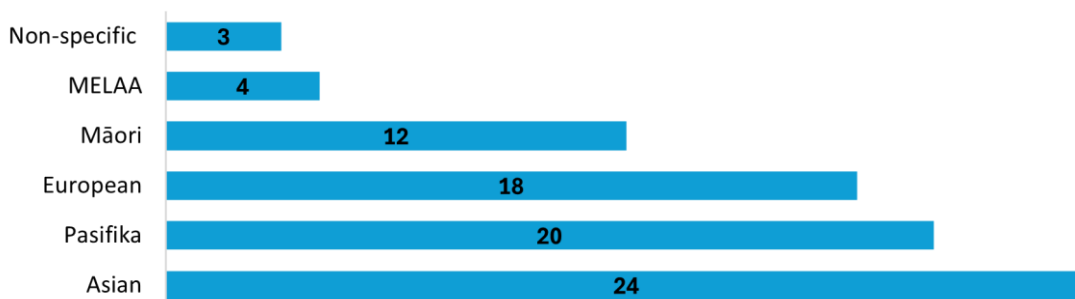
Caregiver

Female: 75 participants

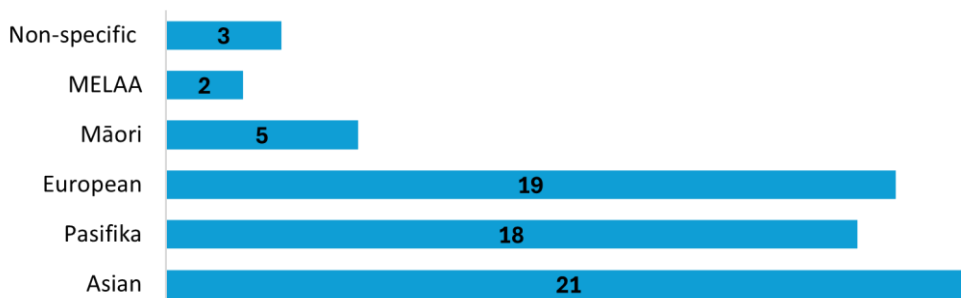
Male: 10 participants

Ethnicity

Child



Caregiver



Randomisation

Participants were randomly assigned to the Let's Play programme or the Waitlist Control group.

44 families were included in the Active Support (AS) condition and 44 were included in the Waitlist Control (WLC) condition.

Setting

The Let's Play programme includes group workshops and in-home coaching. Workshops were delivered in-person at the Autism New Zealand community clinic in Auckland, Aotearoa New Zealand. In-home coaching took place in the family home.

Measures

Participants in the AS group were provided with immediate access to the next available programme. Participants who were randomly assigned to the WLC group accessed the programme after a 9-week wait.

Participants completed baseline (pre-trial assessment), post-programme, and follow-up measures.

The WLC group also completed measures immediately before commencing the programme to assess change during the 9-week wait period.

Results

Attendance Rates

Group workshops

The Let's Play programme includes three group workshops. Most participants attended all three workshops.



Active support

34 families attended all three workshops



Waitlist control

30 families attended all three workshops

Home visits

The Let's Play programme includes five home visits.



Active support

31 families completed at least 4 home visits



Waitlist control

28 families completed at least four home visits

Support Effects

The most salient research question is whether participating in the Let's Play programme has positive effects on the outcome measures over and above life-as-usual.

AS participants scores after they had been in the Let's Play programme were compared to the WLC participants' post-wait baseline scores (i.e. 9 weeks after being put on the waitlist control, but prior to starting the programme).

This compared scores after 9 weeks of accessing the programme to scores after 9 weeks of accessing life-as-usual.

Active support:

Week 0: Baseline

Week 9: Post-support

Waitlist control:

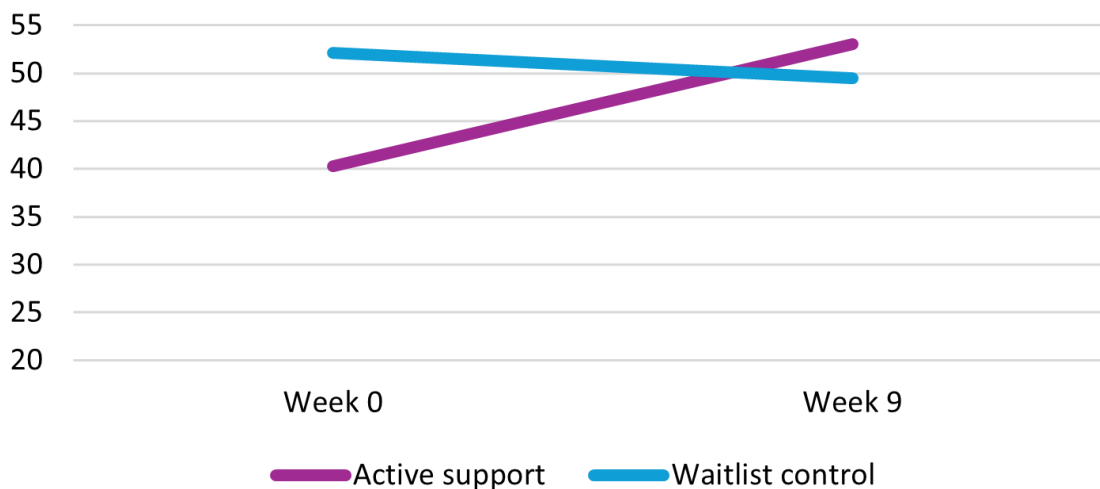
Week 0: Pre-wait baseline

Week 9: Post-wait baseline

Caregiver-child engagement

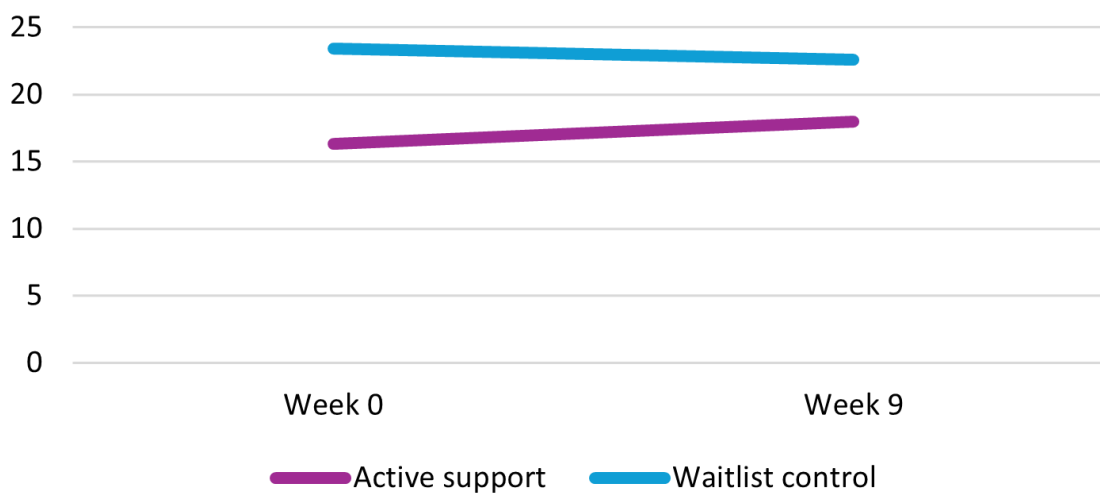
Children's level of engagement was coded based on 10-minute video recordings of caregiver-child play. A higher percentage indicates greater levels of caregiver-child engagement.

Average percentages for engagement at week 0 and week 9



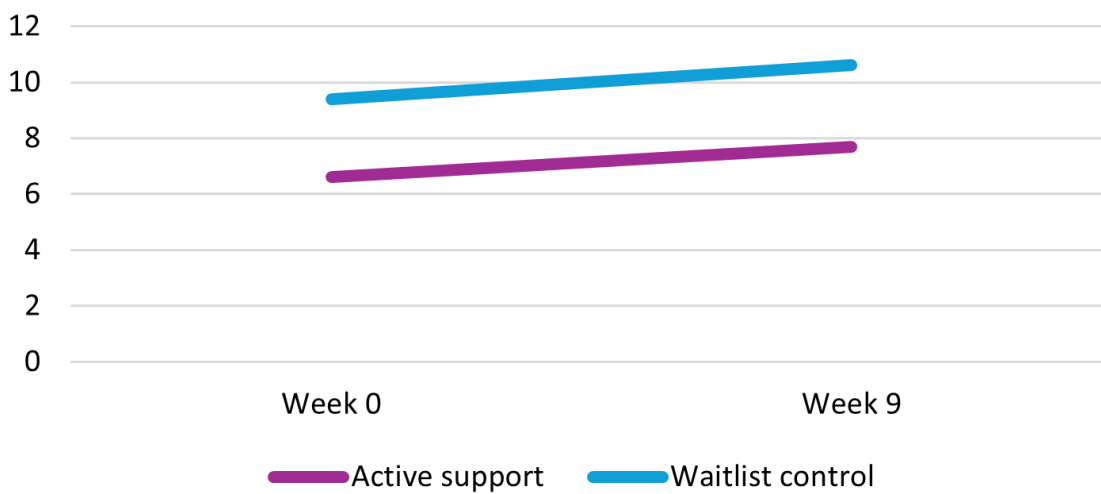
Number of utterances

Average number of utterances at week 0 and week 9



Number of different words

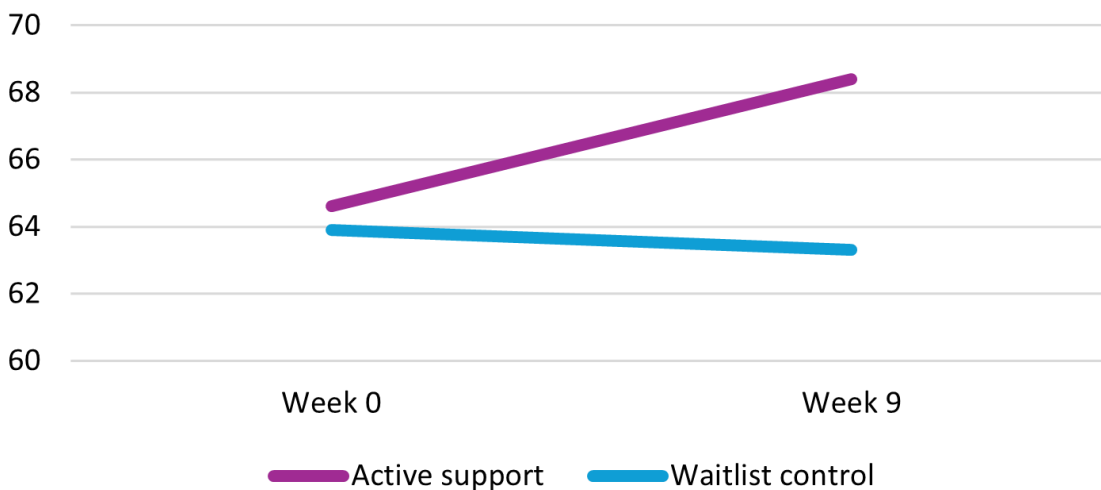
Average number of different at week 0 and week 9



Health-Related Quality of Life

The Pediatric Quality of Life Inventory Generic Core Scales is a 18-23 item measure of children's health-related quality of life. **Higher scores reflect greater health-related quality of life.** Total scores were used for this analysis.

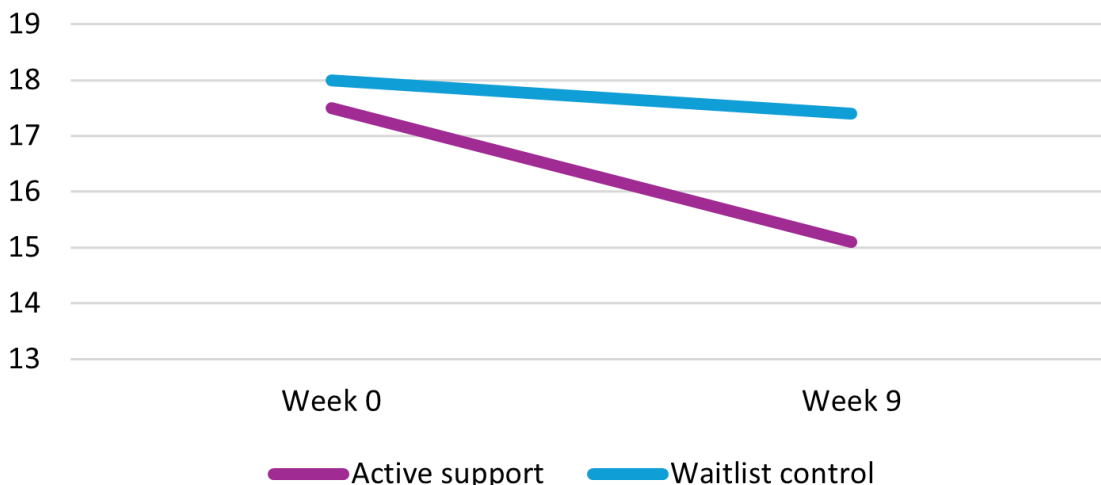
Average total Health-Related Quality of Life scores at week 0 and week 9



Behaviour Differences

The Strengths and Difficulties Questionnaire (SDQ) provided a measure of child behaviour. The 25-item, caregiver-report measure includes five subscales: Emotional Problems, Conduct Problems, Hyperactivity, Peer Problems, and Prosocial Behaviour. Total Difficulties scores on the Emotional Problems, Conduct Problems, Hyperactivity, and Peer Problems subscales were used in this analysis. **Higher scores suggest more emotional, conduct, hyperactivity, and peer relationship differences.**

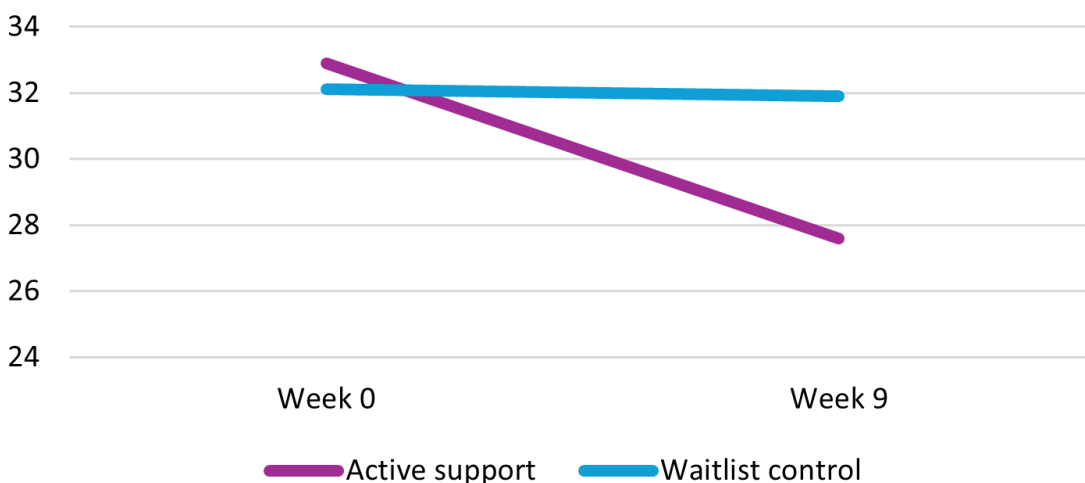
Average total SDQ scores at week 0 and week 9



Parental distress

The PSI-4-SF is a self-report measure consisting of three subscales: Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. Subscale scores are combined to give a Total Stress score, **with higher scores indicating greater parenting stress.** Only the Parental Distress subscale was analysed in this trial.

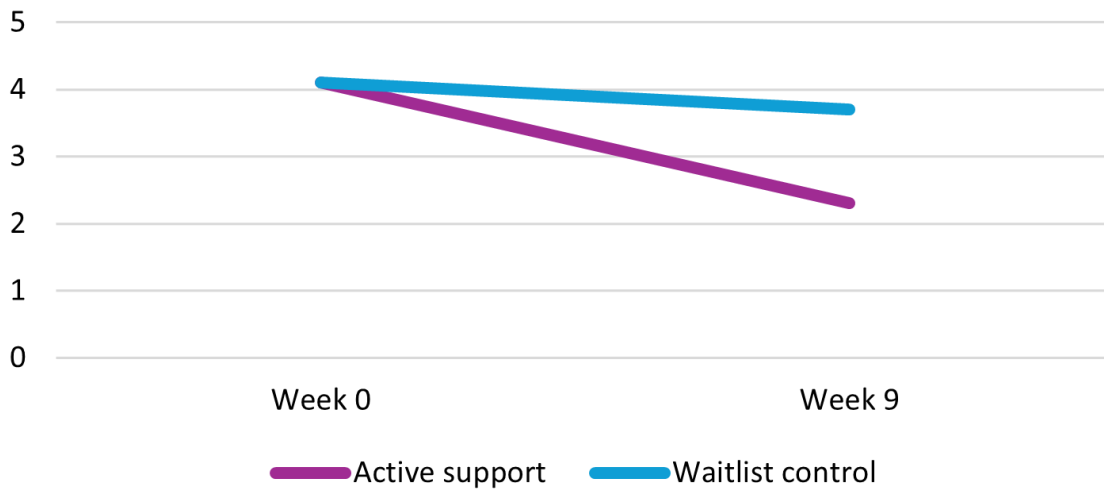
Average parental distress scores at week 0 and week 9



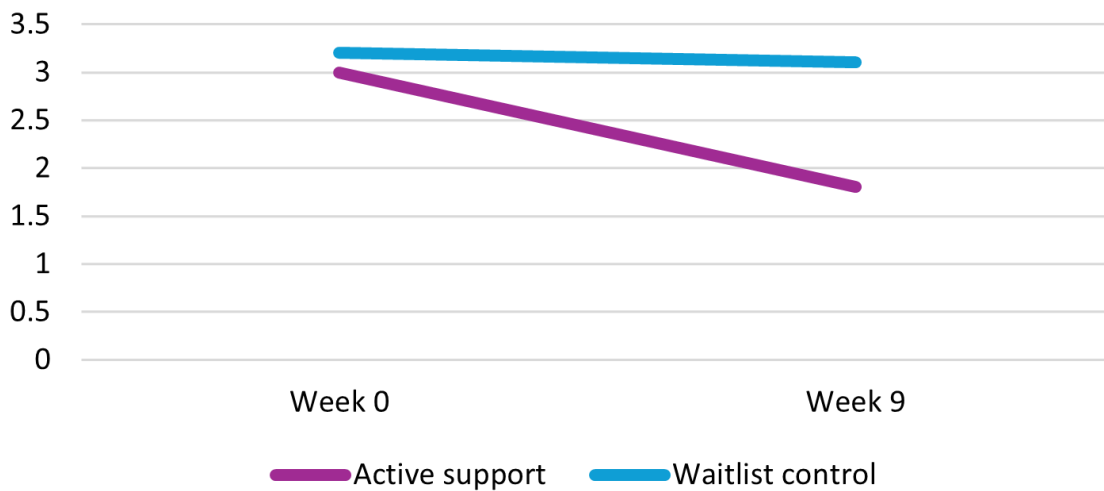
Depression and anxiety symptoms

Participants provided responses on the Depression, Anxiety, and Stress Scale-21 **Higher scores indicate higher distress.**

Caregivers' average Depression subscale scores at week 0 and week 9



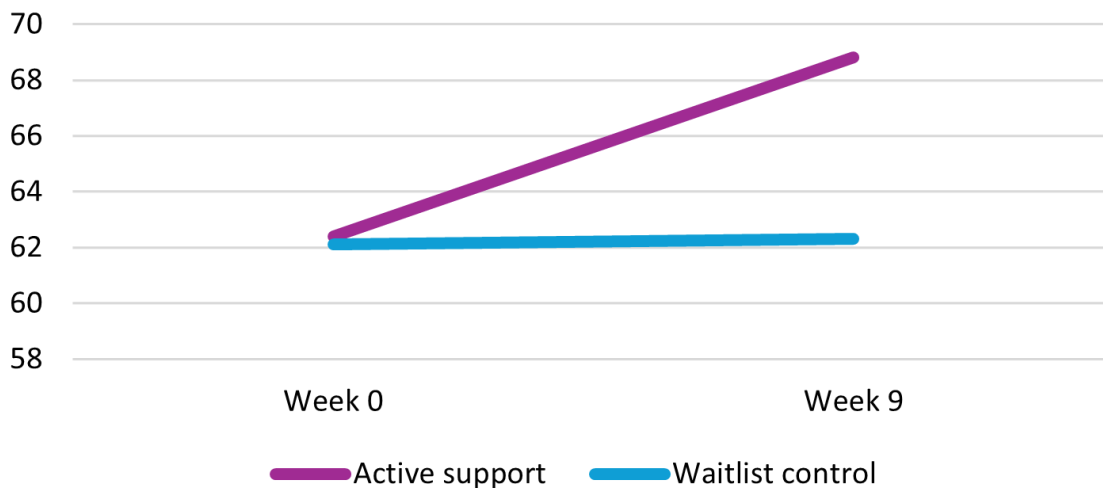
Caregivers' average Anxiety subscale scores at week 0 and week 9



Parenting Sense of Competence

The Parenting Sense of Competence Scale provided a caregiver-reported measure of parenting self-competence. **Higher scores indicate higher self-perceived parenting competence.**

Average total scores for self-perceived parenting competence at week 0 and week 9



Treatment acceptability

The participants rated that they understood the programme well and acceptability was high on all acceptability component measures (i.e., Effectiveness, Reasonableness, Willingness, Cost, and Negative Side-effects). The lowest rated component was Disruption/Time.

Qualitative Interview Data

Interviews were undertaken with 16 caregivers after they had participated in the programme. Several themes emerged from the data including that participation in the Let's Play programme increased knowledge and skills, connecting with others, and enhancing caregiver-child relationships. No interviewed caregiver reported any concerns about cultural responsiveness of the programme.

Conclusions

To our knowledge, this is the first study to evaluate the effects of a community-based, caregiver-implemented, group coaching programme on both caregiver's mental health and self-perceived parenting competence, as well as their children's caregiver-child engagement, language, health-related quality of life, and behaviour.

Together, the findings suggest multiple positive outcomes from participating in the Let's Play programme, including improved caregiver-child engagement, caregiver self-perceived parenting competence, child health-related quality of life, and child behaviour; and reduced parental distress and caregiver psychological distress. These support effects were significantly greater after participating in Let's Play than accessing life-as-usual.

Overall Conclusions

Study 1 evaluated the MoSAIC training as potential option for training ECEs in Aotearoa New Zealand to identify Autistic in their care. Study 2 evaluated Autism New Zealand's Let's Play programme which is designed to support families while they await further government provided assessment and support.

Findings from Study 1 suggest the MoSAIC training is a feasible, acceptable, and culturally appropriate option for preparing ECEs in Aotearoa New Zealand to identify Autistic children using the SACS tool. Participants showed increased confidence and autism knowledge after training and retained these improvements through to follow-up. Participants viewed the MoSAIC training and SACS tool highly, and suggested incorporating the MoSAIC training into ECE qualification requirements and offering it as a professional development course to ECEs already certified and practicing.

Further, findings from Study 2 suggest that Let's Play programme participation leads to better outcomes than accessing life-as-usual. Namely, children showed greater engagement when playing with their parent and greater health-related quality of life, as well as fewer behavioural differences. Moreover, caregivers showed lower parental distress and psychological distress, as well as higher self-perceived parenting competence. Caregivers perceived Let's Play to be highly acceptable and culturally reflexive, endorsing the programme for other families with an Autistic child.

Early identification and support are paramount to maximising health and wellbeing outcomes for Autistic children and their families. In combination, MoSAIC training for ECEs would help prevent Autistic children going unidentified (or misdiagnosed) and unsupported, and the Let's Play programme would help support families while they wait to access formal diagnosis or supports. As Autism New Zealand is a charitable organisation, continued delivery of these training programmes depends on procurement of external funding.

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