Learning from Each Other

The benefits of a participatory action research project on the culture, activities and practices of the adults supporting a young child with autism spectrum disorder

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ABSTRACT

Participatory action research advocates for teachers, parents and others to engage in practical inquiry as part of their everyday work for the purpose of improvement. Findings from this project affirm that a collaborative community of researchers, one in which the participants can critically analyse and transform their own situations, can have a significant impact on outcomes for students with autism spectrum disorder (ASD) (Meyer, Park, Grenot-Scheyer, Schwartz & Harry, 1998). This article identifies the shifts in perspectives resulting from engagement with this process for a team of adults. It also identifies the features of the team's experience that offer effective ways to work with students with ASD and their families.

Keywords

Action research, autism spectrum disorder, effective practices, parent participation, participatory action research, professional practice, teacher development, teams.

INTRODUCTION

Participatory action research (PAR) involves the people most concerned with an issue in evaluating and reflecting on the success or otherwise of their ideas and actions. In this way, teachers, families and support personnel become researchers. Working within the wider Ministry of Education-funded PAR project, this local project team included a parent, classroom teacher, teachers' aides, the resource teacher: learning and behaviour (RTLB), and the Ministry of Education, Special Education psychologist and speech-language therapist (SLT) working in the school.

Even with the distance of several years, it seems an anathema to talk about the child who was the focus of this project as "the child". For the purposes of this article we will call him John. At the time of this project, John was seven years old. He had been identified as 'a child functioning at the upper end of the autistic spectrum' (letter from paediatrician, RTLB files). For his family, his teachers and the external support people involved, the combination of above average cognitive ability, poor adaptive behaviours, characterised by an over-dependence on routines, idiosyncratic communication difficulties, a limited desire to interact socially with peers, and a tendency for inappropriate social interactions with peers, provided a set of challenges.

The local project team sought to: a) discover the most effective strategies across settings to increase reciprocal social interactions and b) to identify the tools and resources that would support that process. They also wanted to understand ways to include the family's goals in the long-term educational planning for John and to support both parents and teachers within their day-to-day contact with John. Owing to the word limits of this article the primary focus is to highlight the positive aspects of the project.

CHARACTERISTICS OF THE PROCESS

Working in site-based teams was a requirement of the project. At the initial meeting the team agreed to meet once a fortnight, in school time, using project funding to finance teacher release and to provide petrol vouchers to enable the parent to travel to meetings.

These fortnightly team meetings became the cornerstone of the project. Early on, a number of shared understandings were explicitly articulated, which guided the culture of the team meetings and, by extension, the interactions between the adult participants. They included:

- maintaining a shared language base for all discussions
- establishing the equality of all team members
- the adoption of a "disciplined listening" approach by specialist professionals
- conscious efforts to remove barriers to engagement
- an ethos of collaborative problem-solving.

Shared language

Prior to the initial team meeting, the specialist professional members of the team (psychologist, SLT and RTLB) determined that they would limit their use of specialist language and professional jargon to the minimum necessary. When necessary, explanations of specialist terms and knowledge would be openly and fully shared with all team members. Glatthorn (1990, cited in Mundschenk and Foley, 1997) identified a common language base as a factor in the process of building an effective team.

Equality of all team members

The equality of team members was seen to be a critical factor in ensuring the voice of the parent and teacher were heard. Friend and Cook (1992, cited in Mundschenk and Foley, 1997) described the process of collaboration as a style for direct

interaction between two or more equal parties who voluntarily engage in shared decision-making to achieve a common goal. Within the team, there was an explicit agreement that the specialist voice carried no greater weight than the voice of the parent or teacher. The expertise of each member of the team was clearly articulated:

- the parent: was the expert on her child in all out-of-school settings, and had the greatest experience of the child's development history
- the teacher: was the expert on the child in the school setting
- RTLB, psychologist and SLT: possessed differing degrees of knowledge about children with ASD and experience with possible strategies for intervention.

"Disciplined listening"

At team meetings the specialist professionals adopted an approach they coined "disciplined listening", consciously choosing not to respond immediately to every issue with suggestions about how to resolve the situation. When issues were raised, discussion was allowed to develop, questions were asked to clarify understanding, and further sharing of information was encouraged. These conscious actions allowed a climate of trust and mutual respect to evolve in which the contributions of all team members were valued equally. The following comments are drawn from the evaluative questionnaire completed by all team members at the culmination of the project:

> **Mother:** It was great to be part of a team where we all had something to offer. I have gained in confidence in talking to professionals about John.

> **RTLB:** It was a privilege to have such access to the parent's perspective, to be able to sit and really listen, clarify and question until I had a really good picture. It has made me reflect on how easy it is to allow the professional viewpoint to overtake the perspective of classroom practitioner or parent, particularly when there are time constraints to meetings. The professional voice becomes louder and more weighty (expert evidence) than the real life reporting of those most closely involved with the child.

Removing barriers to engagement

The informality of team meetings and the ability to meet regularly and within school time, allowed all team members to be equal participants. The negotiated teacher release freed the teacher from the need for additional meetings outside contact hours, and the ability to reimburse the parent for travel costs ensured neither was constrained from attending by their professional or family responsibilities.

Collaborative problem-solving

The team deliberately developed an ethos of collaborative problem-solving. Because there was no one "expert" taking the lead, the responsibility for problem-solving was shared. Agreement from all parties was a crucial aspect of the project at all stages: identifying areas of concern, determining the initial goals, designing and implementing interventions, and developing a means to share reflections and track progress.

> **Teacher (2003):** Team members treated one another equally – used each other's strengths and knowledge to improve their own.

DEEPENING UNDERSTANDING OF THE ISSUES FOR THE FOCUS CHILD

At the outset, each team member undertook to get to know John well. The team began with an examination of existing records. They also shared information about John's interests, skills and challenges. In order to establish the accuracy of the assertions made, further data were collected using checklists (Cumine, Leach & Stevenson, 1998; Gutstein & Sheely, 2002).

The Relationship Development Intervention Progress Tracking Form (Gutstein & Sheely, 2002) proved extremely valuable in this process. As it was revisited throughout the year the complex nature of the form forced the team to examine the critical factors that affect communication and the way they applied to John. These discussions led to critical distinctions between John's behaviour patterns at home and at school, which in turn led to an examination of the causal factors for behaviour. The deeper understanding gained by all team members proved valuable in developing targeted interventions.

> **Mother:** I have much more awareness and understanding of his behaviour and learning at school because I now know he behaves completely differently at home to what he does at school. I can also anticipate situations that might cause him distress, such as cross country or camp, and work with teachers to increase his chances of participating and not becoming overloaded.

> **RTLB:** I am more informed and aware of the subtleties of social interaction, the complexity of skills required in the development of social relationships and the development of empathy.

Each team member agreed to keep a reflective diary. John's mother recorded her personal reflections and comments on the social relationships within the family, extended family and friendships. The teacher kept anecdotal records of classroom interactions and events and of social interactions in the playground. These diaries became a record of ideas, reflections and anecdotes, which were often shared at meetings.

INTERVENTIONS

As the team learned more about John, and shared communication, a number of strategies were used to varying effect.

Social Stories™

Carol Gray asserts that the purpose of Social Stories™ is to 'teach social understanding over rote compliance, to describe rather than direct' (Gray, 2000, p. 12). Therefore the goal of a Social Story™ is to share social information, not to change behaviour.

A number of Social Stories™ were used successfully throughout the project. Each story followed Carol Gray's premise that 'the child's needs determine the topic of the story; the child's perspective determines the focus of the story' (Gray, 2000, p. 12). See Appendix 1 for a Social Story™ example.

Comic Strip Conversations

Comic Strip Conversations, as described by Carol Gray, are a way of conducting a conversation between two or more people, which incorporates the use of simple drawings. 'Comic Strip conversations systematically identify what people say or do and emphasise what people may be thinking' (Gray, 1994, p.1).

Comic Strip Conversations were introduced in the latter stages of the project. The goal was to introduce a tool that would increase John's ability to communicate concerns or worries with his mother and his teacher. Whilst Comic Strip Conversations did not prove useful with John, they were very useful for his mother, revealing further subtle dimensions of social communication, which became the focus of ensuing team discussion.

Teacher strategies

The teacher incorporated a number of adaptations to her teaching style and classroom management techniques to optimise John's inclusion in both the social and academic dimensions of the classroom. In the early stages these adaptations grew out of discussion at team meetings or were in response to suggestions from others in the team. As the project evolved, adaptations grew out of the teacher's own reflection. This process became an instinctive part of her repertoire. The teacher would think of a new way to do something, trial it in her classroom, and then share the results with the team at the next meeting. Strategies incorporated by the teacher included communication strategies, organisational strategies, modification of the classroom environment, and curriculum adaptation.

Modelling and rehearsal sessions with teacher's aide

Teacher's aide support was used briefly for modelling and rehearsal of specific communication skills as a follow-up to Social Stories™. It was evident from his behaviour and comments to the teacher's aide that John did not enjoy these withdrawal sessions, preferring to remain in the classroom with his classmates. Following discussion at the fortnightly meeting the team discarded this intervention after the fourth session.

Background information for teacher and parent

Professional development for the teacher was provided to give background knowledge about ASD. Reading material was made available to John's parents and teachers throughout the project (see Attwood, 1998; Myles, Cook, Miller, Rinner & Robbins, 2000; Winter, 2002).

OUTCOMES

What was the specific impact of the PAR project: on John's family, and the culture, activities and practices of the educational setting?

The knowledge and understanding of ASD of all team members was increased through the stimulus to read and discuss information from all sources including the literature associated with the project. The combination of the provision of reading material and opportunities for follow-up discussion provided a dynamic learning situation, which was particularly appreciated by the parent who found it assisted her to build a much deeper understanding of the impact of autism for her son.

Mother: Before the project I knew John was an "unusual little boy" but I did not connect his behaviour with what I had read and been told by professionals. Now I am able to analyse issues and problem-solve situations as they arise and see what is behind his behaviour. My learning has had a flow-on effect to John's father. He has read some of the books I have brought home and has a greater understanding of John.

The usefulness of the reading material supplied through the project, in comparison to reading material supplied previously, has implications for professionals handing on reading material to parents where there is no opportunity for follow-up or discussion.

What was learned?

Learning from, and with, each other

Carol Gray asserts, 'the impairment in autism is shared' (Gray, 2000). By definition, social communication involves more than one party. Whilst those with ASD may not easily understand typically developing peers, equally, typically developing peers do not easily understand those with ASD.

Over time the shared perspective of the team members shifted the focus of intervention from a pathological model, that is, how the child's communication was impaired and how it might be "fixed", to a shared communication model. The consensus decision of the team was to be guided by Carol Gray's statement. As a result, team discussions gained the additional foci of developing greater understanding about what motivated John's behaviour and reflection on how the significant adults in his life modified their behaviour to allow them to communicate effectively with him. Intervention strategies became vehicles for sharing information about communication with John, rather than strategies to "fix problems".

The emerging culture of team and individual reflection

Team meetings became a forum for an emerging culture of reflection that led team members, particularly the parent and teacher, to modify their own behaviour. As the project evolved, both the teacher and parent reported modifying their interactions with John as a result of keeping a diary and discussing issues at the team meetings.

Teacher (2003): I noticed how many questions I ask John in a day. The majority of conversations can actually be questions.

The team discussions and the reflective diaries became recognised as interventions in themselves. The mother commented in team meetings that keeping the diary had given her a great deal of insight into the way her son thought and felt, how he saw the world and how this differed from her own perceptions. She noted that keeping the diary had made her much more observant and aware of her son's behaviour and interactions with others. It had also been instrumental in helping her find ways to minimise his stress.

Mother: I have a much deeper understanding of environmental situations and how they might impact on John's thinking and feeling so I can anticipate how he might react. I understand he often misses the point of communication and I am continually learning how to communicate effectively with him.

The PAR model made information about ASD come alive for the mother. She was no longer being **told** about her son but acting from a point of inquiry which, over time, evolved into a culture of self-reflection.

Team meetings vs. the individual education plan (IEP) process
The regularity and frequency of the fortnightly meetings ensured issues were dealt with as they arose, before escalating to crisis stage. The team reflected on the value of the team meetings as compared to the term-by-term or twice-yearly IEP meetings common in New Zealand schools.

> **Teacher**: The IEP process gets you set up for receiving these children but then you feel like you are a bit out on a limb. Regular meetings keep you focused and trying new things. IEPs don't give you the chance to continually follow up concerns and problems and find out relevant information that helps make life easier for the child.

CONCLUSION
Three significant themes emerge from this case study:

1. **The positive impact for children with ASD of a committed support team, which includes school, home and consultant specialists and the processes that support effective teaming.**

   Consultant special educators wishing to develop an effective collaborative relationship need to be sensitive to the background and training of all team members and ensure that conversations promote a shared language. When specialist educators adopt an approach that ensures the parent and teacher voices are heard and allowed to guide the process, interventions are more likely to be appropriate and feasible thus ensuring "buy-in" from those implementing the interventions.

   The key components of effective practice that supported the development of an effective team are encouraging:

   • all participants to communicate in a natural mode
   • equality within the team by explicitly identifying the expertise of all participants.

2. **An indepth examination, by the team, of behaviours and issues of concern regarding the individual child with ASD, can contribute to greater understanding, the development of empathy, and shifts in perspective for team members.**

   Team discussions between equals (hearing another's story) encourage the development of empathy, can precipitate shifts in perspective from a social deficit paradigm to a paradigm of shared communication and can lead to the practice of critical self-reflection. This process can precipitate shifts in interaction patterns and create different outcomes for the child with ASD as the significant adults accept responsibility for a "shared impairment of communication" (Gray, 2000).

   A combination of data collection tools is a valid means to precipitate and guide focused and meaningful discussions.

3. **The positive impact of flexible resourcing that allowed the team to meet regularly.**

   There are benefits from regular, less formal contact between home, school and consultant specialists. There is a positive impact when resourcing is committed to allow the classroom teacher release time. In this project the benefits of using financial resources in this way exceeded the benefit of using those same financial resources to provide teacher's aide support.

   Regular team meetings can become an alternative to the IEP process. Goals are smaller and more relevant as meetings become focused on key competencies and remain more responsive to the day-to-day reality of the child's changing world.

FOUR YEARS ON
Four years on what has been the long-term impact of participation in this process for one team member – the classroom teacher?
Following two years away from school, the 2003 teacher from this team returned to classroom teaching in 2007. One of the children in her class was a boy identified with ASD (identified below as A). In early 2008 she agreed to an interview to explore the impact of this project on her practice and her perspective regarding teaching children identified with ASD:

> Thinking back I think the biggest thing for me was I'd never had an ASD child in my class before. I really knew nothing about it so it educated me a lot about what Asperger syndrome actually is. Last year when A came along he had a lot of similar characteristics. It got me back into that framework of making everything visual and making sure he wasn't panicking about what was going to happen … I was more relaxed with him. I could just straight away make changes within my classroom.

> I could use a lot of those things that I learned about John in the classroom. It's just little things that you don't particularly take too much notice of – they might not seem important to us but you get to understand that, to people with ASD, it's a huge thing – it's their coping strategies – it's just making little changes that made his day a whole lot easier …

> I didn't stress at all with A. There wasn't one moment there – you know he used to have his little outbursts and things – but there was not one moment there where I felt unable to cope or like I didn't know what was going on …

> I think about those meetings and what a difference it made putting different perspectives into it … it just made everything make more sense and you could understand more where John was coming from. I think that's a huge thing … we had the chance to piece together all those little bits and it made everybody's job easier …

> It's been an amazing journey for me and I feel really lucky to have gone through it – I've enjoyed working with those kids so much and I've learned so much about them – I'd really encourage anyone who could to be part of something like this – you know watching [John's mother] become more confident in our meetings and say more. There's so much we can learn from them. It's got to be beneficial for everybody.

APPENDIX 1
A sample Social Story™
My class next year: Christopher[1]

My name is Christopher. I go to Corokia Primary School.

At Corokia Primary School I am in Room 7. My teacher is Mrs Smith. Here is a picture of Mrs Smith.

After my holiday my new teacher will be Mrs Brown. Here is a picture of Mrs Brown. It is OK to be in Mrs Brown's class next year.

After my holiday my new classroom will be Room 11. Here is a picture of Room 11. It is OK to be in Room 11 next year.

The children in Room 11 put their bags outside the classroom. I will put my bag outside Room 11 too. In Room 11 we will all eat our lunch on the deck.
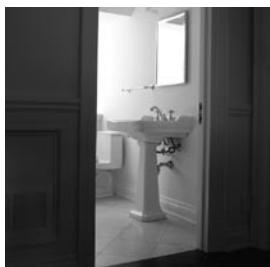
The toilets for Room 11 children are beside Room 12 and 13. Here is a picture of the door to the toilets. Mrs Brown will show us where the toilets are again when we are in Room 11.

This is a picture of Room 11's reading corner. In Room 11 the children read books in the reading corner. When I am in Mrs Brown's class I will read books in the reading corner too.

[1] This is a fictitious Social Story™ example, using photo library images.

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From a background as a primary teacher, Robbie Lamont became involved with special education in the early 1990s. Since then she has worked as a specialist teacher, a special needs coordinator, an RTLB and a special education advisor. Since 2004 Robbie has been involved with Te Kōtahitanga. She currently works in Te Kōtahitanga Research and Professional Development team with Waikato University.