I just want friends: a 'relational wellbeing' approach to providing school support for a young person with Asperger syndrome

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The lame goat

You've seen a herd of goats Going down to the water.

The lame and dreamy goat Brings up the rear.

There are worried faces about that one, But now they're laughing,

Because, look, as they return, That goat is leading!

There are many different kinds of knowing. The lame goat's kind is a branch

That traces back to the roots of presence. Learn from the lame goat, And lead the herd home.

Jellaludin Rumi (in Intrator & Scribner 2003, p. 63)

Abstract

Vulnerable young people with impairments in their capacity to relate to others, such as those with Asperger syndrome, present a particular challenge to education professionals, schools and systems. Their social and behavioural patterns tend to place them at odds with school structures and staff expectations thus increasing the risk of exclusion (Swayne & Fielding n.d.). School and systemic responses may need to be tailored to individual needs in complex cases. This paper uses a case study of a young person diagnosed with Asperger syndrome to explore how an intervention incorporating the student's own ideas and insights into how his wellbeing at school could be improved contributed to an improvement in his capacity for social interaction as well as a significant reduction in his aggressive behaviour over a two-year period.

Introduction

The focus of this paper is on the potential benefits of an alternate approach to educational supports for young people with difficulties in interpersonal relating, such as those with Asperger syndrome. I suggest that current school and systemic responses to the needs of young people with difficulties in relating, such as those with Asperger syndrome, may need to be more sensitive, responsive and tailored to individual needs to address the complex learning, emotional and behavioural issues that can arise. I hope that this paper will provide insights into how it is possible to understand and address the underlying cause of the highly challenging behaviour of young people with Asperger syndrome by incorporating their own ideas and insights into how their school experience could be improved by helping them to make meaningful connections with their peers.

Asperger syndrome is a disability characterised by a deficit in the essence of relating, closeness and connection, limited capacity for imagination and a tendency towards fixation (Emmens 2007). Young people diagnosed with this condition present a particular challenge to education practitioners, schools and systems since their complex social and behavioural patterns tend to place them at odds with school structures and staff expectations, leading to bullying, social dislocation and suspension or exclusion from mainstream schooling (Swayne & Fielding n.d.).

At a system level, the education department in South Australia recognises in principle that, while a majority of young people may be seen to be catered for by universal care and education services, a smaller group of individuals and groups may benefit from targeted interventions, and a much smaller number of especially vulnerable children and young people require an individualised strategy to cater for their complex needs (Department of Education and Children's Services 2007). There has been a shift in recent times towards individualised education planning to ensure that all young people with disabilities can 'enjoy the benefits of education in a supportive environment that values diversity, inclusion and participation' (DECS Students with Disabilities Policy 2006). While the DECS 'Negotiated Education Plan' proforma does includes a 'student voice' section, in the researcher's previous experience as a project officer in the area of disability the planning process often

occurred with minimal meaningful engagement or involvement of the young person and therefore may not be tailored enough to meet his or her individual needs.

An alternative approach however, as proposed in this paper, is to gain an understanding from the young people about what is out of kilter in their environment and what might be changed to reduce potential difficulties (Tyrer 2002). This involves learning how to interpret the classroom environment from their point of view in order to gain a greater understanding of their perceived priorities. It also involves giving the young people an active role in identifying potential areas of change and contributing to improving the fit between themselves and their learning environment.

I explore this approach in this paper through a case study focusing on the experience of 'Jack', his teacher and myself as the researcher as we worked together to try to create a classroom environment more conducive to his needs. The goal of the intervention in this case was to build, via mentoring support that I gave to the class teacher, the capacity to understand, respond to and resolve issues related to Jack's social isolation and reactive behaviours and to increase opportunities for the generation of wellbeing and connection in her classroom to improve the quality of his school experience.

This case study research is nested within a larger project funded by an Australian Research Council Linkage grant and undertaken by researchers at Flinders University with partner organisation the South Australian Department of Education and Children's Services (DECS) between 2007 and 2010.

Methodology

This relational co-research case study (Finlay & Evans 2009; Ospina & Dodge 2005) is based in a particular orientation to research rather than a technique, with a focus on doing research 'with' people rather than doing research 'on' people. Unlike traditional research methods, relational researchers seek to develop relationships with research participants; they are viewed as co-explorers of a topic and highly valued (Finlay & Evans 2009).

In the relational approach 'data' is seen to come from the researcher and the participants in relationship with each other, emerging from the intersubjective space between researcher and co-researcher(s) and within the broader research context (Finlay & Evans 2009). The process of gathering data is thus viewed as 'primarily a co-creation' (Finlay & Evans 2009, p. 88) and the interview method is woven through the research project rather than being a discrete procedure applied at a certain point (Kvale 1990, in Curry & Wells 2006). In relational research, it is important that questions are 'held lightly' so as to leave space for responses to deviate into new territories that may be more significant and are yet unknown (Curry & Wells 2006, p. 40).

The relational, case-study and co-research orientation of this study formed the backdrop to a series of informal conversations with the young person and his teacher during a two-year period. These conversations were initially prompted by

questioning designed to explore what was going well and what was not going so well for the young person.

After listening to the young person's ideas and insights for improving his experience of schooling, I worked with the teacher to try to put some of these ideas into practice in order to improve their environment. As we got to know each other through these conversations, which were followed up with email conversations and reflections between the teacher and myself, it was possible to find commonality through 'natural and reflective' conversation which, according to relational researchers Curry and Wells (2006, p. 51), holds potential for insight and even transformation. From the outset I viewed the partnership between student, teacher and researcher as having the potential to lead to the 'making of an alternative knowledge' (Epston 1999) as we worked together to develop ways to improve a young person's schooling experience.

Background to the case

Jack was in Year 5 when I met him and causing significant concern to his teachers, the principal and his parents due to his highly aggressive, reactive and impulsive behaviour in class, the yard and at home. Since the school was part of the university–school research partnership the principal emailed me to indicate her concerns:

I'm really worried about the level of violence in the yard. It's really escalating. I think we need some help. (email, 10 September 2007)

This was reinforced in an interview with Jack's current teacher who stated:

He worries me. He doesn't have any friends. He is desperately lonely. He doesn't go the right way about making friends. He alienates the other kids all the time by his behaviour. (research diary, 10 September 2007)

Jack's behaviour in the yard over the rest of that year was leading some teachers to call for his suspension or even exclusion and some believed he would be better placed in a special school or class even though his above average intelligence would preclude such a placement. Early in the following year Jack's new teacher 'Pam' wrote to me in an email:

I am surprised by how challenged I am by this student, but I feel I have to go back to square one with him, to really get to know him. I want to go with a wellbeing approach and give it a good try. (email, 3 March 2008)

The new teacher and I shared a vision to create a genuinely inclusive classroom environment in which Jack would be given the opportunity to develop his relational competence through genuine 'experience-sharing' relationships (Gutstein 2000), rather than have him leave the classroom for social skill development in a withdrawal setting. We both believed, as does Male (2007) that young people can be assisted to build their capacity for social interaction and understanding if they are in 'a naturalistic environment that is dynamically enabling of genuine and meaningful relationships' (Male 2007, p. 470). We therefore decided to work together to

develop a more tailored, responsive and relational approach based on working with Jack and the whole class to help him feel a sense of belonging and of being valued by his teacher and by his peers.

I interviewed Jack at this point to gather information to inform the direction of the intervention. I found him a willing interviewee who seemed very pleased to be asked about his point of view. When asked about how things were going at school he replied:

I just want friends. I want to have a friend at school. Nobody likes me. Nobody wants to play with me.

He went on say:

I don't mean to hit them but they annoy me and they are mean to me and tease me. I know I am annoying sometimes, but some of my noises and things are meant to be annoying and some are not.

And:

I try to tell teachers but they don't listen. They are too strict and make me sit right in front of them. They don't let me have any fun. They are ok sometimes, but they don't know when I need a break. (research diary, 10 September 2008)

I then asked Jack about his strengths and interests and found out that he loved to draw and model out of clay, was passionate about racing cars and collected jokes and limericks, which he liked to share with people. He talked at length about how he would set up racetracks at home and draw up schedules for races involving cars with different engine sizes and modifications. He finished the interview by saying:

Now can you go and tell my teacher and Mrs D [the principal] what I have told you? I'm bored at school! I would really like to have a friend I could play with at school. I would be much happier then. (research diary, 10 September 2008)

As a result of speaking with Jack I became aware of his many skills and also his dry sense of humour. I shared the new information about his interests and concerns with Jack's teacher who was then released to spend time with me to plan an intervention. We agreed on a number of strategies drawn from the DECS resource *Recreating the circle of wellbeing* (Burrows 2007) and our respective experiences.

The intervention

Jack's teacher and I agreed to implement the following strategies:

- create a 'quiet' space at the end of the classroom for a racetrack area
- allow Jack to invite two classmates into this area at particular times during class
- establish a small supervised lunchtime racing club involving students from this and other classes

- share (with Jack and his parents' permission) information about Asperger syndrome with the class
- encourage classmates to invite Jack outside for a short run or to shoot some hoops when he was having difficulty staying focused
- engage the whole class in listening and sharing activities to find out about each other's strengths and interests
- create opportunities for Jack to demonstrate his skills in drawing and modelling to the class
- create opportunities for exchanges of jokes and limericks
- meet regularly with Jack and his parents for informal, supportive conversations to share how he was going at school
- engage in regular email conversations with one another for reflection, information sharing, documentation and support.

Outcomes of the intervention

Once Pam had been working with Jack for approximately three months she sent me an email:

I wanted to share a great [Jack] story with you. He has just worked so well with three boys who volunteered to work with him on his new racetrack. It was probably the best day I have had with [Jack] this year. He was totally engaged. (email, 18 May 2008)

Towards the end of the first year Pam emailed me with a more lengthy reflection on the intervention.

With Jack I had to look at how Asperger's affected him socially, emotionally and academically ... I had to go deeper in getting to know him because of his Asperger's. I realised the importance of knowing more about his personality and how Asperger's affected him rather than trying to control his behaviour.

At this school Jack stands out as being very different and it meant working with staff and the other kids in the class especially to be inclusive and accepting of him. At my previous school he would've blended in more.

I knew how important building relationships with kids was and I'd done that for years, but I knew that the behaviouralist stuff was not going to work best for Jack. I realised after a while that, as you suggested, stress did have a lot to do with how he reacted and that it was about keeping him calm and not stressing him out by putting pressure on him that he couldn't handle. I used your wellbeing resource to give me ideas, especially about how to keep him peaceful – I liked the more calm, gentle approach and ideas, the idea of him having a quiet space in which to work, of setting up routines that would be successful. (email, 22 November 2008)

In an interview that took place the following day Jack began by saying:

Can we have the interview in my racetrack room? I can't remember what I said to you last time but I am, oh yeah, much happier. Almost everyone likes me now.

I like Mrs F because she is so nice, she is really nice. She is fun and she helps me.

I really like having my racetrack area. I like to come in here and just be in here and have friends come in. My friendships are more interesting now I have this room and the racing car lunch club.

What I like best is that Mrs F doesn't talk to me like I am different or I have Asperger's or anything. She just talks to me like I am the same as the other kids. That's what I really like. (research diary, 23 November 2008)

When this was shared later with Pam she commented on how valuable it was to have the opportunity to reflect on the intervention in the context of the research project as:

There were so many changes I had forgotten because so many of the things that used to be of concern just weren't there any more. (email, 29 August 2008)

The school decided that Jack would have Pam as his teacher again the following year so as to build on the gains so far. At the beginning of the year he told his teacher:

I just want to be a Year 7. I am not that Asperger's kid any more. I am just a Year 7. (email, 28 January 2009)

He decided at this point he no longer needed his 'racetrack room' or lunchtime club as he did not wanted to be treated any differently from any other student. Pam found in any case that he was now able to work successfully with other students, participate in whole-class activities, excursions, fitness activities, sporting events, assemblies and a camp interstate. He was also elected as a class representative.

While there had ceased to be any behavioural concerns in relation to Jack when he was in Pam's class or when she was on yard duty, there were still occasional instances when Jack responded to teachers' demands to wear a hat or stay within bounds by running away or pulling faces. When Pam followed up his behaviour later on to ensure he made some kind of reparation he told her:

I did it because it was fun. I don't like this part, having to have meetings and talk about what I did and that but it is fun to make teachers mad. (email, 10 October 2009)

At the end of that year, which was also the end of the research period, I interviewed Jack again. He commented:

I've improved because I've changed everything that made me stand out as that weird kid. I'm not that weird dumb kid any more. Some kids just don't fit in. You can tell I am not one of those kids any more.

Kids seem to be happy to be my friend now. Year 4 and 5 were the worst years because I had no friends. In Year 5 kids bullied me because I was weird. Last year in

Year 6 they tried to be my friend – they included me in stuff. I could tell, I could read their minds, that some still thought I was weird. This year in Year 7 I'm not really weird at all and everyone considers me a normal friend.

I find it really hard to explain. It's about how teachers treat me and their attitude towards me. Mrs F is just the right teacher for me. (research diary, 18 November 2009)

In these interviews Jack provided information, not only about his own situation, with disarming frankness and insight. Throughout the study he remained directly involved in his own support provision whereby any decisions or changes were made through dialogue with him. Pam also conversed regularly with his parents and myself, and involved her students in supporting her to support Jack. In this way the emphasis in this case study research was on mutual responsibility for establishing a positive classroom environment.

At the end of the two-year intervention Jack was preparing to move on to high school. Had he been continuing on at his primary school it would have been timely to begin working more closely with selected other staff members to support the development of a more conducive whole-school environment and to help them understand the value of an alternate approach. Not all teachers at the school had supported the approach, which placed a great deal of responsibility on Pam to carry the intervention.

At the time of writing Jack had successfully made the transition to high school. There had been no incidents during the first two terms and the high school reported that he was able to develop positive relationships with his new teachers, thus indicating the transferability of the intervention to a new context (personal communication, 11 June 2010).

Summary and discussion

The focus of the intervention designed for Jack was not on trying to change him but rather on making changes in the classroom environment and atmosphere. This objective was addressed through a collaborative exploration of his needs and goals in relation to his schooling experience which were used to develop a supportive intervention.

Asking Jack about his concerns at school provided an opportunity to learn about and empathise with his feelings of extreme isolation and frustration due to the difficulties he experienced when interacting with others. His teacher and I came to see that these were clearly playing a significant role in his behaviour difficulties, something which according to Cumine et al. (2010) has not been sufficiently addressed in theory, research and practice in relation to conditions on the autism spectrum such as Asperger syndrome.

Jack was able to communicate his need for friends at school clearly and to demonstrate the importance of the social dimension for his wellbeing and learning if only someone would take the time to listen to him. According to Bauminger and Kasari (2000), young people with Asperger syndrome report greater feelings of

loneliness, such as those reported by Jack, than those without the disorder, while, as Male (2007) argues, peer acceptance and social status are widely understood as vital to the wellbeing of young people whether or not they have disabilities.

As Sherwood has noted, 'relationships are the centre of the classroom atmosphere' (2008, p. 27) yet the most common supports for young people with difficulties in relating are social skills programs delivered in a segregated setting by someone other than the regular class or subject teacher (Male 2007). Current approaches to support provision may therefore serve to make the young person even more isolated from peers and thereby further reduce social competence and the opportunity for teachers and peers to build their own relational competence through learning how to connect with the young person with difficulties in relating (Jordan 2008; Male 2007).

Recent research findings from this case study and others (Burrows 2008, 2009; Jordan 2008; Male 2007) have provided an incentive to re-evaluate the established approaches to support for this group of students. These studies have clearly identified the importance of providing opportunities for young people with disabilities on the autism spectrum such as Asperger syndrome to develop the skills of 'give and take' that are so necessary for friendship, in naturalistic, non-contrived settings as Pam was able to do in the context of her classroom.

While the main purpose of placing young people with disabilities in mainstream education is generally understood to be based in the desire to give them the opportunity to gain from cooperation and collaboration with peers without disabilities (Jordan 2008), positive social interactions between young people with and without disabilities do not tend to occur spontaneously and relationship building does not happen easily, especially for young people from diverse backgrounds or with different abilities (Cuckle & Wilson 2002, cited in Male 2007). In order to meet Jack's need for friendship and connection at school, and his teacher and school's need to reduce his frustration and aggression, it was necessary for Pam to scaffold Jack's social development by structuring opportunities for interaction with peers in the context of participating in mutually enjoyable activities, as Gutstein (2000) suggested.

In the intervention tailored for Jack there was a focus on creating opportunities to help him construct new meaningful relationships. The context for the generation of these new relationships was the naturalistic environment of his regular classroom, and firstly in the racetrack area or 'niche' which, as Tyrer (2002, p. 471) has observed, can provide a safe, calm space to assist in reducing eccentric, annoying and aggressive behaviours through minimising stress and incoming stimulation and enhancing physical and social wellbeing. As Male has noted, while 'Friendships cannot be created or manufactured ... opportunities to forge them can. In a climate of inclusion the challenge is to find ways of facilitating authentic friendships among children and young people with and without disabilities' (Male 2007, p. 469).

Jack's transformation through friendship and connection has clearly demonstrated the significance of peer acceptance and social status as important determinants of wellbeing for such young people (Jordan 2008; Male 2007). Having the opportunity

to voice his concerns and contribute to an intervention through his own ideas for improving his school experience is likely also to have increased his sense of self-acceptance and empowerment (Tyrer 2002).

Conclusion

I began this paper by suggesting that school and systemic responses to the needs of young people with difficulties in relating, such as those with Asperger syndrome, may need to be more sensitive, responsive and tailored to individual needs. I have explored the journey taken by a young person, his teacher and myself as we collaboratively developed an intervention designed to improve his school experience and reduce his aggressive, reactive, impulsive and annoying behaviour through addressing his underlying loneliness and isolation. Over a two-year period I observed an improvement in his capacity for social relating, emotional expressiveness and the ability to maintain attention and engage in classroom learning as well as a reduction in agitation and reactivity, leading to a successful transition to high school at the beginning of the following year. In this paper, through the vehicle of this case study tracing positive changes in the young person, I have offered a rethinking of traditional approaches to Asperger support.

This study found that taking into consideration the young person's strengths, interests and wishes and drawing on his insights into his own situation led to both an enrichment of educational experience and an enhancement of wellbeing in himself, his teacher, researcher and the whole class community as we all participated in and contributed to his unfolding growth and development. This study has found, as Tyrer (2002) has also demonstrated, that when people's strengths and eccentricities are acknowledged and accepted, their behaviours tend to become both less intense and less challenging to others.

The findings of this case study and others I have conducted (Burrows 2008, 2009) indicate that there is indeed a need for education professionals to be more sensitive to the needs of those who are different and to take their views into consideration when designing supports so as to create more tailored and responsive interventions. As Male (2007) has noted, teachers and teacher assistants are seldom given training in enabling young people with disabilities to have positive contact with their peers. I hope that this case study can contribute in a small way to the development of more tailored supports for young people with difficulties in relating, as in Asperger syndrome, through sharing the story of Jack, his teacher, his class and a researcher and their 'mutually enhancing connections' (Miller & Stiver 1997).

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