

School Connectedness: Acceptance, respect and support

FINAL REPORT

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working together to support school-aged students on the autism spectrum





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The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

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A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, when speaking of adults we use the terms 'autistic person', 'person on the autism spectrum' or 'person on the spectrum'. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector, and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder'. Please note that Focus 1 uses this terminology when referring to diagnosis; and that when Focus 2 and Focus 3 use this terminology it is because RAP-ASD (the Resourceful Adolescent Program for adolescents on the spectrum (RAP-A-ASD) and the Resourceful Adolescent Program for parents of adolescents on the spectrum (RAP-P-ASD)) was developed prior to involvement with the Autism CRC, and is designed for young adolescents who have a formal diagnosis of ASD and their parents.

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Table of contents

1	Ba	ackground	7
2	Re	esearch design and methods	9
	2.1 Fo	ocus 1	9
	2.1.1	Study design	9
	2.1.2	Participants	9
	2.1.2	2.1 Students on the autism spectrum	9
	2.1.2	2.2 Parents of students on the autism spectrum	9
	2.1.2	2.3 Educators of students on the autism spectrum	10
	2.1.3	Data collection	10
	2.1.4	Qualitative data analysis	11
	2.2 Fo	ocus 2	11
	2.2.1	Study design	12
	2.2.2	Participants	12
	2.2.3	Data collection	13
	2.2.4	Data analysis	13
	2.2.4	4.1 Qualitative data analysis	13
	2.2.4	4.2 Quantitative data analysis	14
	2.3 Fo	ocus 3	14
	2.3.1	Study design	15
	2.3.2	Participants	15
	2.3.3	Data collection	15



2.3.4	Qualitative data analysis15
3 Fin	ndings16
3.1 Fo	cus 116
3.1.1	Influence of the unique learning needs of autism on school connections 16
3.1.2	Challenges to meeting autism-specific needs inhibiting school connections . 16
3.1.3	Autism-specific classroom strategies supporting connections
3.1.4	Peer group dynamics that inhibit or promote school connectedness
3.1.5	Family factors that help promote school connectedness
3.1.6	Characteristics of the community that promote school connectedness17
3.1.7	Characteristics of an inclusive culture that supports school connectedness18
3.1.8	Professional learning in the community that supports school connectedness 18
3.1.9	Roles of education staff in supporting school connectedness
3.2 Fo	cus 219
3.2.1	Key quantitative findings
3.2.1	.1 For adolescents
3.2.1	.2 Parents' experience of their adolescents
3.2.1	.3 Teachers' experience of their students
3.2.2	Key qualitative findings21
3.2.2	.1 For adolescents, with illustrative quotes21
3.2.2	.2 For parents (for quotes and detail see Shochet et al., 2019)22
3.3 Fo	cus 322
3.3.1	Key findings



4	Limitations
4.1	Focus 1
4.2	Focus 2
4.3	Focus 3
5	Implications for research and practice25
5.1	Focus 1
5.2	Focus 2
5.3	Focus 3
6	Key recommendations
6.1	Focus 1
6.2	Focus 2
6.3	Focus 3
7	References



1 Background

School connectedness is the extent to which a student feels accepted, valued, and supported in their school environment (Ciani et al., 2010; Goodenow, 1993; Osterman, 2000; Shochet, 2016). School connectedness has been highlighted as a key protective factor associated with academic and emotional wellbeing in adolescents (Shochet, Dadds, Ham, & Montague, 2006). It correlates with factors such as mental health, academic motivation, indexes of school performance and adjustment, and decreased problem behaviour (Anderman, 2002; Anderman & Freeman, 2004; Chapman et al., 2013; Frydenberg et al., 2009; Goodenow, 1993; Kidger et al., 2012; McNeely, Nonnemaker, & Blum, 2002; Shochet et al., 2006; Shochet, Homel, Cockshaw, & Montgomery, 2008; Shochet & Smith, 2012). Extensive research has found school connectedness to be an important protective factor for current and future mental wellbeing and positive adolescent development (Jose et al., 2012; Lester et al., 2013; Shochet et al., 2006; Shochet et al., 2016; Shochet et al., 2018).

The risk of developing depression increases in early adolescence (Lewinsohn et al., 2000). Young adolescents on the autism spectrum tend to experience the developmental challenges associated with the transition to adolescence as more challenging than do their non-autistic peers due to difficulties with communication and social interaction that can impede the development and maintenance of relationships with peers and teachers (Downs & Smith, 2004; Humphrey & Symes, 2010; White & Roberson-Nay, 2009), difficulties adjusting to unfamiliar situations (Kanne et al., 2009), difficulties with affect regulation (American Psychological Association [APA], 2013), and reduced likelihood to seek help from an adult (Humphrey & Symes, 2010).

Not surprisingly, young adolescents on the spectrum are at greater risk than their non-autistic peers of developing depression, with prevalence estimates as high as 54% (Mayes, Calhoun, Murray, & Zahid, 2011). The effect of depressive symptoms in the young adolescent can impact in many ways. These symptoms can be detrimental to the quality and quantity of relationships in familial, educational and wider social settings. They can heighten the risk of the young adolescent withdrawing socially and displaying anti-social behaviour towards others, erode capacity for coping, decrease levels of self-care and adaptive functioning, and increase levels of self-injury and the risk of suicidal ideation (Ghaziuddin, Ghazuiddin, & Greden, 2002; Matson & Nebel-Schwalm, 2007; Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006; White & Robertson-Nay, 2009). Also, these symptoms may impact negatively



on parental mental health (Zablotsky et al., 2012) and the adolescent's wider support network (Ghaziuddin et al., 2002; Matson & Nebel-Schwalm, 2007).

Left untreated, depressive symptoms are likely to extend into adulthood, and reduce future prospects such as engaging in and completing tertiary education, finding jobs, and remaining employed (Taylor, Henninger, & Mailick, 2015). However, there is a paucity of research on effective early intervention or depression prevention approaches tailored for this population (Ghaziuddin et al., 2002; Stewart et al., 2006).

The characteristics of autism (including difficulties with social understanding and interactions, communication, emotion regulation, optimism, self-esteem, and transitions) can reduce the ability of young adolescents on the spectrum to feel connected to their school. Therefore, it is important for schools to investigate ways to promote school connectedness in young adolescents on the spectrum to reduce their risk of developing depression. Vast differences in school connectedness within and between schools (Shochet et al., 2006) mean that there are important individual differences that need to be taken into account when considering appropriate interventions and supports to encourage school connectedness.

Research has shown a link between school connectedness and attachment between students and parents, indicating that a core component of effectively fostering school connectedness may mean intervening at an individual and family level, in addition to the classroom and school personnel level (Shochet et al., 2008). The topic, therefore, calls for further research on how to effectively foster school connectedness at a whole school, class, family, and individual level by identifying critical factors that help promote school connectedness Eurthermore, understanding how to promote school connectedness effectively requires that socio-demographic and individual factors are considered. Children in schools in rural and remote areas often face unique challenges due to limited schooling and support services, choices and access that can influence their connections to school.

As there was no research on effective ways of promoting school connectedness for students on the spectrum, this project aimed to:

 Survey the experiences and perspectives of school connectedness in students on the spectrum, their parents and teachers in urban, rural and remote schools in Australia so as to identify the individual, school, community and system factors that contribute to or threaten school connectedness in this population (Focus 1);



- 2. Develop and implement a multi-level School Connectedness Program in South East Queensland schools to support an inclusive school culture and promote wellbeing at an individual student, family and school level (Focus 2); and
- 3. Support school connectedness in rural, remote and urban locations (Focus 3).

2 Research design and methods

2.1 Focus 1

2.1.1 Study design

The research employed an exploratory case study (Thomas, 2011; Yin, 2012) that allowed researchers to conduct an in-depth and comprehensive assessment of the case of interest (Simons, 2009). Exploratory case studies are one of three prominent types of case studies described by Yin (2003) and allow for a phenomenon such as school connectedness, characterised by a lack of detailed preliminary research to be explored in-depth (Streb, 2010). This research design is ideally suited to the current research where limited previous research into perspectives of school connectedness in urban, rural and remotes regions of Australia have been explored for students on the spectrum, their parents and educators.

2.1.2 Participants

Three key participant groups were recruited from urban, rural and remote communities in Northern Territory, Western Australia, and New South Wales.

2.1.2.1 Students on the autism spectrum

Students with a diagnosis on the autism spectrum aged 11-16 years of age living in urban, rural and remote communities in Northern Territory, Western Australia, and New South Wales.

2.1.2.2 Parents of students on the autism spectrum

Parents of students on the spectrum living in urban, rural and remote communities in Northern Territory, Western Australia, and New South Wales.



2.1.2.4 Educators of students on the autism spectrum

Educators of students on the spectrum from the age group stipulated within identified urban, rural, and remote communities in New South Wales. These teachers had either currently or previously taught students on the spectrum within this age group.

Numbers recruited for each participant group were dependent upon the availability of suitable candidates that met the recruitment criteria in each of the communities. Recruitment was by means of purposive sampling (Patton, 2002) and occurred in each state by working through relevant education organisations, autism associations, and community organisations to invite participants who met recruitment criteria. Recruitment took place via a range of methods including letters to school principals seeking involvement and consent, purposive sampling via autism associations and Catholic education offices, and advertising within communities via autism, disability, remote families, and home education groups in the form of letters, emails, flyers, verbal promotion at events, social media, and website postings. Participants were provided with information sheets about the project, including privacy and confidentiality information and the contact details for the research team.

2.1.3 Data collection

Interviews were semi-structured, with questions closely linked to the research objectives outlined above, and with scope for interviewees to add additional content. The semistructured interviews with educators, parents, and students on the spectrum aimed to gain a rich perspective of their experiences of school connectedness and factors influencing school connectedness in urban, rural, and remote communities across Australia. A semistructured interview schedule was developed to guide the structure and content of the interview. This semi-structured schedule enabled the interviewer to probe further by posing follow-up questions and engage in longer conversations with the participants where the exploration of key experiences could be shared and particular observations or perceptions about the participant's experience of school connectedness could be unpacked (Patton, 2002). Interviews were conducted either face-to-face, via telephone or videoconferencing depending on the preference of the participants. At the beginning of each interview, interviewees were provided with a definition of school connectedness as well as an explanation of the purpose of the interview. The interviewee obtained both written and verbal consents from participants to be involved. The semi-structured interview framework was used to focus on participants' lived experiences.



Data was collected from 106 participants: 24 mothers, 27 students, and 55 educators in a variety of roles including teachers, teacher aides, learning support teachers, year level coordinators, and school leadership staff such as Deputy Principals (See Table 1). Participants resided in New South Wales, Western Australia, and the Northern Territory, including 8 educators, 8 parents and 5 students from metropolitan locations and the remainder in rural or remote locations. The students attended a range of Catholic, state or independent schools, or, in one case home-schooling. Educators were from a range of Catholic, state or independent schools in New South Wales including 8 from metropolitan areas.

Region of Australia	Parents (<i>n</i> = 24)	Students (<i>n</i> =27)	Education Staff (<i>n</i> =55)
New South Wales	10	21	Teachers: 32 Teacher Aides 14 Year Level Coordinators: 3 Learning Support: 4 Leadership staff: 2
Northern Territory	4	2	0
Western Australia	10	4	0

Table 1. Focus 1 participants

2.1.4 Qualitative data analysis

The audio recorded interviews were transcribed verbatim by a member of the research team and a thematic analysis of the transcripts was conducted using NVivo software. The thematic analysis was based on a constructionist theoretical position, and aimed to examine ways in which events, realities, meanings, and experiences were the effects of different discourses operating within society (Braun & Clarke, 2006). As such, analysis considered how participant experiences influenced school connectedness and what were the perceived individual, school, community, and system factors that enable or hinder school connectedness in urban, rural and remote areas of Australia.

2.2 Focus 2

In Focus 2, a School Connectedness Program drawing on elements of the Index for Inclusion to support an inclusive school culture, and implementing the Resourceful Adolescent Program (RAP) at the student, family, and school levels was developed and implemented in schools across Brisbane, Queensland (see Shochet et al., 2016 for detail).



2.2.1 Study design

A multisite proof-of-concept study using a mixed-methods design was used to pilot and evaluate the School Connectedness Program in schools in Brisbane.

2.2.2 Participants

Six schools in Brisbane, Australia were recruited to participate in the project. Participants (N = 86) included:

- 30 adolescents (24 male, 6 female) aged 11 to 14 years (*M*_{age} = 11.84; *SD*_{age} = .86) who were enrolled in the first two years of a secondary school participating in the intervention, had a diagnosis of autism spectrum disorder, autistic disorder, Asperger's disorder, or PDD-NOS, and did not have intellectual impairment or severe behavioural difficulties or psychosis. Each adolescent attended 11 to 14 one-on-one weekly 1-hour sessions of the Resourceful Adolescent Program adapted for adolescents on the autism spectrum (RAP-A-ASD; Shochet, Mackay, & Wurfl, 2011).
- 40 parents/caregivers (referred to as parents from here on) of the adolescent participants were requested to complete questionnaires and participate in semistructured interviews.
- All parents/caregivers of adolescent participants were invited to attend the Resourceful Adolescent Program for parents of adolescents on the spectrum (RAP-P-ASD; Shochet & Wurfl, 2016a, 2016b), a series of 4 x 2 hour resilience building workshops for parents. Attendance was high, with 31 participants (20 mothers, 7 fathers, 1 grandmother, 1 step-mother, and 1 foster mother and 1 foster father) availing themselves of this opportunity.
- 16 teachers who were closely involved with the students (5 classroom teachers, 3 special education teachers, and 8 case managers).
- Teachers at 5 of the 6 participating schools were able to attend a 2-hour Resourceful Adolescent Program for Teachers (RAP-T, Shochet & Wurfl, 2006) workshop facilitated by the research team.
- At each participating school, the research team formed a School Connectedness Committee consisting of principals/deputy principals, special education heads and teachers, classroom teachers, school captains/vice-captains and student leaders, project researchers, and parents. Together, the School Connectedness Committee identified a project to increase school connectedness, and worked with the students to implement and evaluate the project.



2.2.3 Data collection

- At pre-intervention, post-intervention, and 3 and 6 and 12 month follow-up, the
 research team gathered quantitative data from adolescents and their
 parents/caregivers about the adolescent participants' depressive symptoms, anxiety
 levels, sense of school connectedness, behavioural and emotional difficulties and
 prosocial behaviours, confidence to use coping behaviours in times of stress, emotional
 and social and psychological wellbeing, and the structural and organisational and
 transactional characteristics of their family's functioning.
- At pre-intervention, post-intervention, and 3 and 6 and 12 month follow-up, the research team gathered quantitative data from teachers about the adolescent participants' depressive symptoms, and behavioural and emotional difficulties and prosocial behaviours.
- The research team conducted semi-structured interviews with adolescents who
 participated in RAP-A-ASD, and with parents who attended RAP-P-ASD to explore the
 value of adding a strength-focused parenting intervention to a depression prevention
 intervention for adolescents on the spectrum.

2.2.4 Data analysis

2.2.4.1 Quantitative data analysis

Quantitative data (primary outcomes (see Table 2) at pre, post, 3 month, 6 month and 12 month follow-up) was analysed using the Reliable Change Index. Reliable change analysis is a calculation that creates a standardised score for change of an individual's score over time and determines its statistical significance. The reliable change analysis was calculated separately for student, parent, and teacher reported data.

Table 2: Primary Outcomes

Primary Outcome	Measure	Abbreviation
Depressive symptomology	Children's Depression Inventory 2	CDI-2
Emotional and behavioural functionality	Strengths and Difficulties Questionnaire	SDQ
Coping self-efficacy	Coping Self Efficacy Scale	CSES
Degree of school connectedness	Psychological Sense of School Membership Scale	PSSM
Separation anxiety, uncertainty, performance anxiety, and anxious arousal	Anxiety Scale for Children with Autism Spectrum Disorder	ASC-ASD



2.2.4.2 Qualitative data analysis

Qualitative data was analysed using Consensual Qualitative Research (CQR; Hill et al., 1997, 2005). Parent and adolescent participants' experiences of the program postintervention was analysed as:

- Domains (broad topic areas),
- Core ideas (summaries of what participants said, within each domain), and
- Common themes (occur within a core idea within a domain).

2.3 Focus 3

As a first step to supporting school connectedness in rural, remote and urban locations, a community based participatory research (CBPR) project was conducted to further inform our understanding of those supporting young adolescents with a diagnosis or traits of autism living in remote Australia. Our research team developed the Resourceful Adolescent Parent and Caregiver Program (RAP-PC), and delivered the program in a strength-based workshop for Indigenous community workers who work directly with Indigenous populations in Bourke, which is a town in a remote area of Northern New South Wales in Australia.

To further support school connectedness in rural, remote, and urban locations, an online resource was developed for communities, schools, teachers, and parents to use to promote school connectedness for diverse learners at the stage of early adolescence. This online resource, the Autism Teen Wellbeing website, provides a range of strategies, resources and cultural considerations that communities, schools, teachers, and parents worldwide can use to increase the school connectedness of these young adolescents. The website was supported by funding from Positive Partnerships.

The website is available at autismteenwellbeing.com.au.





2.3.1 Study design

A CBPR approach, which acknowledges the community as an equal partner in all aspects of the research (Ahmed & Palermo, 2010), was adopted to develop a sustainable program to promote wellbeing and support inclusion and connectedness for adolescents on the spectrum, their families, and the wider community.

2.3.2 Participants

- Prior to the RAP-PC workshop, key stakeholders from the community were consulted about the nature of a program that would best meet the needs of the community, which led to the development of the Resourceful Adolescent Parent and Caregiver Program (RAP-PC; Shochet & Wurfl, 2018)
- 11 community workers attended a 3 day workshop about the RAP-PC program so that they could then implement the program with parents and families in their communities.

2.3.3 Data collection

The research team gathered qualitative data from the community workers who attended the RAP-PC program workshop at various timepoints across the 3 days.

2.3.4 Qualitative data analysis

Qualitative data was analysed using a thematic approach.



3 Findings

3.1 Focus 1

Focus 1 of the School Connectedness Project carried out an exploratory case study exploring factors influencing school connectedness in urban, rural, and remote communities of Western Australia, Northern Territory and New South Wales from the perspective of students on the spectrum, their parents and educators viewpoint through semi-structured interviews. Findings highlighted the importance of an inclusive culture and community, a supportive peer group, family and staff involvement, and implementation of appropriate supports that address the autism-specific needs of the students.

Based on the experiences of participants, nine key themes were identified from the data about factors at an individual, class, whole school, and school community level that influenced their experiences of school connectedness.

3.1.1 Influence of the unique learning needs of autism on school connections

Factors that were identified by participants that could negatively influence school connections included levels of anxiety that students on the spectrum experience in the school environment, the challenging behaviours that could surface when needs of students on the spectrum were not adequately met in the school environment, and the constant social challenges presented by the school environment for the student on the spectrum. These results highlight the importance of schools being responsive to the often unique and individualised needs of students on the spectrum in order to support their school connections. Working with students to implement strategies that can help to manage their anxiety, support their social connections, and help them to self-regulate is critical to developing and sustaining school connections for students on the spectrum.

3.1.2 Challenges to meeting autism-specific needs inhibiting school connections

Participants identified several challenges for meeting the autism-specific needs of students that could influence school connections for this group of students. These included adequate levels of funding or resources to support students' learning needs, the importance of ensuring adequate support for life skills, playground difficulties, and the transition to high school. Working collaboratively with parents and students to identify what was needed to



meet their needs was also important for maintaining positive school connections. This theme highlights the importance of considering how resourcing (e.g., financial, physical, and material resources) in schools can best be used to cater to the autism-specific needs of students on the spectrum in order to promote connectedness. Some examples of factors that promote school connectedness include tailoring support to adequately support transitions, providing support to promote understanding and navigation of social situations, teaching life skills, reducing the size of class groups, teaching groupings, and promoting relationships with teaching staff and peers.

3.1.3 Autism-specific classroom strategies supporting connections

Classroom strategies that could be implemented in schools to support connections for students on the spectrum were identified as individualised accommodations, as well as ensuring that there was a balance to support provided so that it was not excessive. Common examples provided by participants of autism-specific strategies that were used to support connectedness included considering seating arrangements, providing structure and predictability, providing quiet spaces to calm down, and using technology to support learning needs.

3.1.4 Peer group dynamics that inhibit or promote school connectedness

Relationships with peers were considered critical to school connections and the strength or weakness of these relationships had a significant impact on school connections for students on the spectrum. This included bullying or its absence, students feeling as though they fitted in with their peers versus being different, having or lacking friends, and having mentors and buddies.

3.1.5 Family factors that help promote school connectedness

The parent role in supporting connectedness was highlighted in this theme, with the parent role as an advocate for their child seen as critical. Therefore, working actively with families and students in ongoing collaborative and consultative ways at a whole school, class and individual level is critical to promote school connectedness and a sense of belonging for students and families.

3.1.6 Characteristics of the community that promote school connectedness

Characteristics that were identified as promoting school connectedness included the religious philosophy (in this case, Catholic) employed by the community, the supportive culture that was developed in the community, the active parent groups available in the



community, and in some cases, being part of a small regional community. Regardless of geographical location, results evident from this theme highlighted that, to support school connectedness, it was important for school communities to be actively promoting a supportive culture at a whole school, class, and individual level within the school community. Previous themes discussed factors that were focused more at an individual and class level by being responsive to the individual needs of the learners involved. However, this theme alluded to the importance of those individual factors being encompassed within the class and guiding school approaches to developing a supportive culture that promoted school connectedness.

3.1.7 Characteristics of an inclusive culture that supports school connectedness

The role an inclusive school culture played in supporting school connectedness was also described. Extracurricular activities, personally connecting with each student on the spectrum, providing opportunities to engage in preferred school activities, having high expectations for all students and making students feel included in the school community were all examples of how schools could support school connectedness though the promotion of an inclusive culture.

3.1.8 Professional learning in the community that supports school connectedness

Participants expressed the importance of actions within the school community that supported school connectedness. These included professional learning to challenge traditional thinking, the promotion of positive communication between school and parents, and inclusive practices.

3.1.9 Roles of education staff in supporting school connectedness

The role of educating staff in supporting school connectedness was highlighted as critical to promoting school connectedness and included the whole school, from administrative staff to caring teachers; access to learning support teams and teacher aides; and a supportive school leadership team.



3.2 Focus 2

Focus 2 developed and implemented a School Connectedness Program in South East Queensland schools to support an inclusive school culture at an individual student, family and school level.

For the young adolescents who participated in RAP-A-ASD, results showed an increase in school connectedness and improved mental wellbeing.

Parents who participated in RAP-P-ASD reported that feeling isolated and unsupported by existing services motivated their participation, and that they valued interacting with other parent participants. They also reported that the program enhanced wellbeing and parenting efficacy, reduced isolation, increased ability to parent calmly, and improved parent-adolescent relationships.

Schools that implemented the Index for Inclusion to improve school connectedness at a whole school level developed an understanding of school connectedness. Further, they reported an increase in inclusive culture and practice in their schools as a result of the collaboration between school staff and students required for implementation.

3.2.1 Key quantitative findings

3.2.1.1 For adolescents

Reliable improvement:

- The greatest amount of reliable improvement was seen for anxiety (assessed with the ASC-ASD), total difficulties (assessed with the SDQ), school connectedness (assessed with the PSSM), and coping self-efficacy (assessed with the CSES);
- Particularly high percentages of improvement were reported at 3 month follow-up: over 45% of students reported a significant improvement in anxiety and over 50% reported a significant improvement in total difficulties at this time;
- Improvement in anxiety and total difficulties peaked at 3 month follow-up (this improvement was not maintained at 12 month follow-up);
- Improvements in school connectedness and coping self-efficacy were maintained across the 12 month period;
- Improvement in depressive symptoms (measured by the CDI-2) increased between post and 3 month follow-up, and remained stable up until 12 month follow-up.



While there was evidence of substantial improvement on a number of key indicators as previously described, not all students improved. Further, some students reported worse outcomes at some of the time points:

- 3 and 2 students reported an increase in depressive symptoms (measured by the CDI-2) at post-intervention and 6 month follow-up respectively;
- 3, 1 and 2 students reported greater anxiety (measured by the ASC-ASD) at postintervention, 3 month follow-up and 6 month follow-up respectively;
- 4, 1, 2 and 1 students reported a decrease in emotional and behavioural functionality (measured by the SDQ) at post-intervention, 3 month follow-up, 6 month follow-up and 12 month follow-up respectively;
- 2, 5, 4 and 1 students reported reduced school connectedness (assessed with the PSSM) at post-intervention, 3 month follow-up, 6 month follow-up and 12 month follow-up respectively;
- 2, 3 and 1 students reported diminished coping self-efficacy (assessed with the CSES) at post-intervention, 3 month follow-up and 6 month follow-up respectively.

3.2.1.2 Parents' experience of their adolescents

Reliable improvement:

- The majority of parents reported change that was not statistically significant across all measures at most time points, with the exception of coping self-efficacy (measured with the CSES) which was equally distributed across improvement, deterioration, and no change;
- The largest percentages of reliable improvement reported by parents were seen for depression (27.78%, measured using the CDI-2), anxiety (38.89%), measured using the ASC-ASD), school connectedness (25.00%, measured using the PSSM), coping self-efficacy (33.33%, measured using the CSES);
- School connectedness and coping self-efficacy appeared to have the most stable levels of improvement across all time points.



3.2.1.3 Teachers' experience of their students

Reliable improvement:

- Overall, teachers did not report statistically significant change among the majority of students across all measures and time points;
- The largest percentages of reliable improvement reported by teachers were seen at 12 month follow-up for depression (20%, measured using the CDI-2) and emotional and behavioural functionality (24%, measured using the prosocial behaviour subscale of the SDQ; and 20%, measured using the total difficulties subscale of the SDQ).

3.2.2 Key qualitative findings

3.2.2.1 For adolescents, with illustrative quotes

- Increased resilience, e.g., "I was bullied when I was younger and I was put down a little bit by my younger sibling ... and one of my friends ... would metaphorically stab me in the back ... but the RAP program helped with boosting self-confidence and identifying what can help ... I find laughter and smiling are probably the best things";
- Increased confidence in managing their emotions and keeping calm, e.g., "I learned how to cope with anger and not taking it out on other people", "A girl in my maths class is bullying me about my autism... and making fun of me. I ... asked the teacher if I could be moved away ... if ... I could ... go for a walk to get a drink and calm down... normally I would have retaliated by saying something... out of order ... something really offensive back";
- Increased confidence in dealing with social situations, e.g., "the RAP program has helped me make more friends... before I did the RAP program I always did these weird things ... there was these really awkward situations where everyone went silent and I, most of the time I didn't know what to do, so I did these really weird things, and that most of the time ended up in the friendship crumbling. And now I know ... what to do in those situations, and not make it really awkward";
- Increased confidence in problem solving, e.g., "I've learned that there's more ways to deal with your problems than just one ... answer";
- Increased ability to consider the perspective of others, e.g., "It helped me realise ... how my parents were seeing things and other people were seeing things"; and



• Experiencing their facilitator as interested in and supportive of them, e.g., "I enjoyed spending time with the facilitator ... previous encounters with other people sometimes leave me a bit ...closed off and isolated but I connected with her".

3.2.2.2 For parents (for quotes and detail see Shochet et al., 2019)

Parents who participated in RAP-P-ASD reported that doing so:

- helped with their sense of isolation and validated their parenting difficulties;
- increased their parenting efficacy by affirming their existing strengths, e.g., one parent said, "That feedback of being a good parent, and that I'm doing the right thing by my kids. No one ever tells me that so that was worth gold to me", while another stated, "I need to, as a parent, remember that I'm important too and my strengths as a parent are important as well";
- increased their confidence to be non-reactive and calmer in their parenting;
- increased their empathy for, and understanding of, their adolescent;
- improved their communication with, and sense of connectedness to, their adolescent;
- increased their understanding of a more optimal way to assist their child to navigate early adolescence; and
- increased their wellbeing by enabling them to manage family conflict in a more adaptive way.

3.3 Focus 3

3.3.1 Key findings

The Indigenous community workers who attended the 3 day RAP-PC workshop in Bourke, NSW consistently described:

- a lack of awareness, services, and resources specific to Indigenous people on the autism spectrum;
- multiple challenges that parents and caregivers encounter when attempting to obtain a diagnosis and support for their child with autistic traits; and
- a need for programs, workshops or resources to support Indigenous people on the autism spectrum and their parents/caregivers in their communities.



During development of the Autism Teen Wellbeing website, in accordance with the CBPR approach, the website was evaluated by school principals, teachers, parents of children on the spectrum, and adults on the spectrum. Feedback was overwhelmingly positive, with evaluators concluding that the website provides much-needed support for parents, teachers, schools and communities who work with children on the spectrum.

The official launch of the website took place on World Autism Day, 2 April 2020, after a delay as a result of the COVID-19 pandemic. It has been made available on the Autism CRC website, and shared on a number of electronic forums with initial traffic analyses indicating good uptake. For example, as at the end of April 2020:

- 1208 users had accessed the website in the week following the website being made available on the Autism CRC website;
- all sections of the website (for parents, teachers, schools and adolescents) had been accessed;
- 23% of users had visited the website more than once, and;
- the majority of users had watched the entirety of the 3-5 minute videos available on the website.

4 Limitations

4.1 Focus 1

It was hoped originally that, as a part of Focus 1, it would have been possible to identify or separate out key influences that impact on school connectedness that are unique to rural and remote regions. However, this was not possible as features of school connectedness appeared to be universal regardless of geographical location. In addition, recruitment of participants with a diagnosis of autism in rural and remote communities was impacted because students in more remote areas are often underdiagnosed (compared to those in metropolitan areas) due to a lack of access to support and services, which meant that fewer students met recruitment criteria.



4.2 Focus 2

Findings from this proof-of-concept study reflect the experience of a sample of parents of young adolescents on the spectrum in urban Australia, with generalisability reduced by its relative homogeneity, and twice as many female than male parents participating in RAP-P-ASD (possibly due to parents' work commitments or difficulties arranging child care when workshops were conducted).

In addition, delivering the RAP-A-ASD intervention was resource-heavy as the program is delivered by one facilitator to one adolescent at a time.

There is the possibility that the analysis of the qualitative parent findings may have been influenced by individual biases of the CQR team members, and the findings were not checked by the parent participants, so it is not known whether they agreed with the analysis.

The long-term sustainability of gains of the School Connectedness Program beyond the immediate program effects are yet to be determined. Intervention gains may diminish over time as a result of the ongoing developmental challenges that adolescents on the spectrum experience.

4.3 Focus 3

Focus 3 was intended initially to evaluate how the outcomes from Focus 1 and 2 generalised to a trial of the School Connectedness Program in schools in rural and remote communities by implementing and evaluating the School Connectedness Program in one rural or remote community in New South Wales. However, recruitment difficulties and low diagnosis rates of autism in rural and remote communities in Australia posed significant barriers. Hence, following the findings from the 3 day RAP-PC workshop that was conducted in Bourke, NSW with Indigenous community workers, the project team, in conjunction with Positive Partnerships, decided to develop the Autism Teen Wellbeing website instead to support school connectedness in rural, remote, and urban locations.



5 Implications for research and practice

5.1 Focus 1

Focus 1 findings highlighted that important elements within a school community that promote school connectedness and a sense of belonging are universal regardless of geographical location. These findings support the importance of school and school communities globally supporting an inclusive culture and practices that support students at an individual, class, whole school, and school community level.

- For students on the spectrum, a key element for school communities is to identify and respond to the unique autism-specific learning needs that may be influencing school connections for students on the spectrum.
- To support school connectedness and a sense of belonging, a focus will be working with students to help them to learn how to understand and regulate their emotions, manage their stress and anxiety, and navigate their social world and relationships.
- At a systems and school wide level, it is essential that school connectedness is
 recognised as an important element that promotes academic learning and school
 success, and that adequate levels of funding and resourcing are provided to nurture
 connections for all students at an individual, class, whole school, and school
 community level. This requires school communities to consider how resourcing (e.g.,
 financial, physical, and material resources) in schools can be used in the most optimal
 manner to cater to the autism-specific needs of students on the spectrum.
- School connectedness is founded in the collaborative partnerships and positive communication established with parents and students. These partnerships help in collaborative ways to identify what is needed to meet the needs of the student on the spectrum, and maintain positive school connections.
- Professional learning is required for schools and school communities to help guide school approaches to developing a supportive culture, and identify and implement autism-specific classroom strategies that support school connections and address the learning needs of students on the spectrum.



5.2 Focus 2

Overall, for the young adolescents who participated in RAP-A-ASD, results showed an increase in school connectedness and improved mental wellbeing. Further, parent outcomes following their participation in the RAP-P-ASD workshops are encouraging: parents reported that participation diminished their sense of isolation, validated their parenting difficulties, boosted their self-efficacy, increased their empathy for their young adolescent, enhanced parent-adolescent communication and connectedness, increased their understanding of a more optimal manner in which to assist their child on the spectrum to navigate the developmental phase of early adolescence, and boosted their own wellbeing. Also, the implementation of the five phases of the Index for Inclusion in participating schools indicates that this framework can support a whole school approach to build a sense of community that supports young people to feel more connected to their school.

These promising findings from the multi-layered School Connectedness Program (RAP-ASD in conjunction with the Index for Inclusion) show some initial evidence for promoting resilience through enhancing protective factors for adolescents with a diagnosis or traits of autism, their parents, and at the school level. School-based strength-focused resilience interventions appear encouraging for promoting mental health in young adolescents on the spectrum and their parents. As young adolescents on the spectrum are more vulnerable to developing depression and other mental health problems than their non-autistic peers, and incidence rates are high, ongoing research should be conducted to explore the optimal focus and frequency of prevention and early interventions to promote more positive mental health with adolescents on the spectrum and their parents. The encouraging findings from this proof-of-concept study justify a randomised control trial of the School Connectedness Program. Further, introducing booster sessions for adolescents and their parents (either face-to-face or online or via SMS), and conducting follow-up sessions beyond 12 months post implementation, may reduce or prevent depression and should be explored.

5.3 Focus 3

Qualitative feedback gathered during the CBPR project that was conducted to further inform our understanding of those supporting young adolescents with a diagnosis or traits of autism living in remote Australia highlighted that, in line with published research (see Shochet et al., 2020, for details of a recent systematic review and catalogue of psychosocial resources), there are very few resources designed to promote the psychosocial wellbeing of Indigenous people with characteristics or a diagnosis of autism, and the psychosocial



wellbeing of their caregivers. The Indigenous community workers who attended the 3 day RAP-PC workshop endorsed previous findings of underdiagnosis of autism in rural and remote areas of Australia. They provided details of difficulties Indigenous parents encounter when attempting to access diagnostic services for their children, e.g., a vulnerable young mother who had never travelled to a metropolitan area was required to take her 3 year-old son on a 10 hour bus journey to Sydney for a diagnostic procedure. They also highlighted a lack of in-service training opportunities for community workers in rural areas, and a lack of social supports such as respite services and school outreach programs for Indigenous people with characteristics or a diagnosis of autism and their caregivers.

As demonstrated from preliminary feedback received from reviewers of the Autism Teen Wellbeing website, the internet provides a promising platform for future development of programs promoting psychosocial wellbeing, and may go some way to addressing the need for accessible resources that can support people with characteristics or a diagnosis of autism as well as their caregivers.



6 Key recommendations

6.1 Focus 1

Several individual, school, community and system factors were described by participants as enabling or hindering school connectedness in urban, rural, and remote areas for students on the spectrum. An important factor that influenced school connectedness was a focus on establishing a sense of belonging at all levels: in remote, rural and urban communities; within the school community and within the class level; and at the student level by supporting individuals to establish supportive peer relationships. It was important that schools promoted a sense of belonging through the implementation of an inclusive culture for all, the provision of support for the individual learning needs of students within their community, and established strong partnerships with each other as well as with families and the students themselves. School connectedness must be actively supported in schools to ensure a sense of belonging for all, regardless of whether the school is in an urban, rural, or remote location.

6.2 Focus 2

The multi-layered RAP-ASD program for adolescents and parents, in conjunction with the Index for Inclusion, shows some initial evidence for promoting resilience through enhancing some protective factors for adolescents on the spectrum, their parents, and school personnel. School-based strength-focused resilience interventions appear encouraging for promoting mental health in young adolescents on the spectrum and their parents.

For the young adolescents who participated in RAP-A-ASD, results showed an increase in school connectedness and improved mental wellbeing. Highlights for young adolescents of participating in this adolescent program included increased resilience; greater confidence in managing their emotions, keeping calm, dealing with social situations, and recruiting problem solving; an increased ability to consider the perspective of others; and the positive experience of developing a relationship with a facilitator who was interested in and supportive of them. Parents, reflecting on changes they had noticed in their young adolescents as a result of their participation in RAP-A-ASD, most frequently identified diminished stress in the family system which they attributed to reduced conflict, a greater sense of connectedness with their adolescent, improvements in their adolescents' emotion regulation, and enhanced parent-adolescent communication. As outlined for Focus 3 following, these promising findings lend support for developing the adolescent section of the



Autism Teen Wellbeing website so that adolescents in urban, rural, and remote locations worldwide can access the key components of RAP-A-ASD that promote affect and emotion regulation, problem solving, interpersonal relationships, and improved mental wellbeing.

Parents who participated in RAP-P-ASD reported that feeling isolated and unsupported by existing services motivated their participation, and that they valued interacting with other parent participants. Highlights for parents participating in the RAP parent program were that it diminished their sense of isolation and a lack of understanding of their difficulties; that it affirmed parents' existing strengths, increased their confidence for adopting a non-reactive and calm parenting style, and boosted parent efficacy; that it increased their empathy for their adolescent; and that it increased their understanding of a more optimal manner in which to assist their child to navigate the developmental phase of early adolescence. Furthermore, that the majority of parents (87%) who participated in RAP-P-ASD valued the sense of connectedness with other parents afforded by attending the workshops suggests that the face-to-face model offers the optimal delivery option.

Future research should continue to offer the RAP-P-ASD workshops while trialling the provision of additional material after the conclusion of the workshops to reinforce and sustain parents' sense of connectedness. For parents unable to attend the face-to-face RAP-P-ASD workshops or who require ongoing revision and reinforcement support in addition to the four RAP-P-ASD workshops, there is value in exploring the development of a hybrid model of RAP-P-ASD that uses communication technology to deliver the program content online, augments it with digital resources and telephone and/or online chat support, and could be accessed worldwide by English-speaking parents of young adolescents on the spectrum. Such a hybrid would extend the reach of RAP-P-ASD to a wider, more ethnically, culturally and racially diverse population, including those living in rural and remote communities, and internationally, and might also help to lessen the sense of isolation experienced by many parents of young adolescents on the spectrum.

Findings from implementing the Index for Inclusion in the schools that participated in the School Connectedness Project indicate that a whole school approach can support inclusiveness for adolescents in the school environment. Schools that implemented the Index for Inclusion to improve school connectedness at a whole school level developed an understanding of school connectedness, and reported an increase in inclusive culture and practice in their schools as a result of the collaboration between school staff and students required for implementation. These findings suggest that the Index for Inclusion framework



can play a critical role in supporting school connectedness and should continue to be implemented in schools.

6.3 Focus 3

The CBPR project that was conducted to further inform an understanding of those supporting young adolescents with a diagnosis or traits of autism living in remote Australia highlighted that, as outlined in a recent systematic review of psychosocial resources developed and trialled for Indigenous people diagnosed with autism spectrum disorder and their caregivers (see Shochet et al., 2020), there is very little published and unpublished literature in this area. Hence, there is a need for research for Indigenous people on the spectrum across the lifespan. Interestingly, several psychosocial resources developed and trialled with success for this population have originated from culturally adapting existing evidence-based programs developed for non-Indigenous populations in metropolitan areas. If future research can continue to adapt existing evidence-based programs that improve psychosocial wellbeing to suit the needs of Indigenous children, adolescents, and adults with characteristics or a diagnosis of autism, and/or the psychosocial wellbeing of their caregivers, and do so by adopting a CBPR approach to foster collaboration, obstacles that inhibit Indigenous people's engagement in and utilisation of such programs may be reduced.

E-health research shows the effectiveness of psychosocial interventions delivered through technology (see Andersson, Cuijpers, Carlbring, Riper, & Hedman, 2014 for review). To further support school connectedness in rural, remote, and urban locations, the Autism Teen Wellbeing website should be extended to provide support for adolescents. As can be seen on the website (<u>https://autismteenwellbeing.com.au/</u>), the adolescent is in the middle of the circle. Providing strategies derived from the Resourceful Adolescent Program (RAP) (Shochet & Wurfl, 2015a, 2015b) at this level will give adolescents access to much-needed support that may improve their coping skills, promote depression protective factors (e.g., self-regulation, stress management, developing social support networks, perspective taking, preventing and managing conflict, and strengthening interpersonal relationships), and build their resilience so as to foster their mental health and wellbeing.



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Inclusion

Working together with those with the lived experience of autism in all we do



Innovation

New solutions for long term challenges



Independence

Guided by evidence based research, integrity and peer review



Cooperation

Bringing benefits to our partners; capturing opportunities they cannot capture alone



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