School Connectedness: Acceptance, respect and support

EXECUTIVE SUMMARY

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positive partnerships
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.

Copies of this report can be downloaded from the Autism CRC website **autismcrc.com.au**.

Introduction

School connectedness is the extent to which a student feels accepted, valued, and supported in their school environment, and has been highlighted as an important protective factor for current and future mental wellbeing and positive adolescent development. The risk of developing depression increases in early adolescence, and 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. 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%. Depressive symptoms in the young adolescent can be detrimental to the quality and quantity of relationships in familial, educational and wider social settings; 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; and may impact negatively on parental mental health and the adolescent's wider support network. 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. However, there is a paucity of research on effective early intervention or depression prevention approaches tailored for this population.

The characteristics of autism (including challenges 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. 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. 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. Furthermore, 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.

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Aims

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

1. 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).

Research design and methods

Focus 1 employed an exploratory case study to survey the experiences and perspectives of school connectedness in students on the spectrum, their parents, and their 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. Participants were recruited from urban, rural and remote communities in the Northern Territory, Western Australia, and New South Wales: students with a diagnosis on the autism spectrum aged 11-16 years of age, their parents, and educators who had either currently or previously taught students on the spectrum within this age group. Data was collected from 106 participants (24 mothers, 27 students, and 55 educators) using semi-structured interviews conducted face-to-face or via telephone or videoconferencing to gain a rich perspective of their experiences of school connectedness. Thematic analysis of the transcripts was conducted using NVivo software, and considered how participant experiences influenced school connectedness, and explored the perceived individual, school, community, and system factors that enable or hinder school connectedness in urban, rural and remote areas of Australia.

In Focus 2, a multisite proof-of-concept study using a mixed-methods design was used to pilot and evaluate 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 in Brisbane, Queensland, Australia. Six schools 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 and had a diagnosis consistent with autism spectrum disorder (ASD), 40 parents/caregivers, and 16 teachers. Each adolescent attended 11 to 14 one-on-one weekly 1-hour sessions of the Resourceful Adolescent Program adapted for adolescents on the spectrum (RAP-A-ASD); 31 parents/caregivers of adolescent participants attended the Resourceful Adolescent Program for parents of adolescents on the spectrum (RAP-P-ASD), a series of 4 x 2-hour resilience building workshops for parents; and teachers at 5 of the 6 participating schools were able to attend a 2-hour Resourceful Adolescent Program for teachers (RAP-T) workshop. At each participating school, the research team formed a School Connectedness Committee consisting of school personnel, students, researchers, and parents; identified a project to increase school connectedness; and worked with the students to implement and evaluate the project.

At pre-intervention, post-intervention, and 3 and 6 and 12 month follow-up, quantitative data was gathered 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; and
- teachers about the adolescent participants' depressive symptoms, and behavioural and emotional difficulties and prosocial behaviours.

This data was analysed using the Reliable Change Index.

Semi-structured interviews were conducted with adolescents who participated in RAP-A-ASD; and with parents who attended RAP-P-ASD, and the qualitative data from students and parents was analysed using Consensual Qualitative Research (CQR).

In Focus 3, 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 3 day program in a strength-based workshop for 11 Indigenous community workers who work directly with Indigenous populations in Bourke, a town in a remote area of Northern New South Wales in Australia. The research team gathered qualitative data from the community workers who attended the RAP-PC program workshop at various timepoints across the 3 days, and the qualitative data was analysed using a thematic approach.

Following, 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 is available at autismteenwellbeing.com.au.

Findings

Focus 1 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, including:

1. the influence of the unique learning needs of autism on school connections, with results highlighting that schools working with students on the spectrum to implement strategies to help them to manage their anxiety, support their social connections, and help them to self-regulate is critical for developing and sustaining their school connectedness;
2. challenges to meeting autism-specific needs that inhibit school connections, highlighting the importance of considering how resourcing in schools can best be used to cater for the autism-specific needs of students on the spectrum in order to promote their connectedness;
3. autism-specific classroom strategies supporting connections, including individualised accommodations; providing structure, predictability, and quiet spaces to calm down; and using technology to support learning needs;
4. peer group dynamics that inhibit or promote school connectedness, with relationships with peers considered critical to school connections; and the strength or weakness of these relationships having a significant impact on school connections for students on the spectrum;
5. family factors that help promote school connectedness, with the parent role as an advocate for their child, indicating that 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;

6. characteristics of the community (its religious philosophy, supportive culture, availability of active parent groups, and in some cases being a small regional community) that promote school connectedness at a whole school, class, and individual level within the school community;

7. characteristics of an inclusive culture that support school connectedness, including 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;

8. professional learning in the community that supports school connectedness: and

9. roles of education staff in supporting school connectedness.

In Focus 2, results for the young adolescents who participated in RAP-A-ASD showed an increase in school connectedness and improved mental wellbeing. Key quantitative findings for adolescents showed that:

- the adolescents' responses reflected the greatest amount of reliable improvement for anxiety, total difficulties, school connectedness, and coping self-efficacy. Particularly high percentages of improvement were reported at 3 month follow-up, with over 45% of students reporting a significant improvement in anxiety and over 50% reporting a significant improvement in total difficulties. Improvements in school connectedness and coping self-efficacy were maintained across the 12 month period. Improvement in depressive symptoms increased between post and 3 month follow-up, and then remained stable up until 12 month follow-up.

- the majority of parents reported change in their adolescents that was not statistically significant across all measures at most time points, with the exception of coping self-efficacy which was equally distributed across improvement, deterioration, and no change; and the largest percentages of reliable improvement reported by parents were seen for depression (27.78%), anxiety (38.89%), school connectedness (25.00%), and coping self-efficacy (33.33%).

- 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%), and behavioural and emotional difficulties (24%).

Key qualitative findings for adolescents included:

- increased resilience;
- increased confidence in managing their emotions and keeping calm;

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- increased confidence in dealing with social situations;
- increased confidence in problem solving;
- increased ability to consider the perspective of others; and
- experiencing their facilitator as 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.

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 reported that the program:

- helped with their sense of isolation and validated their parenting;
- 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, thereby improving the parent-adolescent relationship;
- 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.

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.

In Focus 3, 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 the development of the Autism Teen Wellbeing website, 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. Initial traffic analyses of the website indicated good uptake, access of all sections of the website (for parents, teachers, schools and adolescents), multiple visits to the website by approximately a quarter of users, and the majority of users had watched the entirety of the 3-5 minute videos available on the website.

Limitations

In Focus 1, it was not possible to identify key influences that impact on school connectedness that are unique to rural and remote regions, as features of school connectedness appeared to be universal regardless of geographical location. In addition, recruitment of participants with a formal 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, hence fewer students met recruitment criteria.

For Focus 2, findings reflect the experience of a sample of parents of young adolescents on the autism spectrum in urban Australia, with generalisability reduced by its relative homogeneity, and twice as many female than male parents participating in RAP-P-ASD. 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. Further, 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. Also, 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.

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.

Implications for research and practice

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, and included:

- school communities identifying and responding to the unique autism-specific learning needs that may be influencing school connections for students on the spectrum;
- 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 in order to support their school connectedness and a sense of belonging;
- the recognition at a school level 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 (including those on the spectrum) at an individual, class, whole school, and school community level;
- collaborative partnerships and positive communication with parents and students to identify what is needed to meet the needs of students on the spectrum, and maintain their positive school connections; and
- professional learning 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.

In Focus 2, findings from the multi-layered, strength-focused School Connectedness Program (RAP-ASD in conjunction with the Index for Inclusion) appear encouraging for promoting mental health in young adolescents on the spectrum and their parents by showing 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:

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

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assist their child on the spectrum to navigate the developmental phase of early adolescence, and boosted their own wellbeing; and

- 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.

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 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.

For 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 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; and 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.

Key recommendations

Deriving from Focus 1, 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.

For Focus 2, the promising findings from the multi-layered RAP-ASD program for adolescents and parents, in conjunction with the Index for Inclusion, indicate that school-based strength-focused resilience interventions appear encouraging for promoting mental health in young adolescents on the spectrum and their parents. These promising findings lend support for:

- exploring the optimal focus and frequency of prevention and early interventions to promote more positive mental health with adolescents on the spectrum and their parents;
- a randomised control trial of the School Connectedness Program;
- developing the adolescent section (the middle of the circle) 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;
- continuing to offer the face-to-face 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;
- exploring the development of a hybrid model of RAP-P-ASD that uses communication technology to deliver the program content online, and augments it with digital resources and telephone and/or online chat to provide support 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; and
- continuing to implement the Index for Inclusion in schools to improve school connectedness and inclusive culture and practice in schools.

The CBPR project conducted in Focus 3 highlighted that there is a need for research for Indigenous people on the spectrum across the lifespan. 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. Hence, continuing 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 doing so by adopting a CBPR approach to foster collaboration, may reduce obstacles that inhibit Indigenous people's engagement in and utilisation of such programs.

Our values

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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