



FRONT COVER
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MINISTRY OF EDUCATION

Te Tāhuhu o te Mātauranga

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Editorial

This special issue of *Kairaranga* celebrates the meeting place between research and practice in the autism spectrum disorder participatory action research (ASD PAR) project. The article *With Hindsight* introduces readers to this project.

Participatory action research is described in an article of the same name, which also introduces some challenges to working in this way, including ethics. *Ethical Principles in Practice* picks up on this and describes the complexities of ethical processes and considerations for the ASD PAR project. Ethical reasoning often raises more questions than answers, yet the requirement to act ethically is something all professionals grapple with whether doing research or engaged in practice. This article stresses the importance of ethical behaviour regardless of ethical approval process used.

In our fast paced world, change as much as new knowledge seem to be constants. A thread running through this issue is the application of newly acquired knowledge to the frontline of service. Both *Building Communities of Support around a Child with Special Education Needs* and *Learning from Each Other* clearly illustrate the value of learning in a team, and celebrate the strength of hearing a range of voices when working together. *Teaming from Three Perspectives* captures diverse voices with excerpts from interviews with participants. *Making Assumptions vs. Building Relationships* effectively challenges readers to carefully examine their own "taken for granted" beliefs and practices. While these articles go deep into the work of specific teams who took part in the ASD PAR project, *What We Did* and *What Works for One* provide a synthesis of the work carried out across the project as a whole.

In this issue of *Kairaranga*, the twine of practice and research has met to provide a contribution to practice-based autism spectrum disorder research. The ASD PAR project is neither the beginning, nor the end of the Ministry of Education's commitment to help support children and young people with ASD as well as their families, whānau and education settings. Exciting evidence of this ongoing commitment is the recent publication of the *New Zealand Autism Spectrum Disorder Guideline*, a summary of which is included with this issue of *Kairaranga*.

Anna, Daphne, Jill, Joanna, Valerie, Vanesse and Paul

Kia tītiro anganui tonu atu
Ki te ao kei mua

Engari, kia mohiotia ai e anga pehia ana tatou
Kia mahara i ahu mai tatou i hea

Live not in the past

Look forward instead towards the future

But in order to know where we are going

It is well to look back to see where we have been

Kairaranga

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With Hindsight

An overview of the autism spectrum disorder participatory action research project

Joanna Curzon

Team Leader – Research, Professional Practice, Ministry of Education, Wellington



INTRODUCTION

Much has happened since nine teams across New Zealand engaged in a Ministry of Education-funded participatory action research project looking at effective practice for supporting children and young people with autism spectrum disorder (ASD) in education. Building on earlier discussions, the project ran from 2002 to 2004, and until now the story has never been told in full. This article is intended to provide a background to the project, describe the project from a national perspective, profile the teams and their work, and share some of the achievements and challenges.

Keywords

Action research, autism spectrum disorder, effective practices, participatory action research, project management, reflection, research projects, teams

BACKGROUND TO THE AUTISM SPECTRUM DISORDER PARTICIPATORY ACTION RESEARCH PROJECT (ASD PAR)

Origins and early stages

In 2000, the government commissioned Dr Cathy Wylie to undertake a review of Special Education 2000. The resulting report, *Picking Up the Pieces* recommended 'Encouragement of teachers and others to research practice in relation to impacts for students with special needs, their peers, and those who work with them, so that practice can be soundly based' (Wylie, 2000, p. 14).

At the time of the Wylie review, the Ministry of Education was supported by the Autism Spectrum Disorder Reference Group, which contained a broad range of representatives with experience and expertise in autism spectrum disorder (ASD) and education, including people with ASD and parents of young people with ASD. One of the main objectives of the ASD Reference Group was to improve services for people with ASD, amidst concern about the lack of information on effective interventions and programmes for children and young people with ASD in New Zealand.

In March 2000, the ASD Reference Group was so concerned that it proposed and seconded the following motion: 'The ASD Reference Group strongly recommends the development of local action research projects for educational and community support best practices in ASD which are research-based and relevant to Aotearoa nationally and regionally (Autism Spectrum Disorder (ASD) Reference Group, 2000). Later that year, the Ministry of Education, on behalf of the ASD Reference Group, commissioned two highly respected New Zealand researchers, Professor

Luanna Meyer and Professor Ian Evans, to draft a proposal for conducting the proposed research. The proposal, which drew on the work of Prizant and Rubin, was presented in final draft form to the ASD Reference Group in December 2000. Subsequently, the Ministry of Education commissioned a two-year action research project to: identify and understand the factors that influence educational outcomes for young people with ASD; put the knowledge gained into practice; and share the findings with other settings.

An ASD Research Committee (a sub-set of the ASD Reference Group), was formed to oversee the project, and was supported by Dr Anne Meade to further develop the Meyer and Evans proposal. Members of the ASD Research Committee were central to the way in which the project unfolded and played a pivotal role in developing the early conceptual framework for the research project; in selecting participants and in overseeing/monitoring the project.

Within the ministry, the project was led by and involved staff from special education and the research division. After a request for proposal process, the ASD Research Committee and the ministry contracted the then College of Education, Christchurch to provide overall project management of the action research programme. Additional researchers from the Donald Beasley Institute, Dunedin, were in turn brought into the contract by Christchurch College of Education. These groups (the ASD Research Committee, Ministry of Education project staff and the researchers from Christchurch College of Education and the Donald Beasley Institute) together formed the joint national project management team.

Principles

The ASD Research Committee developed principles for the focus of the research project. Drawing on the Meyer and Evans paper, it was agreed that the local projects would:

- include a process to plan and implement individualised interventions based on the child's developmental/curricular needs, family and functional priorities, and socio-communicative inclusiveness
- be age appropriate and culturally sensitive
- focus on the core characteristics of ASD
- consider how learning would be generalised across settings
- consider home-school-community links
- include new learnings as they became available.

The full list of principles developed by the ASD Research Committee is provided as Appendix 1.

Effective practice and ASD

Despite anecdotal reports of effective programmes and supports in New Zealand early childhood education services and schools, there was no formal record of what was happening. This meant that people who wanted to learn more about effective practice in action did not know where to look. Questions abounded: What did "effective practices" look like in the range of New Zealand education contexts? What helped and what hindered these practices? How did they compare with formally researched overseas approaches? Could such practices be used in other settings and contexts?

The research project sought to identify and build on existing effective practices and programmes. The key aim was enable teams around children and young people with ASD – families, whānau¹ and education professionals – to critically examine their practices and, if need be, modify them to enhance education outcomes for the young people at the centre of the project.

Working with Dr Meade, the ASD Research Committee and the Ministry of Education project staff fine-tuned the focus of the research and generated the following research questions

- What are the key components of effective practice in education for children and young people with ASD as identified through the participatory action research projects?
- What is the specific impact of the participatory action research project on the child or young person with ASD; their family, whānau; the culture, activities and practices of the educational setting?

Why participatory action research?

A research approach was needed that captured the elements of effective practice already occurring in the New Zealand context and supported those who were poised to enhance their practice. It was intended that the project would thus act as a catalyst for greater understanding and awareness of the characteristics of effective practice for supporting young people with ASD, in the full range of education settings.

'Ultimately it is for *us* to examine our own practices and act to improve them' (Wadsworth, 1991, p. x). Action research provides a flexible yet rigorous research framework for examining everyday practice in action². The term "participatory action research" (PAR) was chosen to emphasise the pivotal roles played by the participants in the project in examining *their* practice in *their* contexts. Strictly speaking, PAR originates from the participants, who decide what they want to examine and why, and who generate their own research questions. In this project, the research questions were generated by the ASD Research Committee, which included parents of people with ASD, and educators, but who were not actually action research participants. Nevertheless, at the start of the project the term PAR was adopted.

Engaging in PAR utilises processes familiar to practitioners. This rationale was provided by Dr Anne Meade, who subsequently wrote 'Both reflective teaching and action research use cycles of planning, acting, observing (studying), and reflecting, before swinging into another cycle of planning and acting' (Meade, 2006, p. 5).

Scope and scale

The PAR project was designed to support nine (originally ten) local project teams based in early childhood education, primary, intermediate and secondary school settings. Intended participants included educators, students, parents and relevant community agencies, who were to critically reflect on their own approaches to teaching and supporting children with ASD.

Mentors

Included in the original Meyer and Evans design was provision for mentors ("critical friends"). Their role was to support the local project teams in developing systems and procedures that were both consistent with effective educational practices and built on teams' own innovative approaches. Working together, it was expected that mentors and local project teams would evaluate the impact of the PAR process on the learning and development of the young people with ASD at the heart of every local project team.

Getting started

Determined to make it as simple as possible for prospective local project teams to learn about and get involved in the project, a plain language expression of interest process was devised. Eye-catching postcard invitations were widely distributed through direct mail from the Ministry of Education team and also via community organisations and networks, with Ministry of Education resources. Recipients included parent and whānau groups; every early childhood education service; every school; relevant professional associations, such as the NZ School Trustees Association; all Child, Youth and Family local offices; all special education services; and health-funded services, including paediatricians, Needs Assessment and Service Co-ordination services and Child Development Teams.

More detailed, yet plain language, information was available on the Ministry of Education website and through various education newsletters. Those who wanted to learn more about the project or submit an expression of interest were encouraged to ring an 0800 number or access the ministry's website and request a full information pack.

Recruiting the local project teams

The criteria for selection were provided on the website and in the printed information packs. Once again, the development of the criteria involved the national project management team. The language was deliberately kept as accessible as possible, as the following extract from the information sheet illustrates.

¹ Immediate or extended family.

² For an introduction to action research, see the article in this issue *Participatory Action Research: An Overview*.

"Each local project team will:

1. include – as a minimum requirement – educators, family, whānau members, and relevant community agencies
2. be based at an early childhood centre, school or identified cluster of centres and schools, preferably close to the home of the child or young person with ASD;
3. demonstrate effective educational practices to meet the needs of identified children and young people with ASD;
4. involve inter-agency collaboration to incorporate selected family, whānau and community support activities outside the school day (e.g. recreation, respite). These will include, where relevant, plans for generalisation of learning across settings;
5. ensure ongoing professional development for educators, family and whānau in effective practices for children and young people with ASD;
6. receive technical assistance and support from a mentor."

The information went on to provide more detail about the support that would be provided and the expectations of the participating local project teams. Specifically, prospective participants were informed that they would:

- ... participate in a national network, which includes
1. communicating with other local project teams and sharing lessons learned from the participatory action research;
 2. contributing to the dissemination of findings from the project
 3. participating in a national evaluation and monitoring framework as mutually agreed.

Selection of the local project teams occurred in two stages and was carried out by representatives of the national project management team. The first stage was a paper-based activity, in which expressions of interest were examined for evidence that they met the criteria provided. The national project management team was also charged with ensuring an equitable spread of local project teams that included child or student ethnicity, the full range of education settings and a range of geographical locations

Every shortlisted local project team was visited by two members of the selection panel, who carried out a structured interview and were provided with evidence that the local project team did indeed meet the criteria.

Despite widespread dissemination of the information, only six local project teams met all the criteria, were matched with mentors and got under way. Six months later a second call for participants was required to secure four further local project teams and achieve equitable representation across settings and locations. Although at this point ten teams were formed, sadly the young person at the centre of one of the teams subsequently died, so that project (in a kura kaupapa Māori setting³) had to be discontinued. Instead, the funding

that had been set aside for that local project team was used to commission a regional study of Māori perspectives of ASD⁴.

More about the local project teams

Local project teams were located throughout New Zealand, including urban, rural and remote regions. Each local project team had a unique and dynamic configuration. Some had a relatively simple structure that involved a typical educational team supporting one child at its centre. Others had a tiered structure, with a team leader and several sub-teams operating quite independently, each one supporting an individual child. A couple of projects spanned early childhood education and school settings.

In total, 16 individual children were supported by eight local project teams and associated sub-teams. (One local project team researched elements of their setting and did not focus specifically on individual children.) The group of young people supported by the local project teams included boys and girls ranging in age from three years to 18 years, all with a diagnosis on the autism spectrum. Children and young people were supported in early childhood education services, at home, in regular school classes (primary and secondary), special school classes, and school-based special education classes (secondary).

Participants across the local project teams included parents, whānau, carers, siblings, peers, classroom teachers, principals, specialist teachers (learning support teachers, resource teachers, learning and behaviour (RTL), teachers funded through the Ongoing and Reviewable Resourcing Schemes), learning support coordinators, teachers' aides, and specialist practitioners from Ministry of Education, Special Education (GSE) (eg. educational psychologists, speech-language therapists and early intervention teachers). Summary information about the teams is included in Appendix 2.

More about the mentors

Every local project team was assisted by a mentor with skills in action research and in educating children and young people with ASD. As with the local project teams, mentors were also recruited through simple expression of interest forms that were sent out to all tertiary education organisations, ASD organisations and known leading ASD educators.

Ten mentors were selected alongside the original ten local project teams, though some mentors supported more than one team and some teams were supported by more than one mentor.

The mentors and local project teams worked together to decide on the team's support needs and therefore the focus of the mentor's role. Common strands to the mentors' roles included supporting the local project teams to clarify and refine their research question(s); identify, gather and analyse relevant data; and provide relevant professional learning and development.

³ Māori language primary school

⁴ Bevan-Brown, J. (2004). Māori perspectives of autistic spectrum disorder. Wellington, New Zealand: Ministry of Education. Available from www.educationcounts.govt.nz/publications/special_education/5479

ASD PAR IN ACTION

Resources and professional development

In keeping with the collaborative intention of the overall project, groups of local project teams and their mentors were hosted at two, two-day national hui.⁵ The first hui was facilitated in person by Yoland Wadsworth, a recognised leader in action research and community initiatives. Yoland joined the second group's hui via teleconference, but the format of both was similar and involved an introduction to action research; support for refining and further developing the local project teams' own research focus; and an outline of the resourcing and processes available to support the local projects.

All teams were provided with a core kit of useful books and articles on action research and ASD. They also received a modest set-up grant (\$2,250 per team) from which to purchase additional resources, as well as funding for professional learning and development (\$6,750 per team), and participant release and any other necessary supports, such as child-care (\$3,600 per team). The mentors' time was funded, as were their travel and resource expenses. The most valued resource was time – time to meet as a team, time to work with their mentors, time to gather and reflect on data, and time to compile their reports. Local project teams reported their appreciation of funded time for parent team members as well as for teachers.

Reporting

The local project teams and mentors provided written reports on the projects to the Ministry of Education, on the understanding that the reports, and any details that might publicly identify the projects, would remain confidential. The format for reporting was open, so that teams could focus on the message rather than the medium.

The teams and their work

The table in Appendix 2 profiles the teams who participated in the ASD PAR project and outlines what each team chose to focus on. For specific findings generated from the teams' efforts, see the articles *What We Did* and *What Works for One* in this issue.

ISSUES, OPPORTUNITIES AND WHAT WAS LEARNED

Project management

Although the national project management team managed the day-to-day running of the project, the Ministry of Education retained responsibility for all the contracting, funding and related reporting arrangements with the local project teams and the mentors. The result was that there were several layers and groups within the project – local project teams, mentors, the national project management team, the ASD Research Committee and Ministry of Education staff from both the special education and research divisions. Once the local project teams and mentors had embarked on their projects, some confusion arose about responsibilities and lines of communication. When reviewing these processes in 2003 it was found that the national management structure did not facilitate effective communication processes between local project teams, mentors, and the ministry. Consequently,

the project management was centralised and brought inside the ministry.

Arguably, a pure PAR approach would be entirely self-managing and self-contained, and no external project administration would be required. In contrast, the ASD PAR project consisted of several local projects and sub-projects, each with a distinct identity. With the benefit of hindsight, perhaps more thought should have been devoted to designing project management structures that better supported a federated approach, encouraging the autonomy of local project teams.

Communication

Local project teams and mentors were encouraged to report on their progress and findings (positive and challenging) using the format or media that best suited their project. One project, for example, used a series of face-to-face presentations with accompanying samples of work. Some local project team members and mentors appeared disconcerted by the absence of formal reporting requirements and templates.

There were two principal expectations around communications. The most important objective was for the local project team, their mentor and their wider community to learn more about their own practices – what was effective, and why. Secondly, it was hoped that local project teams would share their learning, their discoveries and their reflections with one another and so discover both commonalities and unique characteristics.

In practice, some teams were so busy actually engaging in their local project that they ran out of time for much reflection and sharing. For others, challenging confidentiality dilemmas surfaced, causing a couple of teams to reduce their interactions with others. Practical challenges, such as changes of team members, caused a couple of projects to lose momentum. These are the realities of fax-roots action research, and this special issue of *Kairaranga* presents some of the forms in which some teams chose to share their findings.

Ethics

In more traditional research, the distinction between researcher and researched is very clear. A participatory action research approach blurs the lines because it involves the participants carrying out research on and about themselves. Can a parent give informed consent for their child to be involved in a participatory action research project when he or she (the parent) is also a researcher? See the article *Ethical Principles in Practicæ* in this issue for an overview of some ethical considerations that are particular to this form of research.

Sharing what was learned

The ASD PAR programme was a complex and ambitious set of nested and highly diverse projects. The death of the student at the centre of one of the projects, changes in personnel, changes in the project management structure, and confusion about the ethical considerations combined

⁵ Meeting

to cause a check to the planned sequence and timescale of the overall project. The duration of the project funding was known from the outset, but when it came to an end, a number of the local project teams had neither completed nor documented their reflections. Some teams have shared their findings at local or regional events. Others have chosen to adopt strategies learned in the project and to use them with all students in their setting. And some have chosen to tell their stories through this special issue of *Kairaranga*.

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Joanna Curzon

Joanna Curzon is currently the Team Leader: Research in the Professional Practice team, Ministry of Education, Special Education (GSE). For over 20 years, in various roles, she has tried to improve understanding, services and support for people with autism spectrum disorder. The participatory action research programme was a wonderful opportunity to find out more about effective practices and programmes being carried out by teams around Aotearoa New Zealand.

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APPENDIX 1

Principles for designing the ASD PAR research

Developed by the ASD Research Committee at their meeting on 1 November 2001:

- interests of young person/child are paramount
- sustainability/continuity of opportunity for students involved;
- exit strategies/succession planning to be worked out from early stages
- canvasses a multiple set of outcomes
- an approach that allows the "unpacking" of the sets of factors involved (eg. training/attitude/values);
- contributes to the development of a holistic development strategy;
- makes an impact on overall provision of education for children with ASD;
- empowering (encouraging those involved, and others to think "this is possible");
- adheres to an agreed set of ethics standards (eg. New Zealand Association for Research in Education (NZARE); ASSR standards; Australian Evaluation Society Ethical Standards) – to include intellectual property/authorship issues. *Guidelines to be provided with the "invitation to participate", along with sample informed consent forms, letters, protocols as a kit*;
- equitable access to funding for action research (which may mean a differential funding allocation across project – numbers involved per project; rural/urban location etc);
- process to be as user-friendly as possible;
- critical friends [mentors] to have an understanding of research; ASD; and the education sector. *Guidelines for critical friends to be developed; possibly an approved list to be developed as a starting point*.

APPENDIX 2

Team profiles and focus

Local project team and context	Young person/people supported by the local project team	Team composition	Project focus
Local project team A, sub-team 1: Early childhood education services and primary	female, 4 years old	Parents, sibling, kindergarten head teacher, education support worker, early intervention teacher, speech-language therapist Additional team members when child transitioned to school: special education needs coordinator, teacher's aide, educational psychologist, special education advisor	Enhancing the child's communication and social interaction
Local project team A, sub-team 2: Primary	male, 8 years old	Parent, teacher, teacher's aide, resource teacher: learning and behaviour, speech-language therapist	Enhancing the child's communication and social interaction
Local project team A, sub-team 3: Primary	female, 7 years old	Parents, teacher, teacher's aide, resource teacher: learning and behaviour, speech-language therapist	Enhancing the child's social skills
Local project team B: Special	whole school	Parents of all children aged from 5 – 11 years with ASD at the school, principal, deputy principal, associate principal, teachers, teachers' aides, educational psychologist, occupational therapist, speech-language therapist, mentor	Exploring the dimensions of supportive relationships and a supportive school environment from the perspective of families and whānau
Local project team C: Secondary, learning support centre	female, 14 years old	Parent, learning support coordinator, learning support teacher, teachers' aides, respite carer, special education advisor, mentor	Exploring how adults and peers can best enhance the young person's socialisation
Local project team D: Secondary, learning support centre	one female and one male, both 19 years old	Parents, siblings, learning support teachers, teachers' aides, mentors	Exploring young people's experience of stress, how best to manage it and supporting their communication while stressed
Local project team E: Secondary, learning support centre	one female and two males, secondary school-aged	The students, parents, head of department student support, teachers, teachers' aides, speech-language therapists, mentors (a sub-team formed around each student)	Exploring ways to make learning and educational experiences meaningful, in order to prepare young people for life beyond school, with a particular focus on enhancing communication
Local project team F: Primary	male, 8 years old	Parents, teachers, principal, teacher's aide, home support worker, educational psychologist, mentor	Exploring how best to enhance the child's authentic friendships with other children
Local project team G: Primary	five primary school-aged students	Teachers, mentor (each teacher worked with the team around one child, particularly their family/whānau)	Exploring young people's special interests and using these to enhance learning
Local project team H, sub-team 1: Primary	male, 8 years old	Parent, teacher, teacher's aide, specialist itinerant teacher (0.1 FTE teacher), principal, speech-language therapist, occupational therapist, mentor	Enhancing the child's access to community environments; enhancing the child's communication
Local project team H, sub-team 2: Early childhood education services	male, 3 years old	Parents, playcentre supervisor, early intervention teacher, education support worker, occupational therapist, speech-language therapist Additional team members when child transitioned to kindergarten: kindergarten teacher, kindergarten head teacher, mentor	Enhancing the child's social understanding and relationships with others; exploring how best to support other adults' interactions with the child; transition
Local project team I	male, 8 years old	Parent, teacher, teacher's aide, principal, special education advisor, mentor	Enhancing the child's social skills particularly during peer interactions

Participatory Action Research: An Overview

What makes it tick?

Michael Gaffney

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ABSTRACT

In this article I outline different elements of action research in an attempt to describe and define participatory action research (PAR). There is a lot more material available to readers these days, some of which I will refer you to in this article. I see my role here is to summarise enough of this material to help support your reading of the other articles that appear in this issue of *Kairaranga*. This material (I have tried to use work from Aotearoa New Zealand in the first instance) refers to the ethical, political and context characteristics of PAR, as well as the design and format for conducting such research.

Keywords

Action research, definitions, effective practices, participatory action research, professional practice, reflection.

INTRODUCTION

My first job as a graduate out of university was as a research assistant in an organisation establishing action research projects within its different departments. However, in the various courses I had taken at university, I could not recall any reference to action research. When I went to the library to find material there was little available other than *The Action Research Planner* (Kemmis & McTaggart, 1982) and *The Action Research Reader* (Deakin University, 1982) both from Australia. Even then they had to be borrowed from another university library.¹

Twenty years on and action research has become a key approach for professionals to conduct research without needing to undertake large surveys or set up experimental conditions to test hypotheses. The underlying aim of action research is not to produce knowledge, but to create social change in the settings within which it is used (Munford & Sanders, 2003). Aligned with this increasing popularity has been the expanding New Zealand reading material available to support teachers and other professional groups in the use of action research (eg, Cardno, 2003; Zepke, Nugent & Leach, 2003; Munford & Sanders, 2003).

WHAT IS PARTICIPATORY ACTION RESEARCH?

Action research has often been linked to notions of professional development and the reflective practitioner,

but not all material will refer directly to action research itself (eg, O'Connor & Diggins, 2002). Scouring the latest Best Evidence Synthesis released by the Ministry of Education *Teacher Professional Learning and Development* (Timperley, Wilson, Barrar & Fung, 2007) there was no reference to action research, but the diagram on the inside cover sets out a format for learning that mirrors action research cycles of inquiry. That is, a person or group sets out a question of professional relevance to their current teaching context, this is usually in relation to student learning, and then activities and experiences are designed to answer or explore these questions, which the teacher(s) then implement(s). This is followed by the teacher or group evaluating the impact of the changed practices. The answers, or non-answers as the case may be, are meant to lead to new questions and the process continues in what is usually referred to as cycles or spirals of ongoing action and reflection. Figure 1 is a simplification of some diagrams and does not show the iterative nature of the research over time that Cardno (2003) refers to, but it does outline the underlying format based on identifying an initial question or problem to start with.

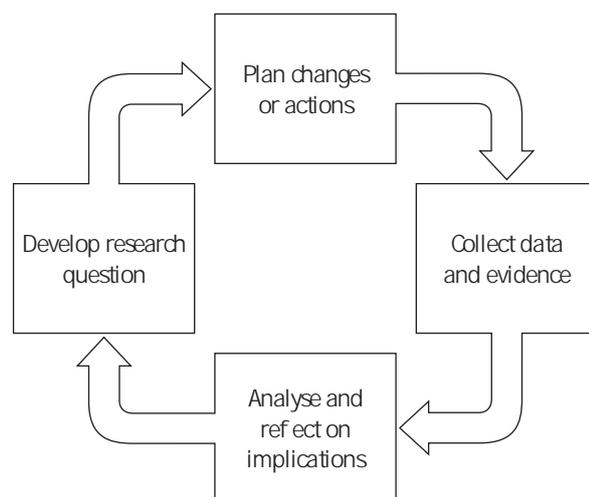


Figure 1. The action research cycle.

¹ There were a small number of New Zealand articles in academic journals also available. See Alcorn (1986) and Marshall & Peters (1985, 1986) in particular.

Participatory action research (PAR) has been described in much the same way as action research with little to distinguish the two, depending on whom you are reading. PAR has also been used as an acronym to remember the process

Planning a change,
Acting and observing the process and consequence of change,
Reflecting on these processes and consequences, and then replanning, acting and observing, reflecting, and so on ...

(Kemmis & McTaggart, 2000, p.595, bold added)

With reference back to my first involvement in action research, even though each group in the organisation followed the above format, it was surprising how different my experiences were as I worked with them to set up their projects. It ranged from large-scale work reviews involving all staff in a department, through to trying to resolve quite specific technical problems working alongside only one or two individuals. Some projects moved very quickly and others felt as though they were always struggling to get started.

The diversity of action research despite this framework or process can be surprising. One key element of PAR that distinguishes it as a subset of action research is the nature of participation by team members. Some writers assume that participation is always involved so do not see the need to add the qualifier *participatory* (eg. Whitehead & McNiff, 2006) and others do (eg. Cardno, 2003). Others have distinguished PAR from action research on the basis that PAR involves individuals with different roles participating as equal partners, such as when teachers and parents might work together, as opposed to teachers participating together as a professional group (Liamputtong & Ezzy, 2005). I will return to the nature of participation later on in this article.

Alongside the increasing use of PAR in New Zealand there have been a number of variations in the name used or the purposes to which it is put. In early childhood education, action research is identifiable in the "prepare, gather, make sense, decide" cycle in the *Nga Arohaehae Whai Hua: Self Review Guidelines* (Ministry of Education, 2006a) and in the "plan study do act" cycle in the *Quality Journey: He Haerenga Whai Hua* (Ministry of Education, 2000), both provided as a resource to improve the quality of early childhood education in New Zealand. As these two examples show, there has been a strong link between internal or self-evaluation/review methodologies and action research. Other examples include *The Cultural Self-Review* (Bevan-Brown, 2003) and participatory evaluation (Patton, 1997). More recently the Ministry of Education has funded the Teaching and Learning Research Initiative (TLRI) (Sandretto, 2008) and the early childhood education Centres of Innovation (COI) (Meade, 2006) programmes, which ask practitioners and researchers to collaborate in action research as a means of developing and researching innovative practice. The Ministry of Education has for a number of years supported action research as a means of professional development for teachers (eg. Ministry of Education, 2006b; Ministry of Education, 2007).

In this current special issue you are being introduced to a smaller Ministry of Education project. The autism spectrum disorder participatory action research (ASD PAR) project aimed to provide opportunities to establish what does and does not work for children with autism spectrum disorder (ASD) in educational settings. Small teams of people worked collaboratively to develop research projects that made sense in their particular educational settings.

THE POLITICS OF PAR

There is an explicit political element to action research often associated with the sub-form of emancipatory action research. For example, Bishop and Glynn (1999) and Smith (1999) recognise the political elements of research and this is the basis for developing kaupapa Māori² research. The same views appear within disability studies (Mercer, 2003), such that Mirfin-Veitch and Ballard (2005) in writing about disability research draw on Bishop and Glynn to articulate these matters. They use the term "participant driven research", which recognises and asks

Initiation: Who initiates the project, who sets the goals and who decides on the research questions?

Benefits: What benefits are intended, who will assess the benefits and who will benefit from the study?

Representation: Whose voice is heard, who decides on the adequacy of the social realities that are represented, who will do this work?

Legitimation: Who analyses the data, who determines the accuracy of the text, what authority does the text have?

Accountability: Who is the researcher accountable to, who has control over the distribution of knowledge? (Bishop & Glynn, cited in Mirfin-Veitch & Ballard, 2005, p. 191)

As these context questions suggest, the nature of the resulting research will take quite different directions depending on how they are answered, who does the answering and why. Those who adopt a very inclusive and open idea about how to answer these questions will tend to adopt a PAR model (Munford, Sanders, Andrew, Butler & Ruwhiu, 2003). Kemmis and McTaggart (2000) go on to describe how PAR is a social process, is participatory, is practical and collaborative, is emancipatory, is critical, is recursive and aims to transform both theory and practice. I had to go back and check out the difference between participatory and collaborative. For these authors, to be participatory means there is no distinction between the researcher and researched, as often happens in other research approaches, and collaborative refers to how all participants are learning together. Munford et al. (2003) point out that participation and collaboration do not mean that everybody has to contribute in the same way. One of the roles of a research facilitator or mentor is to understand the varying demands on team members so as to maximise the opportunities for contribution without overwhelming participants. One key point they go on to identify is

² Māori philosophy.

Listening and acting on suggestions from participants and being sensitive to their role as research participants. This included knowing when the research needed to slow down so that the work of the community centre would not be disrupted. We were always clear that the research would not disrupt the daily activities of the workers and young people. (Munford & Sanders, 2003, p. 273)

The challenge is establishing a groundswell of support for action that is interpreted as changing practices for the better rather than disrupting participants' current routines.

Ownership in a project comes from maximising individual involvement without compromising commitment or creating a feeling of exploitation (Miskovic & Hoop, 2006). This is why the facilitators have to be so focused on the process of action research as well as keeping an eye on the research outcomes. This is something that is much more difficult to do if there are contractual obligations involving time. The article *What We Did* in this issue confirms that finding time to conduct the work was a consistent theme raised by participants in the ASD PAR projects.

For the ASD PAR project it has been acknowledged that the projects were not initiated by the teams that conducted the work. Potentially, there were tensions with a funder and the project teams being different and giving life to the concerns raised by Mifflin-Veitch and Ballard (2005). In programmes like the COI and TLRI, the initial work is by competitive application. The proposals come with general questions laid out by the participants. The funder's role is to choose the proposals that are found to be of interest according to pre-set criteria. This suggests that those who are successful are then funded to pursue their own questions.

Munford et al. (2003) recognise the high demand on time and energy within action research and without funding, the capacity to sustain PAR is much more problematic. Sustainability may be supported by having an external funder and that must be weighed against the potential and realised influences. In the end it is a collective judgement to be made by the participants – is there enough scope in the project to make it worth doing? There is a balance to be found that should satisfy all PAR participants.

Receiving funds for the study is not a neutral act, it implies a certain relationship between the funder and researchers in terms of obligations, responsibilities, and expectations. 'In the FSN project, all our meetings needed to be accounted for with a finished result, such as a paper or a research piece' (Miskovic & Hoop, 2006, p. 283).

Writing, for example, tends to be a very academic or contractual exercise that not all team members may necessarily appreciate in the same way. Cardno (2003) makes the point that action research needs to be reported, although in the age of multi-media this does not need to be formal writing. However, if a group's learning is going to benefit a wider community beyond their own changes in practice, then some form of recording and reporting is desirable.

Cardno (2003) refers to publication giving action research the credibility of proper research. For her this is what

distinguishes professional or organisational development from action research. Also, in the wider world of organisations and external funding opportunities, reporting can constitute evidence of the worth of a project, and often more importantly, its continuation. This is why action research and evaluation have been so closely linked as referred to above (Duignan, 2003; Patton, 1997).

The means of reporting is important for creating a sense of "voice" in terms of who is speaking through a report. Cardno (2003) reminds us that there can be multiple reports that seek to address different audiences. There is a temptation to leave writing and reporting to only a few, but like all aspects of the action research process, they provide learning opportunities for less experienced members of the team to develop their presentation skills. One of the strategies for success here is to leave plenty of time for newcomers to experience success rather than being overwhelmed with the demands of meeting deadlines. Even partial experience in differing parts of the action research cycle builds confidence in preparation for the next cycle, making PAR a platform for experiential learning through apprenticeship. This confidence building was reflected in the *Making Assumptions vs. Building Relationships* article where the research contributed to peoples' improving confidence in their professional practice.

CONTEXT FACTORS IN PAR

One of the aims of my description of PAR in this article is to highlight how the differences in research context determine what type of action research might be achieved. Bruce-Ferguson (2003) defines three types of action research – technical, practical and emancipatory. The definition varies according to the relationship between the facilitator and practitioners, and the purpose of the particular project.

Technical action research happens when an outside facilitator persuades practitioners to test findings from external research in their own practice ... The aim of the research is to add to external research literatures.

Practical action research happens when outside facilitators form cooperative relationships with practitioners, helping them to articulate their own concerns, plan strategic action for change, monitor the problems and effects of changes and reflect on the value and consequences of the changes actually achieved ...

Emancipatory action research is the final level of action research ... when a practitioner group takes joint responsibility to change and improve practice 'aiming to explore the problems and effects of group policies and individual practices'. (p. 62, citing Carr & Kemmis in the last sentence)

Of these, only the last two would seem to meet the criteria set out by Kemmis and McTaggart (2000) as PAR referred to above.

The differences in type reflect the process of question development or "why are we doing this in the first place?" In the ASD PAR project, each team had a mentor in the role of facilitator. Within the definitions above we have an arrangement that reflects practical action research.

forms of participation

The definitions also assume similar understandings across a participating practitioner group. In larger groups, a few people will be leading the team on the basis that it is a good idea and the others will follow, not necessarily having the time or enthusiasm to contribute to work in the same way. Timperley et al. (2007) commented that student outcomes were not related to whether teachers voluntarily participated in professional development, but rather it was determined by whether there was a point when the teachers engage in the learning process. Thus different participants in the same project may choose different labels to describe the action research. What is practical action research for one could be viewed as technical for another. There may also be participants who start a project viewing it as technical, but through engagement with it get to the point where they feel that it is now practical. Ideally, when they have had enough positive experiences and developed their research skills they will initiate further work themselves which will warrant calling it emancipatory action research. Unfortunately, the reverse could also happen. A lack of flexibility and opportunity for contribution means a project could seem more technical than practical. Likewise, just because a mentor is involved does mean that the outcomes cannot be emancipatory. The definitions from Bruce-Ferguson (2003) outlined previously focus on the means rather than the ends.

This approach to defining action research is written as though you chose one or the other rather than learning the possibilities by experiencing action research in different ways. There are certain levels of capacity or understanding and knowledge required, which is usually provided via a facilitator. Thus, in my first action research experience I was in situations where, even though working with a large group, there was a common understanding and enthusiasm for developing a project, to the point that I was not so much a facilitator, but rather a resource person searching the library for relevant material or administering the project.

At the same time another group directed me to work with one team member to see if I could resolve an organisational concern they had. If I could resolve it, all well and good, but the answer was not going to be a collaborative experience to change practitioner practices or understandings. During another project I met with teachers who had been told to meet with the facilitator, their expectation was that I would do the research and so they waited for the research to happen or to be told what to do. Based on these experiences and others, I believe it is important for professionals to build up their skills and experiences of small-scale practical action research before they can appreciate the possibilities of, and work toward, the more idealised emancipatory research as described by Bruce-Ferguson (2003) above. Whitehead and McNiff (2006) have found that establishing teacher independence of researchers is very problematic.

My own experiences also suggest that a facilitator or mentor must also have an understanding about the way an organisation works. Outside facilitators may have developed relationships with individuals within an organisation, but

their assumptions about the way the organisation operates may never have been tested. For example, does the facilitator know who is able to make significant decisions or allow certain questions to be asked? There is no recipe to follow because, as suggested by the action research cycles described above or reading articles like this, the learning is experiential and political although reading other people's projects can be very motivating and enlightening (as I hope this issue of *Kairaranga* will be).

PAR as group problem solving

The shared experience of participating in PAR provides the language and opportunities to articulate the direction for ongoing research and establish what possibilities there are for solutions or action within the organisation or group (Miskovic & Hoop, 2006). This is articulated within the article *Learning from Each Other*. The limits of what is possible within schools will depend on the organisational context and management systems when establishing solutions for certain problems faced by the group. The starting point is to establish which solutions are within the control of the group to provide. After this there is a significant role in advocating for the group's work across the school or network of potential contributors. Innovation, within and between schools, is supported by networking to share experiences (Hopkins, 2007). The local context and systems, including limited research experience, could also mean that a group may never get to the big questions or will restrict itself to certain solutions in the first instance. Whitehead and McNiff (2006), prominent action research theorists, refer to this as establishing the validity of the knowledge generated by action research. There are limits to how much questioning we are capable of, which is why self-study can only go so far, reflecting the old adage "we don't know what we don't know". There is a spectrum of change and research outcome – from that which does not seem to challenge or take us further, to that which requires ongoing review of personal and group understandings. A significant role of the facilitator can be that of critical friend (Bruce-Ferguson, 2003) to re-ask questions that may have been glossed over too quickly or support the strategising within the organisation and beyond.

PAR AS RESEARCH PROCESS

I have alluded to many of the challenges and the fluid nature of action research. It is so process orientated and, as a result, energy intensive, the full story is often not reflected in write-ups of the action research (Meade, 2006; Miskovic & Hoop, 2006). The article in this issue, *Building Communities of Support*, describes many of the issues I have referred to. There was reference to participant turnover, which I have experienced in the action research process myself. At first it seems very distracting having to engage new team members in the process, but this provides new opportunities to review progress and re-establish purpose. A new member can ask the naive question to keep a team on track. In larger teams it would be better to plan ahead for some turnover on the assumption that the research is not reliant on particular individuals.

In my descriptions of different projects above I have implied that they only occur in the context of single organisations,

but in the *Building Communities of Support* article the project was around a single child in one particular context and the participating adults came from different organisations. Thus there is no guarantee of shared understandings about each other's work demands or professional or personal thinking and there is an extra demand on coordination to achieve success as acknowledged in the article. Also, the methods of working together had not been established, this can be an advantage as fewer assumptions can be made and more questions about "how are we going to do this?" must be asked – referred to in the article as "developing practices".

This same article also acknowledges the link between evaluation and action research. In this context PAR is not only about agreeing on the performance of practices, but also agreeing on how to judge their success or otherwise. There is acceptance that not everyone has to have the same commitment to the project, which is true, but you can certainly tell when someone's commitment is insufficient. This is not always with respect to time and energy, but in terms of team members' understandings of their own practices and how they interact with each other.

Broadening participation

Several articles in this issue describe parents as being a critical part of the team. Increasingly researchers and practitioners are also being inclusive of children and young people as part of the "team". This was evident in several accounts in this issue, where the adults followed the child's interests and listened to the way children expressed their preferences. This approach has been promoted in New Zealand by Margaret Carr (2004) in the context of narrative assessment in early childhood education and I hope to see more appear within the context of the new school curriculum.

The articles in this issue highlight the adults' learning and experience of PAR. A balance between this and reporting the outcomes for students is a likely indicator that all, adults and students, are active participants in the team. The *What Works for One* article recognises that the research was not about changing students but instead, as one heading suggests, there was a "focus on changing ourselves" the adults. This is an appropriate starting point when thinking about including the students as part of the team.

There was some concern in the *Ethical Principles in Practice* article that the traditional approach to ethics does not fit the PAR model. It is likely that this misfit was owing to the blurring of roles between researchers and the researched. If researchers and practitioners are collaborating then it makes no sense to gain informed consent or obligation to maintain confidentiality. Instead, there must be explicit rules about how the team is going to participate and collaborate together. The trickier question is how many people need to sign up. As the author of the *Building Communities of Support* article recognise, people have varying levels of commitment to and awareness of the project. Also, many professional bodies have their own ethical principles or guidelines alongside organisational requirements that should hopefully support research rather than compromise

it. This suggests the importance of a group of participants being ready to address issues as they arise, with each context likely to create new concerns for the group to resolve.

CONCLUSION

I have endeavoured to provide an outline of the nature of PAR, its characteristics and the important contextual factors that make it distinctive. The notion of researchers, teachers, students and families participating together to find out what will make life better for them, is a strong motivating factor in support of PAR. However, there are high costs or demands to make the process successful. It comes down to establishing working relationships based on a collective purpose. This makes PAR a very challenging process, but at the same time it can be very rewarding for those who participate. The leaders within PAR projects are having to make ongoing judgements about context issues by anticipating and acknowledging the political and ethical concerns in advance. Each context presents its own configuration of challenges and opportunities within which to develop PAR. From establishing a working team that allows different members to make their own contribution to the PAR process, through to using group learning to reflect on practices and look for new solutions I think the articles in this issue of *Kairaranga* reflect many of these challenges and show how participants in the ASD PAR project found their own solutions.

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Ethical Principles in Practice

Evidence from participatory action research

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ABSTRACT

A significant challenge for all participants in the autism spectrum disorder participatory action research (ASD PAR) project, including the Ministry of Education, the local project teams (LPT) and mentors, was the lack of availability of a single ethics approval process for the project in its entirety and, in particular, one that could accommodate the iterative, dynamic and participant-led action research process. To address this gap, participants in the ASD PAR project adopted both individual and shared responsibility for ethical reasoning. As with ethics in general, there was no one right answer that could be routinely applied to ethical dilemmas. A guiding framework of ethical principles proved useful for participants. Central to the success of the ASD PAR project was participants' ability to self-reflect, question and share resolutions. In essence, reflections on ethical dilemmas as they arose were an interwoven strand through the life cycles of the ASD PAR project.

Keywords

Action research, autism spectrum disorder, effective practices, participatory action research, reflection, research ethics, responsibilities

INTRODUCTION

In May 2002, the Ministry of Education, in conjunction with the Autism Spectrum Disorder Reference Group, set up the autism spectrum disorder participatory action research (ASD PAR) project. Teachers, parents and young people, as the local project teams (LPT) working with their mentors, were responsible for reflecting on their situation, defining their problems, implementing solutions to produce a "better" situation, and for evaluating these solutions. The ASD PAR project sought, therefore, not just to understand but to empower teachers, parents and young people to act and create change.

Early in the ASD PAR project, there were difficulties in obtaining ethics approval for the project as a whole. Further, there were noted tensions in seeking to apply traditional ethics principles to a participatory action research (PAR) project. This article shares the ethical challenges faced by the ASD PAR project, focusing on five ethical principles applied and the strategies used by many people involved in the project to facilitate ethical reasoning. Appendix 1 presents an overview of questions developed by Zeni (2001) to assist ethical review and reflection through the action research phases. People who are planning to use action research in education contexts may find Zeni's questions useful.

INDIVIDUAL AND SHARED ETHICAL RESPONSIBILITY

From the outset, it was anticipated that the national project management team would be able to facilitate access to a single ethics committee for all the individual LPTs. When the project management structure changed, the links to the ethics committee were no longer available. Mentors from tertiary organisations sought and received ethical approval for their ASD PAR project teams from their respective accredited ethics committees. However, for the equally senior and experienced mentors not aligned to a tertiary organisation, there were no existing accredited ethics committees from which they could seek review and approval for their ASD PAR project teams. This situation reflects the fact that currently in New Zealand, while there are ethics committees accredited to assess health research as defined by the Ministry of Health (2006) *Operational Standard for Ethics Committees*, there is no equivalent accreditation process for social and education research. The Health Research Council (HRC) is currently scoping the need for such a function.

At the time the ASD PAR project took place, guidance was sought from the HRC that advised that even though the project focused on children with autism spectrum disorder (ASD), accredited ethics approval was **not** required as the research activities focused on normal classroom practice. This response was disconcerting to participants who felt there was a need for a mechanism to address ethical issues. While the ASD PAR project as a whole could not obtain accredited ethics approval, ethical consideration and reasoning was an integral strand woven through the project. In line with the principles of PAR, the Ministry of Education endeavoured to ensure control for the ASD PAR project rested with the LPTs. In this context, and consistent with codes of ethics and practice, ethical considerations were the responsibility of each individual involved in the project, that is, the LPTs and their mentors, and the special education and the research division in the Ministry of Education. In addition to individual responsibility for ethical behaviour, there was also a shared and interlinking responsibility towards ethical reflections and considerations for the ASD PAR project. In response to ethical dilemmas that arose, the Ministry of Education developed a draft guideline on ethics and the ASD PAR project.

Figure 1, developed to illustrate the responsibilities of the various participants in the ASD PAR project, and drawing on the work of the Institute of Medicine (Federman, Hanna & Rodriguez, 2003), summarises the ethical responsibilities of

each stakeholder and their linkages within the ASD PAR project. It shows that consideration of ethical issues mirrors the cyclical action research process of reflection, collaboration and action. Thus, ethical consideration in the ASD PAR project was a dynamic and ongoing process of open and transparent communications between the stakeholders. In this way, ethical management is continuous throughout the entire research process (Alton-Lee, 2001).

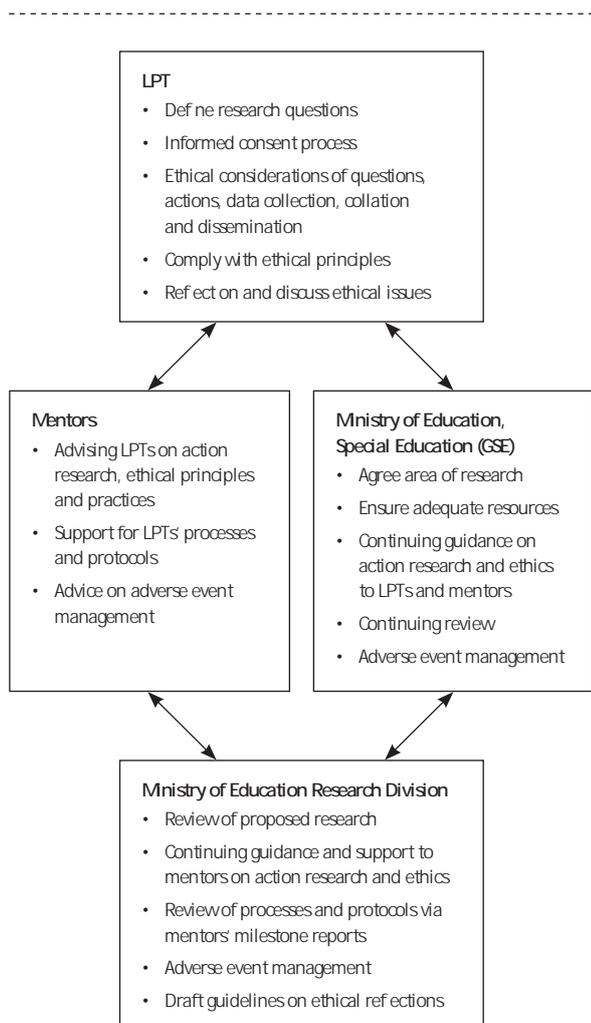
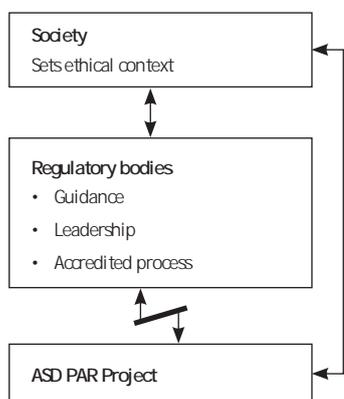


Figure 1. Ethical responsibility in the ASD PAR project (developed from Federman, Hanna & Rodriguez, 2003)

ETHICS IN ACTION

Within New Zealand, the principles and protocols of research ethics draw on the medical model developed in response to unethical experimentation on people (Tolich, 2001). Consequently, ethics focuses on active researchers doing research on passive participants for a clearly defined purpose and in situations where the risks are known. Emphasis is therefore placed on the rights of participants over the self-interest of researchers using, in the main, the following guiding principles:

- validity of research
- respect for persons
- informed and voluntary consent
- minimising risk of harm
- respect for privacy and confidentiality
- avoidance of unnecessary deception
- avoidance of conflict of interest
- social and cultural sensitivity to participants
- distributive justice.

(Ministry of Health, 2006).

Even when available, traditional ethics committees and their guiding principles do not sit comfortably with the active role of the participant/researcher in the PAR model. For the ASD PAR project, five of the above listed principles were particularly relevant and required careful reflection. The principles and challenges relating to the ASD PAR project are discussed below. It is acknowledged that the ethical challenges arising from the ASD PAR project were not unique, but are more a reflection of a wider international debate about ethics occurring amongst PAR participants/researchers from a range of disciplines. Williamson and Prosser (2002) suggest that political and ethical tensions arise in PAR as a result of the close relationship between researcher and researched, and the degree of "exposure" this brings. This is particularly the case for those working in their own organisations.

Validity of the ASD PAR

For research to be considered ethical it must also be valid (Snook, 1998). The validity of the ASD PAR project was at no time brought into question by those involved. The ASD PAR project was seen as significantly benefiting teachers, parents and especially the young people involved in this project, as well as contributing to wider knowledge about effective practice in education for young people with ASD. In essence, the ASD PAR project was seeking to narrow the gap between research and practice so that innovative practices validated in research could be adopted in education settings (Meyer, Park, Grenot-Schever, Schwartz & Harry, 1998).

The concept of validity also contains the notion that researchers must have appropriate qualifications and/or expertise to conduct the research. From the start, the Ministry of Education acknowledged the LPTs were "novice" researchers. The Ministry of Education built LPTs' capacity and capability by contracting mentors with a depth of ASD, PAR and education research expertise. All LPTs received resource packs containing relevant articles, papers and

books on ASD and PAR. The Ministry of Education also funded "release time" for parents and teachers to work on the research and to take part in professional learning and development opportunities with a focus on methodology.

Informed and voluntary consent

Traditional ethics principles require that participation in any research project must be voluntary and based on understanding adequate and appropriate information about what participation will involve. PAR, by its very nature, makes it challenging to meet the criterion for informed consent. PAR's cyclic process of planning, action, observation and reflection means that much is unknown at the project's commencement beyond its overarching research questions. Thus, the researcher is unable to provide full and detailed information about what participation will involve, and the implications and risks of participation for the project's duration.

Further, traditional informed consent places the participant in a passive mode as the "subject" of research. In contrast, PAR expects participants to be active in the research design and at all stages of the research process. As a result, the boundary between researcher and participant is blurred. The latter, therefore, begs the questions: Who is the researcher? Who is the participant? Who is seeking consent from whom? And can participation be truly voluntary, given the strong inter-linked relationships and beliefs about friendship, reciprocity and power underpinning them?

To resolve these dilemmas, within most LPTs, participants sought informed and voluntary consent from one another during the early stages of the project. For most LPTs, informed consent was not a solitary activity at project commencement, but an ongoing and negotiated process throughout the project. The LPTs' mentors and the Ministry of Education recognised ongoing active involvement in the project as signifying members' willingness to continue. Although there was some variation between LPTs in the extent to which this occurred, on the whole informed consent was maintained throughout the project by reflection, open communications, negotiations and agreed actions within each LPT and at the overall ASD PAR project level.

Avoidance of conflict of interest

Parents, teachers and the young people with ASD in the LPTs had existing inter-related professional and personal relationships with each other. Unlike traditional researchers, members of the LPTs cannot be considered to be neutral, unbiased, and objective.

To resolve any potential conflict of interest, members of the LPTs had to recognise and share their positions, beliefs and values about the project and their relationships with other LPT members. They had to openly discuss with their team members how these factors might impact the research and their analysis of information collected. When researching one's own context, it is important to acknowledge the perspective one brings; however, the goal is not to overcome or change this perspective, but rather make known how it has affected the research (Kirsch, 1999).

Minimising risk of harm

Ensuring research participants are not exposed to unnecessary harm is a core ethical principle, and one of great significance to the ASD PAR project, given its focus on young people with ASD. Minimising the potential risk of harm required LPT members to negotiate the potential conflict of interest between their roles as parents/guardians and teachers of the child and their roles as researchers. For example, issues arose around parents who were members of the LPT giving consent for their children's involvement in the projects. In this instance, LPT parent members had to reflect on whether their consent for participation was in their child's best interest or more whether it reflected their expectations about the project. Through the process of reflection, LPT members had to acknowledge that they were active in the research process and as such there was the potential to do harm (no matter how unintended).

In minimising harm to the child and their family, LPTs had to recognise that harm can occur both during the project and years after its completion. Potential harm for the child and the family can arise inadvertently through casual communications about the project with non-members and other LPTs. This is especially pertinent with the involvement of children with ASD and their families as they are easily identifiable in their communities, and possibly not everyone would support their involvement in the project. In the long term, there was potential for information dissemination choices made about the findings from the LPT to have long-term repercussions for the child and their family, that is in 5 or 10 years what impact will others' knowledge that the child was involved in this project have on them as a young person or adult?

Respect for privacy and confidentiality

Traditional research ethics principles contain the expectation that it is the role of the researcher to ensure the privacy and confidentiality of the participant. Within the context of the ASD PAR project, again the boundary issue arises of whose privacy and confidentiality is being maintained, by whom and whether confidentiality is, in fact, possible. Throughout the ASD PAR project, the LPTs had to recognise that neither the Ministry of Education nor the mentors could offer guarantees of confidentiality.

Of particular note, LPTs grappled with the issue of confidentiality around information dissemination, particularly as the project came to a close. Some LPTs wanted to share findings from their projects with wider audiences so others could learn from their experiences of what worked or did not work in their educational settings. This disclosure met the ethical requirement of distributive justice, though it raised concerns about confidentiality. However, others did not want to share the findings from their projects, as doing so would clearly identify the child and the family, and had potential to create harm for them. This approach denied the family and other LPT members recognition of their participation and their valuable contribution to educational strategies and wider knowledge in this field. As is often the case with ethics, there was no one right answer but differing defensible positions. Consequently, each LPT collectively

agreed on a position regarding information dissemination that all members of that LPT, including the young person and their family, accepted.

CONCLUSION

The ASD PAR project was unable to access an accredited ethics committee to review and approve the project in its entirety. Although the HRC committee advised formal ethics approval was not required, the ASD PAR project teams and the Ministry of Education ensured ethical consideration was a strong and consistent thread weaving through the project. Consequently, all members of the ASD PAR project became more sensitive to the inherent ethical dilemmas of a PAR project, and had greater awareness and appreciation of their own ethical responsibilities. It may be surmised, therefore, that the lack of an avenue to gain accredited ethical approval serendipitously resulted in richer and more robust ethical self-reflection throughout the life cycles of the ASD PAR project.

As demonstrated, there are underlying tensions between a traditional ethics top-down researcher driven model, which views participants as passive, and the PAR model where participants are actively involved in the process. Key tensions noted include the challenges of obtaining informed consent, given the iterative and action-focused nature of PAR, and issues of confidentiality, validity, minimisation of harm and conflict of interest, owing to the active role of participants as researchers.

These tensions required ASD PAR stakeholders to be more reflective throughout the project, and for the LPT members, in particular, to self-reflect on how their positions, beliefs and values influenced the project. Mason (1996) calls this an 'active and self-questioning approach' (p.167) and goes on to say, '[it] is because of the complexities of research ethics, and because there is unlikely ever to be one clear ethical solution, that a practical approach to ethics which involves asking yourself difficult questions – and pushing yourself hard to answer them – is particularly appropriate' (p. 29).

In conclusion, the ASD PAR project emphasised the responsibility for behaving ethically remains with the researcher and the wider project team, regardless of the formal ethical approval process applied.

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APPENDIX 1:

Questions to guide self-reflective ethics in PAR

Further insight and practical guidance on a self-questioning and self-reflective approach to ethics in PAR is offered by Jane Zeni (2001) who details the "hard questions" requiring reflections, if not answers, at each stage of the PAR cycle.

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I. Overview of the Study

1. Briefly describe your project as you see it today.
2. What is your time frame? Is this a one shot project or do you anticipate several cycles? Have you done a preliminary study?
3. What problem does your research address? Is it a problem in your own practice? Or is it a problem with your students or with your administrators? Who owns the problem?
4. What (initial) action will you take? What do you hope to accomplish?
5. List your research questions as they appear at this time. (Questions will be revised or refocused during your project.)

II. Location

1. Are you, the researcher, also a participant in the setting where this research will take place? Specify your role (teacher, supervisor, principal, counselor, social worker, and so forth)

2. Map your position on such dimensions of culture as gender, race, age, region, ethnic heritage, education, class, and family.

III. Methods

1. For this research, will you gather data on your normal educational practice and on changes in curriculum, instruction, and assessment that you could make in your role according to your own professional judgment?
2. List the kinds of data you plan to collect (e.g., fieldnotes, taped interviews, writing samples).
3. How is this plan different from the way you normally document your practice? Consider two or three alternative ways you could gather data for this project. What are the ethical implications of choosing your preferred method?
4. At this time in your research, what do you aim to understand? What do you aim to change?

IV. Subjects, Subjectivity, and Relationships

1. Describe the individuals, groups, or communities you expect will be touched by your project. List their roles (student, parent, resource teacher, and so forth). Which participants are minors?
2. Analyze the power relations in this group. Which people (e.g., students, parents) do you have some power over? Which people (e.g., principals, professors) have some power over you?
3. What shared understandings do you have with these people? Do you have personal bonds, professional commitments? Will your research strengthen this trust or perhaps abuse it?
4. Will your study attempt to read and interpret the experience of people who differ from you in race, class, gender, ethnicity, sexual orientation, or other cultural dimensions? How have you prepared yourself to share the perspective of the "other" (coursework, experiences, other sources of insight)?
5. Will an insider review your questionnaires or teaching materials for cultural bias? Have you provided for consultation by adult members of the community? How will you reduce or correct for your misreading of populations who differ from you?
6. Does your inquiry focus on people with less power than you? Children in classrooms are always vulnerable – especially if their families have little money or education ... How does your project demonstrate mutual respect and justice?
7. What negative or embarrassing data can you anticipate emerging from this research? Who might be harmed (personally, professionally, financially)? What precautions have you taken?
8. Might your research lead to knowledge of sensitive matters such as illegal activities, drug and alcohol use, or sexual behaviour of participants? How do you plan to handle such information?

V. Consequences

1. Describe the possible benefits of your research – to students, teachers, or other participants; to society or to the profession.

2. Describe any risks to participants. For example, might your current students be disadvantaged for the possible benefit of future students? What steps are you taking to minimize risks?
3. Explain how you will protect the people from whom you collect data through surveys, interviews, or observations.
4. Describe how you will obtain informed consent. Do you need permission from students, parents, or both? How will you work with any students who refuse to be interviewed or to allow their materials to be quoted?
5. Are different kinds of consent needed at different stages in the project? (a) A blanket *consent to participate* from all students at the start of each year (with parent signatures of minors). (b) An individual *consent to publish* from selected students, giving you access to writing samples, videotapes, photographs, or fieldnotes that describe recognizable people.
6. Do you wish to protect the anonymity of students, teachers, parents, and other participants? If so, it is wise to use pseudonyms even in your fieldnotes. If your report is eventually published, you can also interchange physical description, age, gender, and so forth or develop composite rather than individual portraits. What are the gains and losses of anonymity?
7. On the other hand, instead of anonymity, it may be wiser to seek full participation and credit for students and colleagues. Research by an educator in his or her own classroom is rarely anonymous. Even if names are changed, students can be recognised in a well-written case study or classroom scene. What are the gains and losses of open acknowledgment?

VI. Publication

1. What data will be contributed by others? Will you record student writing, oral histories, or other documents that may be considered someone's intellectual property? How have you arranged with colleagues or students for credit in your manuscript?
2. If your study is collaborative, how are you negotiating authorship and ownership? University researchers, colleagues, students, and parents may interpret their stake in the research in quite different ways. Who owns the videotape of a classroom writing group, the dialogue journal between teacher and mentor, the transcription of talk by teacher-researchers in a college seminar?
3. Who is responsible for what is said in the final report? Will other stakeholders (teacher, principal, school board) review your report in draft? Will this (a) improve your accuracy or (b) compromise your candour? Which participants (students, colleagues) might be embarrassed if they were to read your report?
4. You will inevitably gather more data than you "need". Consider why you choose some data to report to a wider audience and why some is left in your files. (On what basis do you select?) Consider the politics of the way you focus your story.

5. How will your report recognise the perspectives of participants who disagree with some of your interpretations? For example, you may revise your views, quote their objections and tell why you maintain your original view, or invite them to state alternative views in an appendix.
6. Have you decided on anonymity or on full acknowledgment of other participants in your report? Perhaps you will identify teachers but use pseudonyms for students. If you began your study with a blanket consent form, have you now requested consent to publish specific material from specific people?

VII. Ethical questions specific to “insider” research

1. [Is there] a formal review procedure for [the] research? If you are collaborating with people at a university or research institute, you may need approval from the institutional review board (IRB) in both settings.
2. Which participants at your school or college have read your research proposal? Which ones have been informed of the research orally in some detail? Which ones know little or nothing of this project? Reflect on the decisions behind your answers.
3. What do your students know of your research? Who told them? What are the risks to them or their families of their knowing (or not knowing) what you write or collect?
4. How do your school [board/principal] view your work? Is action research under suspicion or is it mandated from the top in a drive for organizational quality control? How safe do you feel in this institutional setting pursuing this research? Would you be free to report your findings and interpretations to a wider audience?
5. Who is sponsoring this research through grants, contracts, released time, course credit, and so forth? Will you evaluate the sponsor's program, textbook, or method? Do you anticipate pressure to report what the sponsor wants to hear?
6. Does your study evaluate your own effectiveness or a method to which you are committed? How will you handle the temptation to see what you hope to see? How will you obtain other perspectives – for example, classroom observation or analysis of student work by people who do not share your assumptions?

(Zeni, 2001, pp. 156-164).

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Making Assumptions vs. Building Relationships

Lessons from a participatory action research project to identify effective practices for learners with autism spectrum disorder

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ABSTRACT

This article describes a participatory action research (PAR) project conducted in a large urban, co-educational secondary school. The project focused on two senior pupils with autism spectrum disorder (ASD) who, seemingly as a result of feeling stressed or anxious, displayed behaviours that inhibited communication. Using questionnaires, observations and teaching activities, factors that both caused and reduced stress for these students were identified. Interventions were introduced that successfully helped the students to recognise and manage their stress appropriately. These were principally the use of a variety of visual strategies and Social Stories™. As a result of the PAR project, school staff learnt to question assumptions made about students and to give priority to getting to know them and developing positive relationships on which teaching programmes could be built.

Keywords

Action research, autism spectrum disorder, effective practices, interpersonal communication, participatory action research, secondary school students, stress, teacher student relationship, teaching strategies

INTRODUCTION

One of the key characteristics of autism spectrum disorder (ASD) is a severe difficulty in social communication. Many children who have ASD have major difficulties in forming relationships and interacting with others. However, educational programmes for these children often do not set a high priority on building student-teacher or student-student relationships but rather focus on developing a range of academic and functional living skills. This is despite the belief that it is only by understanding the particular challenges faced by students at school that teachers are able to make changes and use strategies that reduce stress and

increase success (Ministry of Education, 2006). This article reports on findings of a participatory action research (PAR) project, which suggest that, contrary to common practice, placing emphasis on initial relationship building may be the key to successful programmes for learners with ASD.

The PAR project was one of a number of small research studies investigating effective practices for students with ASD funded by New Zealand's Ministry of Education. It focused on Aroha and Maurice¹, two senior secondary school students who received part of their education in regular classes and part in the school's learning support facility. Both students were involved in transition to work experiences in order to prepare them for life beyond school. Frequently and seemingly as a result of feeling stressed or anxious, these students displayed behaviours that inhibited communication with work experience personnel, their teachers, teachers' aides and parents. Therefore the PAR project was developed to discover: What factors appeared to cause stress for Aroha and Maurice; what strategies were effective for them when they felt stressed; how they could be taught to recognise and understand their own stress levels and to use this knowledge to manage stress independently; how knowledge of what caused stress could be used to maintain effective two-way communication; and what constituted a supportive environment when Aroha and Maurice became stressed.

Stress is something that is commonly associated with ASD, however, despite 30 years of ongoing research, there are relatively few published reports in this area (Grodén, Diller, Bausman, Velicer, Norman & Cautela, 2001). One such report (Mullins & Christian, 2001) noted the worth and success of interventions around coping strategies to reduce anxiety in people with autism.

¹ Not their real names

In their consideration of stress and autism, Groden et al. (2001) hypothesised that 'persons with autism may be even more vulnerable to the effects of stress because they may lack a repertoire of appropriate coping mechanisms' (p. 207). They added that many of the "autism" behaviours may, in fact, be related to an individual's lack of coping skills rather than to their autism per se. The present study was motivated by these hypotheses, by the potential of interventions to reduce anxiety in people with autism and by a firm belief in the importance of this field of research.

WHO WAS INVOLVED?

PAR involves a collaborative approach where people work together to investigate and improve their own practice. It aims to use critical reflection and analysis to drive changes within and beyond the immediate environment (Mills, 2003). Weiskopf and Laske (1996) consider that PAR recognises a role for the researcher as a 'facilitator, guide, formulator, and summariser of knowledge, and raiser of issues' (pp.132-3). These issues include the possible consequences of actions and the awareness of structural conditions. Within an educational context it can be argued that teachers are more likely to change their behaviours and attitudes if they have been engaged in collaborative research, such as PAR. Their involvement and ownership of the research problem helps them to see the need for change and also to realise that it can be done (Cohen, Manion & Morrison, 2000; Oja & Smulyan, 1989).

The collaborative team for this PAR project consisted of teachers, teachers' aides, parents, family members and three mentors appointed by the Ministry of Education. The mentors had expertise in special education and research and played a supportive, advisory role in the project. The team also drew on the expertise of a speech-language therapist and a music therapist.

WHAT WAS DONE?

The nature of PAR is that it is cyclical: information is collected, analysed and, as a result, interventions are devised and introduced. In turn, these are evaluated and consequent refinements and changes made. This process of ongoing and evolving improvement was followed in the PAR project.

Data gathering

This project began with a concerted data gathering exercise. More information was needed on when, where, and why Aroha and Maurice became stressed; how their stress was exhibited or avoided; what happened before and after stress-related incidents; and the intervention and diversion strategies that parents, teachers and teachers' aides found to be either helpful or unhelpful. A variety of data-gathering techniques were used to answer these and other relevant questions. The techniques included:

- observations employing anecdotal and event-recording techniques to gain information on the nature and frequency of stress-related behaviours

- a questionnaire to teachers' aides, focusing on stress factors, the students' likes and dislikes and modes of communication (this questionnaire was developed from ideas in Watson, Holton & Andrews, 1997 and is included as Appendix 1)
- a questionnaire to parents asking about their child's ability to recognise their own feelings and the parents' interpretation of these feelings (this questionnaire was developed from ideas in Baron-Cohen, Howlin & Hadwin, 1999 and is included as Appendix 2)
- student worksheets probing their ability to interpret situations and associated feelings (developed from Baron-Cohen, Howlin & Hadwin, 1999)
- reflective journals used by the two lead teachers to record student observations and issues related to the PAR process
- specialists' evaluations – relevant data was gleaned from speech-language and music therapists' reports

Professional development

Data gathering was complemented and informed by a substantial, ongoing professional development component. Initially one of the mentors conducted a literature review of research relevant to the PAR questions. This review provided some insight into how similar problems had been addressed elsewhere and highlighted issues that had arisen in previous research. In addition to this, the two lead teachers and two mentors attended a two-day PAR workshop at which they developed the proposal for this project.

Staff at the school's learning support facility participated in a full-day session run by a New Zealand consultant on autism and a shorter session conducted by an international expert. Also offered to all staff were: a three-hour compressed version of SPELL Training²; a two-hour workshop on PAR; and a half-day session on effective strategies for working with students with ASD run by one of the mentors.

The two lead teachers spent a day with a consulting psychologist who has acknowledged expertise in the ASD field. This consultation included in- and out-of-school observation of the students, and related discussion. These lead teachers were released from their teaching every Friday afternoon to work on PAR-related tasks. These included: professional development activities; reflection on and analysis of data; intervention planning and monthly meetings with the mentors. At the fortnightly learning support staff meetings both general ASD information and specific project-related data and issues were shared and discussed.

Finally, the lead teachers, a mentor, a parent/teacher's aide and two sisters of one student attended the National ASD Conference in Christchurch³. The parents of Aroha and Maurice also attended two local workshops run by an expert on ASD. These workshops were partially funded from project money.

² SPELL is a framework for intervention when working with people with ASD. SPELL training is offered in New Zealand through Autism New Zealand. SPELL stands for Structure, Positive Expectations and Approaches, Empathy, Low Arousal, Links.

³ The conference entitled *Autism: Unlocking the Potential Within* was hosted by Autism New Zealand in 2004.

In addition to the organised professional development programme, money from research funding was used to purchase a wide range of books and videos recommended by the various ASD experts. These were housed in the staff library and were freely available for staff and parent use. Computer software for students' use was also purchased. (See Appendix 3 for a list of recommended resources purchased from research funds.)

Interventions

As a result of the analysis of initial information, a number of interventions were introduced. Ongoing data gathering throughout the cycles of PAR led to the dropping or modification of unsuccessful approaches, the extension of successful interventions and the development and trialing of new strategies. For example, the first intervention to be trialed was Tony Attwood's *Exploring Feelings* programme (Attwood, 2004a & b). A teacher in the project used this programme individually with each student. However, very early on, observations and work samples revealed that Aroha and Maurice did not have the conceptual understanding needed to benefit from the programme. Consequently, this intervention was discontinued.

On the other hand, the previously mentioned questionnaires and focused observations identified both factors that caused stress for Aroha and Maurice and also situations and activities that helped them avoid or lessen stress. Teachers successfully incorporated this new-found knowledge into developing interventions around the use of Social Stories™ and visual strategies^{4,5}, which had proven to be effective teaching approaches in the past. These were developed specifically to address the students' stress-related communication difficulties.

Social Stories™ were used to help Aroha and Maurice prepare for and cope with situations and events that were identified as being stressful. These were particularly successful with Aroha who helped write and illustrate her own Social Stories™. Examples included stories to help her: cope with her fear of balloons; make good food choices when away from home visiting relatives; stay calm when being re-directed; identify situations and times when it was appropriate to write letters to people; and cope with the transition from secondary school into the community. While Social Stories™ were usually initiated by adults, a breakthrough came when Aroha, recognising that a visit to her mother who had shifted to a new city would be stressful for her, asked her step-mother to write a Social Story™ about the upcoming visit. Together they prepared a story that focused on areas Aroha identified as stressful. The Social Story™ included what food to avoid, how to behave towards her siblings and what to do when she felt stressed.

Neither Aroha nor Maurice coped well with change so daily visual timetables were introduced and used for stress prevention, and as reminders of what should be happening. For example, if either of the students became stressed, they were shown their visual timetables that outlined the programme for the day.

Visual prompts were prepared for Aroha with photos of things she liked to do. These included dancing, listening to music and time on the mini-trampoline at school, and tennis, basketball and trampolining at home. When Aroha showed initial signs of stress in either location, she was shown a card with photos of the appropriate calming activities. On the back of each card were directions for the adult to read: 'Aroha, I think you are feeling stressed. You need to do one of these activities to make you feel better. Which one do you choose?'

Observations also revealed that on some occasions Aroha and Maurice became stressed because the information that was given to them by adults was not properly understood or they were not given sufficient time to process the information. As a consequence, staff members developed their ability to give clear, specific and easily understood information. They also gave advance warnings and allowed the students more time to process and communicate.

HOW EFFECTIVE WAS THE PAR PROJECT AND WHAT WERE SOME OF ITS POSITIVE OUTCOMES?

The effectiveness of the PAR project can be determined from two different perspectives. Firstly, it can be judged by how well Aroha and Maurice learned to recognise, understand, communicate and manage their stress in an appropriate manner. A second measure of effectiveness is how well the adults involved in this project learned to identify stressful situations and behaviours; maintain communication; assist their students to cope with stress; and provide a supportive environment for them. A further measure of success for school staff relates to how well they learnt to use the skills of PAR to improve their own practice.

Anecdotal observations throughout the project showed that Aroha and Maurice made slow but steady progress. Given the nature of their disabilities dramatic changes were not expected. However, a decrease in incidents of stressed behaviour and an increase in the students' abilities to recognise and deal with stressful situations indicate that the interventions introduced were beneficial for both students. As previously reported, Aroha began taking the initiative and participated in writing her own Social Stories™ to help her handle situations she recognised as stressful for her. School staff considered this an important step for a student whom the initial observation data identified as unable to recognise stress or to use her own volition to avoid or reduce stressful situations.

Similarly, initial data showed Maurice's usual mode of handling stressful situations was to: 'throw himself on the ground and become vocal and agitated or repeat actions/verbalisations over and over again' (teacher's observation journal).

⁴ For information on writing and using Social Stories™ and visual strategies refer to: Gray, C. (2000). *The new social story book: Illustrated edition*. Arlington TX: Future Horizons. Hedeon, D.L., Ayres, B.J., & Tate, A. (2000). Getting better, happy day, problems again! The ups and downs of supporting a student with autism in her home school. In M. Grenot-Scheyer, M. Fisher & D. Staub. (Eds.), *At the end of the day: Stories of ordinary lives and youth in inclusive schools and communities*. Baltimore: Paul H. Brookes. Hodgdon, L. (1995). *Visual strategies for improving communication*. Michigan: Quirk Roberts.

⁵ See also the article *Learning from Each Other* in this issue for a description and example of a Social Story™.

However, towards the end of the PAR project, observed incidents of such behaviour were minimal. Instead, Maurice would remove himself to a place of “sanctuary” (the equipment room or foyer). Additionally, the parents of both students reported improvements in stress-related behaviours in the home environment. They noted that Aroha and Maurice generally appeared more happy and content. Furthermore, parents reported that they felt better equipped to meet their children’s needs.

Aroha and Maurice’s progress also reflects how effective the PAR project was for the adults involved. In depth, focused observations, questionnaires and activities enabled the identification of a wide range of stressful situations and behaviours and resulted in the compilation of a dossier on the students’ likes, dislikes, ability levels in various areas, communication strategies, behaviour patterns, environmental supports, learning preferences and so forth. (See Appendix 4 for an approach to compiling an information leaflet about a student with ASD.) Ongoing data collection, analysis, reflection, and sharing of information and ideas, combined with an increased knowledge of ASD and appropriate teaching and behaviour management strategies gained from professional development activities, all contributed to the development of successful interventions.

However, arguably the most valuable lesson that was learned from the data-gathering process was the extent to which adults made assumptions about the students’ ability level in various areas. For example, because Aroha was verbal and Maurice was non-verbal it was assumed that Aroha’s understanding of emotions and feelings exceeded Maurice’s. When a mood barometer was introduced as part of Attwood’s *Exploring Feelings* programme it was discovered that in fact Aroha’s understanding of emotions and feelings was more limited than Maurice’s. Staff realised that the programme activities she was being asked to do were actually adding to Aroha’s stress levels rather than decreasing them.

On the contrary, Maurice’s understanding of feelings and emotions exceeded people’s expectations. He was able to recognise stress, anger, unhappiness and relaxation both in himself and others. He could also recognise happiness and hurt in others but not in himself. Being non-verbal, Maurice used an Ultimate 8 talking machine to communicate. Messages relating to his emotional state and his likes and dislikes were recorded onto this machine. For example:

I am feeling grumpy. I want to be left alone.

I would like to type on the computer.

While Maurice regularly used the talking machine to request favourite activities, he did not progress to using the messages that communicated his feelings. However, he did learn to use visual cards to express a limited range of emotions and enjoyed and responded well to music therapy sessions.

Through the PAR process, staff learnt about the danger of basing teaching activities on assumptions of what students could or could not do and the value of taking time to build trusting relationships, of getting to know the students well and of developing programmes based on this knowledge and trust. Staff members now place emphasis on initial

student-teacher relationship building before they launch into their teaching programmes. It is reported that this has taken pressure off staff and students and has led to more relaxed working relationships and more effective teaching activities. This appears to be verified by parents of newly enrolled ASD students who, since the introduction of the PAR project, have reported very positively on their child’s entry into secondary school.

Staff learned to use their increased knowledge of Aroha and Maurice to make adaptations and introduce teaching activities based on Aroha’s and Maurice’s individual needs and strengths, likes and dislikes. However, it was acknowledged that getting to know their students and building effective relationships with them was a time consuming and ongoing process. A supportive environment was considered to be one that allowed time for this to happen – both time within the school day and time over the student’s lifespan.

A further change the project brought about was in teachers’ aides’ attitudes and approaches to teaching students with ASD in general. Previously there had been a focus on changing the student to fit the environment. With the new-found knowledge gained from professional development, emphasis is now placed on understanding the student’s behaviour, by asking, “What is happening for the student in this situation? Why are they behaving in a particular way? How are they feeling? What are they trying to communicate? And what changes can be made to our practices and the environment to reduce stress and to support our students?” As one teacher’s aide explained in her evaluation of the project:

The project has changed the way I relate to Aroha and Maurice and other students with ASD in so many ways! I feel I can communicate at a much better level than before. Using visuals has helped me no end, i.e., stories, rules, signs etc. I have more confidence in my own ability and I have a much better understanding of autism. I now speak to Aroha and Maurice not at them. I try and think ahead of ways to make up-coming tasks and events as easy as possible for them to accept, i.e., Social Stories™, simple instructions etc. I also see their behaviours as a way of their communicating to us that things aren’t going right instead of naughty behaviour. I’m not scared of Aroha and Maurice any more! I can “push” harder and end up getting much better results. (Teacher’s aide evaluation.)

As a result of this project, staff have introduced two new resources. The first is a portfolio for Aroha and Maurice to take with them when they leave school. This includes information on their respective signs and causes of stress and on strategies that future teachers or employers can use to reduce stress for them. The second resource is a booklet that outlines effective practices when working with students with ASD. This resource is a useful starting point for new staff who have not previously worked with students with ASD.

Meyer, Park, Grenot-Sheyer, Schwartz and Harry (1998) note that PAR is a process which involves narrowing the gap between research and practice and allows for innovative

interventions validated by research to be adopted into everyday educational practice. This was evidenced in this particular PAR project. In addition to the positive attitudinal and teaching changes that were made, staff are now able to use their newly acquired PAR skills to inform their future teaching. Not only do they have increased confidence and competence in meeting the needs of students with ASD but also in meeting the needs of students in general.

CONCLUSION

When staff were asked what they would recommend to other teachers who work with students with ASD or who were considering becoming involved in PAR they emphasised the following five points:

- In respect to PAR, active support from school leaders is a vital ingredient. PAR involves a time commitment over and above a teacher's busy work life. There needs to be financial support from school leaders to release classroom teachers from some of their normal commitments. School leaders also need to provide support that demonstrates the importance of such projects.
- Collaboration is critical. Staff members and parents need to work together as a team and keep each other fully informed of the student's behaviours, programme and progress. This collaboration allows for the information sharing needed when interventions are implemented across settings. It also allows for the sharing of expertise and experience that occurs when parents, teachers and other professionals work together.
- School staff must be given time to reflect upon their practice and to share their thoughts and observations with others. The teachers in this study reported their weekly meeting and reflection times as one of the most important benefits of the research. They believed that this time helped them to shape their understanding of autism in general and the needs of Aroha and Maurice in particular. Funding support and careful scheduling may be required to ensure this reflection and sharing time happens on a regular basis.
- In respect to working with students with ASD, the importance of staff taking time to get to know students and to build relationships with them cannot be over-emphasised. Before teachers focus on academic tasks, social skills programmes or the like, a supportive, mutual relationship should be developed. Teaching plans and strategies are best built on a positive student-teacher relationship and an accurate knowledge and understanding of each individual. This may require teachers and other professionals to be less hasty to establish intervention programmes and instead give priority to the development of meaningful relationships.
- Ongoing professional development is essential to developing effective practice for students with ASD. Professional development should include not only teachers and teachers' aides but also parents and other interested family members.

This PAR project showed that no single strategy could provide a panacea in the education of learners with ASD. Rather, it is the combination of a collaborative, informed approach, positive student-teacher relationships and teaching strategies based on the interests and abilities of students that underpins effective practice for learners with ASD.

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APPENDIX 1

Questionnaire for teachers' aides (developed from Watson, Holton & Andrews, 1997).

(This is a compilation of the questionnaires used for Aroha and Maurice.)

GETTING TO KNOW AROHA

Date:

People who contributed information:

Likes

What activities or places appear to relax Aroha?

What are Aroha's favourite things and special interests?

What are Aroha's favourite places?

What are Aroha's favourite foods and drinks?

Dislikes

Are there any places where Aroha doesn't like to go?

Are there any activities in which Aroha doesn't like to participate?

Are there any objects which Aroha doesn't like or where she becomes agitated/frightened if they are around?

Unusual behaviours

In which situations does Aroha show unusual behaviours and what does Aroha do?

How does Aroha use her senses?

How does Aroha explore new objects and places?

Which sense does Aroha appear to rely on?

Does Aroha smell or sniff some objects?

Does Aroha appear to be looking at some things "out of the corner of her eye"?

How does Aroha react to certain sounds?

Which sounds are causing difficulty?

If Aroha is concentrating on something and you speak or there is a sudden noise, does Aroha respond?

Does Aroha touch or tap things as she moves around?

Does Aroha appear to be disconcerted if the surface on which she is walking changes? If yes, when?

Movement

Does Aroha sometimes have difficulty getting started on a task even though you are sure she knows what to do? If yes, when?

Does Aroha sometimes "freeze" halfway through doing something that you are pretty sure she knows how to do? If yes, when?

Does Aroha have difficulty doing different actions with each hand? If yes, when?

Does Aroha sometimes repeat an action over and over again? If yes, when?

How does Aroha communicate?

In what situations is Aroha able to use speech effectively?

How would Aroha let you know she wanted you to help?

How would Aroha let someone know that she wanted them to go away?

Does Aroha have any manual signs she uses? If yes, which signs?

Does Aroha use sounds to let people know she wants something? If yes, when?

What gestures or body movements does Aroha use to let people know what she wants?

Does Aroha repeat something someone has just said?

Is Aroha repeating part of a conversation which she may have heard some time ago?

What gestures or body movements does Aroha use to let other people know what she wants?

Does Aroha use facial expressions? Are they appropriate?

Does Aroha use eye-contact to communicate? If yes, when?

How would Aroha draw your attention to something interesting?

How does Aroha show emotions?

How does Aroha show pleasure?

How does Aroha show unhappiness?

How does Aroha show fear?

How does Aroha indicate ill health or pain?

How does Aroha show excitement?

How does Aroha show boredom?

How does Aroha show that she is tired?

How does Aroha show frustration?

How does Aroha show affection?

How does Aroha show sadness?

How does Aroha show other emotions?

Routines

What parts of the day go smoothly most of the time?

Which parts of the daily routine are most likely to cause upset?

What are the signs that Aroha is becoming upset?

Calming activities and places

What activities appear to calm Aroha down? (List as many as possible.)

Are there any actions which Aroha uses to calm herself?

Are there any places which Aroha seems to use as a refuge to get away from the world when she is overwhelmed?

Teaching strategies

What strategies have you used successfully to teach Aroha a new routine or skill?

Are there any ways which you have discovered to help prepare Aroha for a change of routine?

APPENDIX 2

Questionnaire for parents (developed from Baron-Cohen, Howlin & Hadwin, 1999).

Do you think Aroha recognises the following emotions in herself or others?

	Self	Others	Comments / How does she show it?
Happy	Y / N	Y / N	
Sad	Y / N	Y / N	
Relaxed	Y / N	Y / N	
Stressed	Y / N	Y / N	
Angry	Y / N	Y / N	
Hurt	Y / N	Y / N	
Afraid	Y / N	Y / N	
Confused	Y / N	Y / N	
Tired	Y / N	Y / N	
Bored	Y / N	Y / N	
Does Aroha recognise when she is stressed?	Y / N		Comments
Does Aroha use any actions to calm herself when stressed?		Y / N	What does she do?
Do you recognise when Aroha becomes stressed?	Y / N		If yes, how?

APPENDIX 3

Resources purchased with research funds

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VIDEOS

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Holliday-Willey, L. (2004). *Aspie Land as experienced by one of its citizens*. Video presented at the Autism: Unlocking the Potential Within Conference, Christchurch 2004.

COMPUTER SOFTWARE

Boardmaker, Mayer-Johnson.

Mind Reading Emotions Library, Jessica Kingsley Publishers.

Writing with Symbols, Mayer-Johnson.

APPENDIX 4

A guide for compiling a "Getting to know me" leaflet about a student with ASD.

FREQUENTLY ASKED QUESTIONS ABOUT THE "GETTING TO KNOW ME" LEAFLET

Who is this leaflet for?

This leaflet has been designed so that teams supporting individuals with differences on the autism spectrum can work together to share ideas and information to assist the individual in situations where they are not known.

Why should we compile a leaflet about a particular child?

Children with differences on the autism spectrum are often referred to as having a "hidden disability". At first glance it may not be obvious that some adaptations are required to assist them. Some quick information and tips may assist both the child and adults through their day. This brief information would assist at transition points for the individual, relief teachers, student teachers, new staff, paraprofessionals and visitors (where appropriate).

When should we do this?

At any time that works for the individual's team. Perhaps times when known periods of change are expected.

Who should do this?

Compiling this leaflet is a team venture. The team will include different people depending on the individual's situation. However, we suggest that a "key" school person and parents would be the minimum team. The individual being discussed should be aware of the leaflet and we would strongly recommend that you include something from the individual themselves if at all possible. It should not be done by only a teacher OR only a parent.

How does this fit with individual plans (IPs) or individual education plans (IEPs)?

This leaflet should contain key information points about an individual and therefore serves a different purpose to individual planning. However, teams may review this document at IP/IEP meetings to keep it updated. There is a section in the leaflet in which IP/IEP goals could be shared.

What should the leaflet look like?

Essentially this is up to you. We have made the leaflet so it can be an A4 sheet folded in half, like a booklet, to give four sides of information. However, please change to suit your needs.

Do we write about an individual in third person or from the person's perspective (first person)?

You decide this. It will depend on the individual situation.

GUIDE FOR PAGE 1 (FRONT COVER)

Photo

It is suggested that you take a photo of the child and include it on the front cover. This ensures new staff can quickly identify the child who this relates to.

Child's name

Include the name of the child on the cover. You could choose to add "and I have Asperger syndrome/high functioning autism/some things you need to know".

Optional headings for personal information:

- A little bit about me...*
- Stuff I want you to know...*
- Important stuff...*
- Did you know?*

Talk to the child to gain some information about what they want to share. Here is a script you can use to talk with the child about the leaflet and why it is being made.

We want to put together some information to help you at school. It will also help people to know you a little better.

I am going to ask you some questions. I will write down some of your answers and then put the information into the leaflet

If there is anything you don't want written down that is okay.

You just need to tell me. We will read through your information and we will check it is correct

Some questions that you could ask are included below. You will need to adapt these to the age and ability of the child.

- Who are you?*
- What is your name?*
- How old are you?*
- Do you have a nickname or something people should call you?*
- Who is in your family?*
- Who is important to you?*
- What do you like?*
- What hobbies do you have?*
- What are your interests?*
- What makes for a good day?*
- What happens at school to make it a good day?*
- What subjects do you like?*
- Who are your friends?*
- What trips do you like?*
- What things do you dislike?*
- Are there any sensory things that do not feel good?*
- What are you good at?*
- What are your dreams?*
- What would you like to do as a job when you leave school?*
- What do you want to do when you leave school?*

GUIDE FOR PAGES 2 AND 3 (MIDDLE OF LEAFLET)

Information about Asperger syndrome

Include some general information about Asperger syndrome using a description of your preferences. Utilise books and articles if required.

Specific attributes and strategies

With people who know the child well, use the headings in the table below as a guide for describing the child's specific attributes. For each attribute, write a strategy that will support the child in that area. The table below is an example only.

Attributes for (insert name of child)	Strategies to support (insert name of child)
<p>Communication</p> <p>I may not make eye contact with you when you are talking to me.</p> <p>I usually understand your words but not your emotional tone, sarcasm, innuendo.</p>	<p>Communication</p> <p>Don't force eye contact from me. If I look at you, I cannot listen properly.</p> <p>Name your emotions for me. If you are mad with me and tell me off, you need to let me know before you do.</p>
<p>Sensory</p> <p>I will have difficulty hearing your voice over background noise.</p> <p>I do not like to be touched or crowded.</p>	<p>Sensory</p> <p>I sit in front of teacher's desk so background noise is lessened.</p> <p>When you talk to me do not get too close.</p>
<p>Mobility and fine motor</p> <p>I have real problems catching small balls</p> <p>I will sometimes walk over people to get to my space on the mat.</p>	<p>Mobility and fine motor</p> <p>Ensure there are a few different sized balls available for use so I can choose a larger one.</p> <p>Leave a space in front of the white board – I know to walk along the front to my space.</p>
<p>Anxiety</p> <p>If I start to rock, you know my anxiety level is getting higher.</p> <p>I get highly anxious if there is a new teacher in the room.</p>	<p>Anxiety</p> <p>At this time, you need to say "You looked stressed, take your reading book to the quiet space"... I will do this. Give me 5 minutes to calm.</p> <p>Write the new teacher's name on the board so I can read it. Tell me you have read my leaflet and I will know you understand me better.</p>
<p>Unusual behaviours</p> <p>You may think my behaviour is unusual. For example: vocalisations, fapping, sucking my clothes. I may be concentrating or anxious.</p>	<p>Unusual behaviours</p> <p>You may simply ignore these behaviours. If they are disturbing others, please tell me what I am doing and how to make it right.</p>
<p>Personal care</p> <p>When I am highly anxious I will not eat lunch.</p>	<p>Personal care</p> <p>If I do not eat and you know I am anxious, please let me go when the other children are released. Ensure my parents know. If I do not eat, allow me to use my quiet place – to enable me to cope with the afternoon.</p>
<p>Safety issues</p> <p>I will talk to anyone!!! I do not have stranger danger awareness</p>	<p>Safety issues</p> <p>When I wait for my parents outside, my assigned buddy waits with me. There is a list on the form room wall.</p>

Attributes for (insert name of child)	Strategies to support (insert name of child)
Organisation My desk is often messy.	Organisation You need to tell me what I need out and what goes away.
Special Interests I will talk to you forever about dinosaurs	Special Interests I am only allowed to talk to you about dinosaurs before morning tea.
Social skills I am practising taking turns in conversation.	Social skills If I talk over you, say "stop, it's my turn to talk".
Curriculum I love maths. I have difficulty generalising learning. I often learn in isolation.	Curriculum As a special reward, give me extra maths – honestly! Give me lots of over learning opportunities. Give lots of examples to help me generalise.

GUIDE FOR PAGE 4 (BACK PAGE)

Current goals/targets and notes

Include some information about the child's current goals and targets. Consider the following when writing this section of the leaflet:

Who is going to fill in this section or will everyone contribute?

Do the goals match the IEP?

When will the goals be reviewed?

Are there sensitive goals that should not be in a public document?

Important people

People to include in this section may be from home, school, other agencies, or emergency contacts.

SOME FINAL THOUGHTS AND CONSIDERATIONS

Checking information is complete

It's a good idea to send a draft copy to all concerned parties to ensure the information is correct.

Reviewing the leaflet

In order to be effective, the leaflet will need up-dating and adapting over time. Therefore, set a review time for the leaflet. An IEP may provide a good opportunity to do this.

Ownership and distribution

The idea of ownership should be addressed when the leaflet is compiled. Who owns this information? When it is no longer needed what happens to the leaflet? This is a different issue to authorship of the leaflet.

This leaflet and guide was developed by the Manawatu High Functioning Autism/Asperger Syndrome working group.

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Building Communities of Support around a Child with Special Education Needs

The effects of participatory action research

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ABSTRACT

Over a period of a year, formal and informal interactions among members of the community around a four-year-old girl with special education needs were focused through participatory action research (PAR). The team included parents, kindergarten teachers, an education support worker, speech-language therapist, early intervention teacher and psychologist. Closer relationships between team members have resulted in more immediate sharing of relevant information, collaborative analysis and responses using appropriate intervention strategies. Strategies used have included intensive blocks of intervention to introduce the Picture Exchange Communication System (PECS) in the child's home and kindergarten settings. The relevance of this system was established when the child made a spontaneous card exchange at the kindergarten to claim something she wanted from an adult with whom she did not have close contact. A variety of methods were used to record and share personal reflections, observations and assessment, formally and informally, within the team. Transfer of information, practice and skills across the child's environments has been expanded in preparation for transition to school. Mutual respect has been enhanced as the value of the contribution of all team members has been recognised, and the use of PAR has been favourably evaluated by the team as an enhancement of the previous practice, which used a six-monthly Individual Development Plan cycle.

Key words

Action research, autism spectrum disorder, communities, early intervention, effective practices, family involvement, participatory action research, Picture Exchange Communication System, professional practice.

INTRODUCTION

Let me introduce the child who was the star of our research project, for privacy reasons code-named by her parents as "Busy Bee". A severe episode of epileptic seizures had changed her from a bright, interactive two-year-old to a private, withdrawn child whose lack of social interaction was attributed, by her paediatrician, to autism spectrum disorder (ASD). At four years old her physical development was on track, but she had not regained any of her two-year-old vocabulary. At the beginning of the study, Busy Bee was choosing to spend most of her morning kindergarten sessions carrying or playing alongside a colourful collection of large plastic beads in a tote tray. Her initial exploration of these was by raking her hands repeatedly and noisily through them or by lowering her head to touch beads with her mouth.

Her family was highly motivated to carry out intervention strategies for their daughter and sister. They coped with large numbers of people working with Busy Bee. Ten people were involved in her daily care and education to varying degrees. Ministry of Education, Special Education (GSE) staff added another two people during the early stages of the research, and two medical specialists were important contributors of assessment and information.

The research project focused on the use of participatory action research (PAR) to promote the progress of Busy Bee in a rural town setting in New Zealand. This article focuses on the contributions of PAR methods to the cohesion and efficiency of the team working with Busy Bee.

FORMING A COMMUNITY OF SUPPORT

The challenges of working with large numbers of people from different organisations, several of whom require similar information and access, are potentially stressful factors for families of children with special education needs. Ideally, a team culture can be developed to reconcile multiple agendas, to share knowledge and skills and to collaborate as members of a transdisciplinary community of support. Wenger, McDermott and Snyder (2002) note that special effort is needed to connect people as members of a group and to share information. As incentives to be involved, tangible value should be evident, and the workload should be as close as possible to normal practice.

Wenger et al. (2002) identify the following four factors as important to a functioning community of practice. They are equally applicable to all communities of support around children with special education needs

- distance: connections and visibility
- size: knowing people
- organisational affiliation: priorities
- cultural differences: communication and values

Distance

Wenger et al. (2002) point out that members of a community usually see each other often and are able to meet relatively easily to share ideas or to collaborate on shared issues. For distributed communities, barriers to effective community connections include reduced opportunities to form and maintain relationships, to network informally or to communicate effectively. Members may be less able to identify significant information or events, to see the reactions of others in the group to information they share, or to monitor the progress of plans made together.

Size and organisational affiliation

The community of support in this project comprised members of five different groups. At the core were the child and her resident experts – her parents and older sister. Her godmother, as the head teacher, provided a strong link with the kindergarten where Busy Bee attended five morning sessions each week. A second established link was that between the kindergarten, home and staff of GSE through the education support worker, employed by the ministry to support Busy Bee full-time in the kindergarten. However, the GSE staff are also a distributed community, as the speech-language therapist, early intervention teacher and psychologist, although based at the same office, usually work independently in locations up to an hour away from the office. Time spent travelling together to visit Busy Bee gave opportunities for sharing and reflecting on information and for planning. Busy Bee also had daily contact with home support staff, who sometimes interacted briefly with others in the kindergarten and occasionally with members of the GSE group when taking her to or picking her up from the kindergarten. The fifth group involved staff of the Child Health Centre, based in the same town as the GSE staff, specifically the paediatrician, who completed six-monthly reviews, and the occupational therapist who was brought in as a consultant at a key point. In summary, while there were opportunities for informal links within the wider community for family members, kindergarten and home support staff,

effective strategies were needed to involve distant members in collaborative relationships as part of a community of support. Where there are large numbers of people and agencies involved, Malone and McPherson (2004) suggest there is a need to reconcile the different needs, priorities, goals and expectations of group members and to coordinate some group activities.

Culture

A team is 'a group of people working together and supporting each other towards shared goals, often taking different roles in achieving the common vision' (Ministry of Education, 2004, p.14). In team work, 'positive relationships are paramount for positive outcomes' (Ministry of Education, 2004, p.15).

Wenger et al. (2002) state, 'engaging all players is the key to getting a good start' (p. 124). They point out that communities of practice are often built on pre-existing networks, and suggest three basic elements: shared focus, community culture, and practices for becoming effective in gaining and sharing knowledge and skills. These elements were reflected in our project in the following ways

- A shared focus of relevance and value to members. Our project focused on supporting the child to develop, use and generalise skills using the Picture Exchange Communication System (PECS).

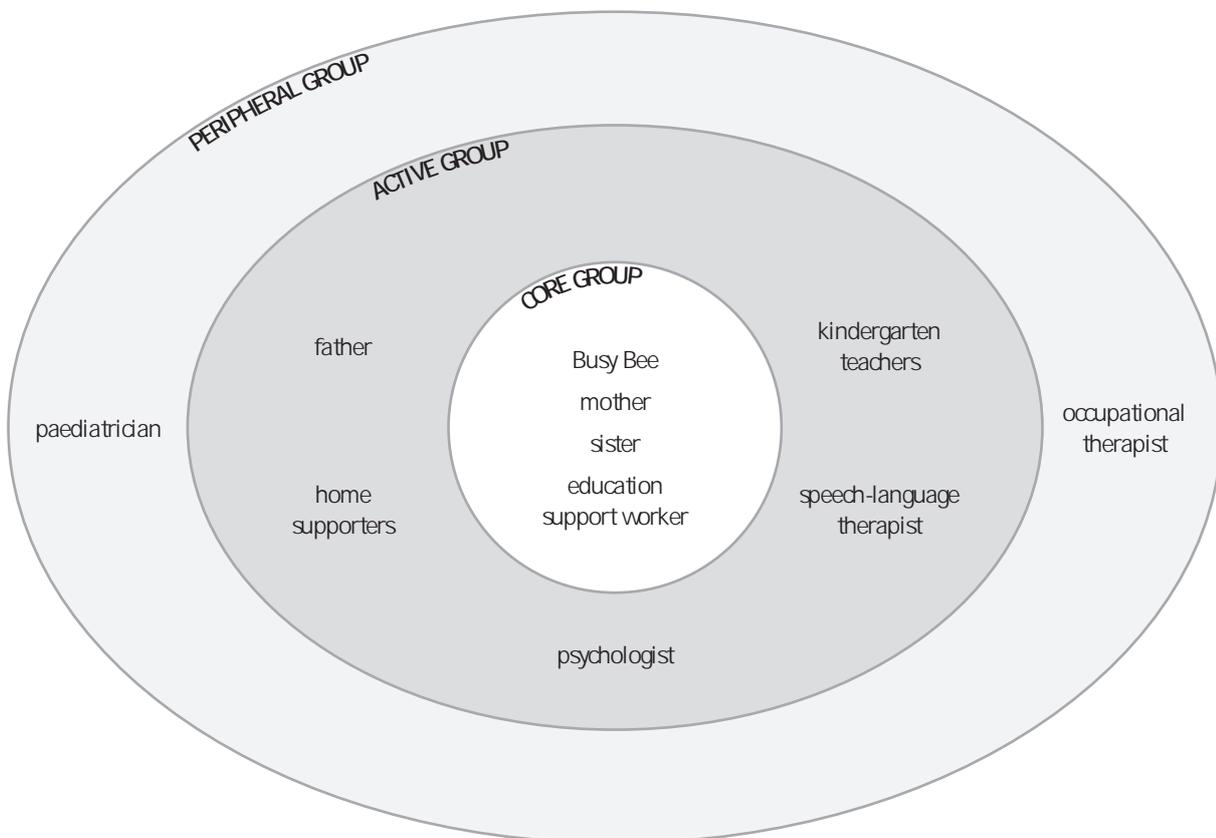


Figure 1: Degrees of community participation (Based on Wenger, McDermott & Snyder, 2002)

- Forming a community culture through establishing trusting relationships and patterns of interactions appropriate to the group. This has sometimes been called a collective empowerment model (Turnbull, Turbiville & Turnbull, 2000). Mutual respect for the experience, skills and knowledge of group members supports members' confidence to ask questions in order to gain understanding of different terms, techniques and perspectives; to disagree with others in public; or to contribute insights from personal experience which may lead to exploration of new ideas or pathways of action.
- Developing practices that help the community to become effective in gaining and sharing knowledge and skills. This may include working through differing communication styles, different ways of relating to others and different expectations and priorities among people according to their occupations and their past and present experiences. A horizontal community structure supports collegial relationships, and empowers all members to use their initiative, to make suggestions and to take responsibility within the agreed focus area. This sharing of leadership means that no one person is constantly essential to or in charge of a project, and that the community continues to function in the absence of one or more members. Time and effort spent in team work is rewarded by the benefits of "collective knowledge at work" (MacArthur, Purdue & Ballard, 2003).

In building a community of practice or support, Wenger et al. (2002) recommend being 'more intentional about connecting people' (p. 22), building interpersonal relationships and establishing and identifying norms of practice around a shared focus. They state that it is not realistic to expect everyone in a team or community of practice to be equally committed to shared goals, and describe a pattern of constant commitment by some community members with brief, strategic involvement by others in an outer circle of active or even peripheral observers.

Evolution of practice

Figure 1 shows the structure of the community of support, with Busy Bee and those most involved in working with her in the core of the circle. As predicted by Wenger et al. (2002), the majority of interactions in the project were carried out by the core group of mother, sister and education support worker. Others in the community took active roles from time to time, some regularly and others for a short period to monitor progress or to observe Busy Bee's capabilities and advise on appropriate strategies. People in the peripheral area, including the paediatrician and the occupational therapist, contributed expertise infrequently. "Intentional connections" occurred at key times, such as when GSE staff attended medical appointments with Busy Bee's mother, on her request. There were several advantages in this wider consultation, as Busy Bee was able to interact with known people in the unfamiliar setting of the hospital clinic, completing picture exchanges with the early intervention teacher and speech-language therapist while her mother and the paediatrician conferred. Information about Busy Bee's demonstrated abilities in a range of settings was shared, and when she was not motivated to demonstrate

skills for a stranger in the clinic, both the paediatrician and occupational therapist took advantage of the opportunity to observe her in the familiar kindergarten setting, where she interacted with familiar people and resources.

PARTICIPATORY ACTION RESEARCH

How could our project goals be best achieved? PAR provided a structure for achieving the working culture described in the following:

Working effectively is about listening to individual needs, sharing expertise and skills, and implementing, monitoring and measuring the interventions we use, and the contribution they make to learning, social and cultural outcomes (Ministry of Education, 2004, p.3)

Yoland Wadsworth, who trained practitioners from teams chosen for the national project in PAR, describes the process thus:

It is important to practice continual cycles of reflection, clarification of what it is we value and why, and the reaching of agreement about how we might change and improve what we are doing in the light of this (as well as the reaching of conclusions about what we are doing that is going well, and should this be sustained.) (1991, p. 47)

The team around Busy Bee used the PAR approach to systematically build on the earlier introduction of the Picture Exchange Communication System (PECS) and extend its use across all settings and to everyone who was supporting Busy Bee.¹

FAMILY-CENTRED INTERVENTION – SHARING EXPERTISE AND SKILLS

Maintenance of links between family and community is a key goal of the New Zealand early childhood curriculum, *Te Whāriki* (Ministry of Education, 1996). The family, as the central hub of this community of practice, worked with the whole team, while representatives of the different groups supporting Busy Bee had connections with some but not all other groups. The mother's key role was the most important in bonding the group together through recording, sharing, interpreting and requesting information, and through involvement with the kindergarten and the wider local community. She also hosted working sessions and Individual Development Plan (IDP) meetings at the family home, where wonderful food added to the positive atmosphere.

Busy Bee's older sister was an enthusiastic trainer. After observing a coaching session, she independently practised card exchanges with Busy Bee from the moment she arrived home from school. She extended the scope past the team's expectations by motivating her sister to complete exchanges over a distance when she took the desired object outside on to the deck. Card exchanges became part of their daily play routine, and Busy Bee's sister was given the responsibility over the school holidays for gradual expansion of an album of photographs of familiar objects, people and places. She also took a turn at using the video camera to record Busy Bee's progress.

¹ For more information on PAR see the article in this issue *Participatory Action Research: An Overview*.

As Busy Bee's father's occupation allowed him to come home occasionally during the day, GSE staff were able to observe her father-specific interactions. We observed and celebrated a breakthrough in skill development when she greeted him with a clear "hello" when he came home for lunch during a home team meeting. Indeed 'team work is built on trust, effective communication and collaboration, which provides a climate for sharing problems and celebrating successes' (Ministry of Education, 2004, p.13).

IDP meetings were held at the child's home during her afternoon nap on Wednesdays when there was no afternoon kindergarten session. All three kindergarten teachers and three GSE staff attended; all contributing to the reporting and planning.

WHAT WE DID

Introducing PECS – strong scents and sharp flavours

PECS is a specific protocol for teaching expressive use of pictures for an individual to communicate wants and needs, and to comment about the world (Frost & Bondy, 2002; Grant, Web & Gardner, 1999). The protocol involves six distinct phases of teaching, as well as strategies for introducing attributes (for example, colour and size) into the individual's language. It combines knowledge from the fields of applied behaviour analysis and speech-language therapy to produce a method for teaching functional communication.

PECS was introduced to Busy Bee a year before the project started, with little response from her. Preliminary testing showed that she was able to associate a clear photograph of an item she desired with the actual object. A block of intensive weekly sessions at home reintroduced the exchange of picture cards to request an item. As her early intervention teacher, I visited Busy Bee at kindergarten once a week, and less often at home, to monitor and contribute to progress. Her family, her education support worker and I used the skills we had acquired to continue PECS use at home and in the kindergarten. We also expanded on the use of photographs to cue Busy Bee to look at and interpret pictures of familiar objects, places and people.

At home, laminated cards used for practising the skills of exchange were initially for food items including vegetable chips, a biscuit and her water bottle. Other desirable items were a telephone and a tube of toothpaste, which satisfied her interest in smelling strong scents and tasting sharp flavours. A picture of the plastic beads was made for the kindergarten. The speech-language therapist led practice in both settings for family members, the early intervention teacher and the education support worker. Kindergarten staff observed interactions in their setting.

Picture exchanges were programmed into Busy Bee's kindergarten routine. After finding her name card (with support) and placing it to indicate that she was present, she was able to request her favoured resource, the tray of beads, by giving a picture card to any staff member in the office. A picture of her lunch box was kept on the wall on a velcro dot, so that she was able to indicate when she was hungry. She then gave the education support worker a card to request access to specific food items until she was able to

open containers independently. Later in the study, the kindergarten head teacher supported Busy Bee in exchanging a card for a ball she was trying to take from another child.

Team reflection, clarification and planning

All members agreed to share in ongoing informal and formal evaluation and planning sessions. Communication opportunities that were used included:

- brief encounters when team members updated each other on and evaluated recent developments
- discussions at the kindergarten over lunch time
- working sessions at the kindergarten or at home – after four weeks of PECS training once a week in both the kindergarten and home settings, the speech-language therapist visited less frequently and the early intervention teacher made a weekly visit to either or both settings
- phone calls made each week by GSE staff to home and kindergarten
- email communication within GSE. Messages were also sent from GSE team members to the kindergarten and to the home. Unfortunately, attachments were not received, and the lack of frequency or time for communication made email an unpredictable method of communication which lacked the immediacy of interchanges over the telephone.

The methods used to record information varied from person to person, and as much as possible, were integrated into normal practice. For GSE staff this included dated file notes, more detailed summaries, written and videoed observations and progress reports. Medical professionals provided written reports to parents and GSE staff. Summaries of daily activities were written in a journal by the education support worker, and kindergarten staff recorded observations for Busy Bee's kindergarten portfolio. Kindergarten staff and the early intervention teacher organised information gained from observations under the headings of the five aims of *Te Whāriki* – wellbeing, belonging, contribution, communication and exploration (Ministry of Education, 1996). As research coordinator, I printed out copies of emails and recorded details of telephone and face-to-face conversations and minutes of meetings. Much information was spread within Busy Bee's community by word-of-mouth, with summaries of behaviours and achievements shared between team members at key contact points including the beginning and ending of kindergarten sessions. Although this level of documentation may be normal practice, PAR provides opportunities and incentives to share and utilise the information more effectively within an agreed group code of ethics.

Towards the end of the project, permission was given by another of the three ASD PAR teams in the region, which were loosely linked under the same administrative coordinator, to adapt a chart they had developed to facilitate data collection over time. The early intervention teacher introduced it as an optional tool, using Busy Bee's team's categories of data collection. Copies of the chart were kept in each of Busy Bee's environments. Although other team

members chose not to use the chart, her education support worker found it an easy way to contribute information for later planning meetings. She followed the practice of the team that developed the chart, writing brief details on post-it notes, which were placed in appropriate positions on the chart. These noted what she had seen, heard or felt when observing Busy Bee's behaviours with familiar or unfamiliar adults, peers or sibling. One row of the chart covered details of Busy Bee's communication in actions, gestures, picture exchanges or verbal utterances. The last row allowed team members to evaluate the action research process.²

Notes made of the content of telephone calls, regular verbal reports and informal conversations provided valuable material to document progress over time. We were able to make sense of new behaviours by sharing information on previous experiences, achievements and observations in different social or physical settings. Collection and exchanges of information were enhanced by the practice of linking observed behaviours to the five aims of *Te Whāriki* (Ministry of Education, 1996), and by standardising categories on the chart.

Busy Bee's influence on our practice

On several occasions we planned to introduce new resources and strategies linked to activities Busy Bee currently favoured, based on theories of developmental progression. Many logical ideas were quickly abandoned because they were of no interest to her. Plans based on collective observation and analyses over time were more successful.

Busy Bee clearly demonstrated her preferences when offered alternatives of different sizes and representation modes in her laminated photographs. She was highly motivated to exchange cards for desired items, even when tired and distressed. Connections between home and kindergarten were carefully planned through common practices, such as serving food on an identical plate so that her choices were clear when presenting a card request.

Our experiences of learning from Busy Bee reflected her central role in the planning process – as shown in Figure 1. Through taking note of her preferences and sharing our interpretation of her communication, we were able to recognise Busy Bee as a competent learner who was leading the way.

Gains for Busy Bee

As a result of success in gaining what she desired through card exchanges in two major environments, Busy Bee was more content. Her early response to frustration was to bang her head on a wall or tabletop. This reduced to occasionally hitting her temple with the heel of her hand. Especially after hospitalisation, when "coming down" from medication, she was inclined to react to frustration by pinching her mother hard on her neck, and her sister was pinched on the arm during an initial PECS training session. Pinching was no longer evident when she understood that a card exchange would get her what she wanted.

On one occasion Busy Bee took a card outside to her mother to request a biscuit. As she got the container down, her

mother put the card on the bench, and Busy Bee promptly picked it up and presented it to her again. When the biscuit container was held out to her, she took two biscuits. The team thought the selection of two biscuits possibly represented her two card requests.

Gains for the team

PAR was very responsive to changes brought about by raised awareness and enhanced communication within the team. The PAR process resulted in the team becoming a community of practice. There were several advantages

- When skills were generalised and emerging in the kindergarten setting, adults were aware of the implications, able to interpret intentions and respond appropriately to them. The most dramatic incident was Busy Bee's first unprompted card exchange, when she deliberately went to get a randomly chosen kindergarten name card from a display board and placed it in the hand of a kindergarten staff member. She then stood and waited expectantly to be handed the banana cake the adult had unpacked for her morning tea. As the adult had observed the speech-language therapist, education support worker and early intervention teacher coaching Busy Bee in exchanging cards for desirable objects, she was able to interpret the intention and was delighted to hand her the cake.
- Coordination of activities and actions at home and at the kindergarten resulted in greater understanding of Busy Bee's actions, such as an explanation of her intention when "doing something" with a kindergarten teacher's fingers as she attempted to repeat a unique finger play developed with her mother.
- New cards were produced for exchange as Busy Bee's interests and activities changed.
- Staff were able to establish daily cooperative routines based on IDP goals and to spontaneously coordinate their support for Busy Bee at times when she was motivated to work on goals such as mastering skills on outdoor equipment.
- Team members were constantly aware of Busy Bee's IDP goals and of her progress towards them.

CONCLUSION

PAR can be a useful tool for collective empowerment in a family professional partnership. The project linked people across and within organisations for the duration of the study, giving greater opportunities to share ideas and insights and greater collaboration through using PAR to plan, act and evaluate. Busy Bee was centrally positioned in the project, was at the core of the community of practice that developed, and was recognised by the team as a competent learner who led the way to valued outcomes. The impetus of the study reflected the dynamics and pace of Busy Bee's progress. Intervention became more responsive and more immediate, more appropriate and therefore more effective than static plans based on goals set at six-monthly IDP meetings. All participants gained confidence through working towards shared goals.

² A similar chart used by another ASD PAR team is included in the article in this issue *What We Did*.

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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 focus 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 in-depth 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: Christopher¹



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.

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This article was prepared and submitted by former RTLB, Robbie Lamont, and seeks to represent the voices of all those involved in the project.

AUTHOR PROFILE

Robbie Lamont



Robbie Lamont

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 Kōtahi tangā. She currently works in Te Kōtahi tangā Research and Professional Development team with Waikato University.

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

Teaming from Three Perspectives

Interviews with participatory action research participants



Judith Cain

Resource Teacher: Learning and Behaviour, Te Tai Tokerau

ABSTRACT

Taking part in the autism spectrum disorder participatory action research (ASD PAR) project was a genuine team effort for the group of people supporting Rose¹, a primary school student with Asperger syndrome. The following excerpts are from interviews with some of Rose's team. This is a collaborative approach to telling the story of the team's collaborative effort. The voice of Rose's parents, the principal of the school she attended and the resource teacher: learning and behaviour (RTLB) who coordinated the project, are all heard here and offer readers some insights on teaming from three perspectives

PARENTS' PERSPECTIVE

first impressions

When we got to the first meeting we were pretty taken aback because we were the only parents there on the day and we had expected a lot more. We were very nervous: really not knowing what was going to happen. I think we were both expecting a lot less than what did actually happen! We found the meeting to be very informative. For us as parents, we left there on a high, knowing that there was some major support out there for our child. We initially attended the meeting not really accepting that there was a problem with our child. We'd had previous experiences with Special Education Services and, not putting them down, but getting information on a piece of paper was not what we were looking for. What we wanted was information from another face, telling us or informing us what to do with a child like Rose and where to go. Anyway, we left the meeting very much on a high note. Everybody there was absolutely great

Meeting with the team

The meetings were brilliant. Because our team had different people, with different experiences, with different levels of knowledge, for us, as parents, we could ask any questions and have them answered. People have to understand that parents are in the dark when they have a child who they perceive to be perfect, as each parent does, and all of a sudden they are told "I'm sorry there is something wrong with your child. They've got this, they've got that". We were very much in the dark. To have those people at those meetings with all that knowledge, answering all our questions was just fantastic. To see what they were doing for our child and keeping Rose involved with her peers was just absolutely fantastic.

Parents' preferences

We decided that we wanted Rose to stay in the class, to stay with her peers and to stay around people of her own age. We felt that it wouldn't do her any good at all if she was taken out and put into a little group of children with similar abilities. So with the team's effort and our effort we decided to keep her in the class.

Changes in the team

For us, as parents, the change of teachers and teachers' aides really hasn't been any difficulty at all. Initially, we felt a bit dismayed because we thought that with each change Rose was going to have to start all over again and go through all the whole rigmarole. But now we think that it was actually a big help to her because it made her interact with different people. She might have got a little bit bored with the same person year in and year out!

Lasting impressions

We have enjoyed the process of working with the team. It's been fantastic. We both agree with that. The information that we have got from everybody is absolutely fantastic. We wish to thank them personally – you have been absolutely marvellous to us. Thank you.

PRINCIPAL'S PERSPECTIVE

At the school, we found the research programme very successful. Rose has become a person who speaks, tells people what she wants them to know and requests information. She has made amazing progress. I feel that this was entirely successful because it was an inclusive programme. Rose was given help, along with the other children in her class. The programme applied not only to her but to her peers. It was also successful because the resource teacher: learning and behaviour had the time to coordinate with all of the people involved in the programme. A teacher could not realistically be expected to do this. The programme also had funding that allowed the teacher, the teacher's aide, me, the parents, everybody, to get together in school time to discuss where the programme was going and how successful it had been.

RESOURCE TEACHER: LEARNING AND BEHAVIOUR'S PERSPECTIVE

A classroom-based project

From my perspective, as a resource teacher: learning and behaviour, I thought the project had to be based on how

¹ Not her real name.

I usually work. To do that, I needed to enlist the help of the teachers, the school, the teacher's aide, the parents – everyone. We all needed to be on the same track. I probably spoke to Rose's parents on the phone once a week, saw Rose once a week, and worked in the classroom with the class for an hour a week.

The teacher and I decided we'd do circle work with the whole class. That was really interesting because at the beginning, our little girl would not speak, she would not even look. She just looked away and played with other things. Then the other children would whisper what she needed to say and she would say it. After a while she said "no!" to the other children and gave her own contribution to the discussion. It might not be what we were talking about but it was wonderful! And by the end, she was actually able to participate in the circle properly. That was one of the amazing things. It probably took six months for her to start joining in like that.

As well as the circle work, we did cooperative techniques within the class. We taught listening techniques and played games that included talking, listening and looking at the other person, and other little communication rules. Then Rose practiced these outside the class with the teacher's aide. She didn't actually pick them up via classroom teaching, but the extra coaching really helped. Because she had already seen it happening in the class, she knew her one-on-one work was for the class and so she was keen to do it. Once she went away from the class and practised, she could come back and actually participate and join in the next time. It was quite amazing. We developed this approach and learned as we went along. The speech-language therapist was really helpful too.

Working with the team

The team had monthly meetings and that was wonderful because we usually are not able to provide support like that in schools. The wonderful thing about the project was the extra resources, because it meant we could set it up so everyone could attend the meetings – the teacher, speech-language therapist, teacher's aide, often the parents, and sometimes the principal.

It was important that the teacher's aide could attend the meetings. She had a big input into the project. She actually gave a lot of support because she was a full member of the team and she saw what went on day-to-day in the classroom. It was important that the teacher's aide came to the meetings and saw the process instead of just "looking after" Rose. She became more focused too because she saw that she was actually teaching Rose skills and not just "looking after" her.

Sometimes the Ministry of Education, Special Education (GSE) early intervention teacher who oversaw all the ASD PAR projects in this area came to our meetings. She supported me and noticed differences that I hadn't noticed because she came from outside.

The speech-language therapist worked in a different way. She didn't come into the class but came to the meetings and talked about the process. She was like a guide.

Working with Mum and Dad was wonderful. They did their very best at home too. For example, they spent a long time teaching Rose how to ride a bike. It probably took three months and they did that every night. Rose can ride a bike now.

Changes in the team

We had many changes of personnel. We worked with three teachers and three teachers' aides. And I thought, well, we need to keep going because this is normally what happens in schools and what happens with these children. The principal and I were the only ones who were constant. This was quite difficult, because my role became making sure that new team members understood what we were doing, particularly the idea of cooperative learning and teaming in the classroom, which weren't normal practice.

Sometimes it was initially difficult for new team members to understand Rose. She was a little girl who looked as though she could manage. New teachers coming into the room would think because she looked like the other children, she could do what they were doing. It took quite a while for them to realise that she wasn't able in many areas and needed some help. It's a great breakthrough once a teacher understands the child's difficulties.

Time and resources

I think it really helped that the project had resources. The funding for people to attend meetings made them feel valued, and because they felt valued they gave more effort and there was more commitment to the process. If it had just been me talking to the teacher in their morning tea time, or trying to have meetings in our own time after work, they may just take it or leave it. We often had our meetings in school hours. We could afford to employ a teacher to take the class, releasing the classroom teacher for the meeting, and that was just wonderful. I think that was what really made the team work. That's something we don't often have the opportunity to do in normal school situations.

Outcomes for Rose

Rose learned to go up to people, speak to them, say "hello", wait for an answer and give answers herself. In a way, she learnt these little techniques to help her with her communication, which made other people happy and it made her life easier. She'll come up to me now and say "Hello Judith!" and "How are you?" and that's great because it normalises her behaviour.

The wonderful thing was that other children started including Rose – in the classroom and in the playground as well. She'd be out there, running around, holding hands and skipping with the other girls. She was a very fashion-conscious little girl, and took pride in her appearance and the other girls liked that too. Seeing her, looking beautiful and playing with her friends, was really heart warming – a joy for all of us.

PARTICIPANT PROFILES

Cathy and Trevor Kehely



Rose's parents, Cathy and Trevor Kehely

Cathy and Trevor live in Northland having spent time in the Hawke's Bay and Wairoa before that. They live on a sheep and beef farm and work in the farming industry. Their eldest son is a carpenter, their younger son hopes to join the navy and their youngest child, Rose, now attends high school. They are happy to be identified as Rose's parents because if she reads this article in the future, they want her to be proud of who she is and know her parents wanted the best for her. Cathy's tribal affiliation is Whakatohea of Opotiki and Trevor's is Ngati Kahungunu of Nuhaka.

Principal of the school Rose attended

The school Rose attended opened in 1870 and is situated in a very small township on State Highway One. It now serves a diverse population from farms, newly settled lifestyle blocks and from the township. The principal has been at the school for the last 10 years, during which time she has enjoyed seeing it become a "community school" where the teachers and students work together as a team, and parents are welcomed into the school to be involved with their children's education.

Judith Cain



Judith Cain

Judith Cain began her teaching career in 1960. She has taught in primary schools in Canterbury, Southland and Northland. In her current role as an RTLB, she has been privileged to work in inclusive settings with teams of people to support children who struggle in the school situation. She has a passionate interest in children's learning, has continually updated her knowledge, and recently completed a Master of Education at Victoria University.

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What We Did

Journeys in autism spectrum disorder participatory action research

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ABSTRACT

This article is an analysis of the work submitted to the Ministry of Education by teams and mentors who took part in the autism spectrum disorder participatory action research (ASD PAR) project. The key findings are grouped under four themes and highlight the value of: team work; positive attitudes; using participatory action research in real-life settings; and learning together as a team.

Keywords

Action research, autism spectrum disorder, effective practices, participatory action research, professional practice, reflection, research methodology, teams

INTRODUCTION

Supporting children and young people with autism spectrum disorder (ASD) is an endeavour associated with both reward and challenge. There are teams of people across New Zealand who provide this support daily, without fanfare or display – it is simply what they do. In 2003 and 2004 nine such teams stepped up and out by taking part in the national autism spectrum disorder participatory action research (ASD PAR) project funded by the Ministry of Education¹. As participants in the ASD PAR project, teams reflected on, scrutinised, adapted, enhanced and documented their practice, while ultimately working towards improved outcomes for the children and young people with ASD at the centre of their teams.

Project teams and their mentors submitted proposals, milestone reports and final reports to the Ministry of Education throughout the project. While such reports may never fully capture the lived experience of the “insiders” who wrote them, they do provide valuable insight into the teams’ work, what they learned and the outcomes they achieved.

‘What we did’ was a heading that appeared in many of the teams’ reports. What teams reported under this heading, however, revealed much more than what they did; more even than how they did it and why. In describing what they did, teams and mentors told a compelling story about how they worked and learned together as a team around a child or young person with ASD, how their attitudes influenced the support they provided and how they came to grips with using participatory action research (PAR).

Specific findings about supporting children and young people with ASD are described in the companion article, also published in this issue, *What Works for One*.

METHOD OF REPORT ANALYSIS

Permission to use the project proposals, milestone reports and final reports was sought from at least one person who participated in each of the nine project teams and each mentor team. One team and one sub-team declined permission. Documents from the teams and sub-teams who granted permission were analysed qualitatively. A process similar to the “constant comparative analysis approach” outlined by Mutch (1995) was used. The permission process and qualitative analysis of project reporting were carried out by the author who was not involved in the ASD PAR project at the time it occurred.

Initially, each report was marked with “flags” that labelled salient ideas. Following this, a software package was used to create a mind map for each project. Ideas on the “flags” were transferred to the mind map and similar ideas were given one descriptor. For each project’s mind map, the many fine-grained ideas were grouped under emergent themes. These themes, and the ideas that fell within them, were then aggregated across the projects. Frequent and powerful ideas were captured. Working with a colleague, the themes and ideas were re-arranged and refined. Linkages and relationships between themes and ideas were tested.

The themes and ideas were then written up as an outline and a copy sent to team representatives and mentor representatives for comment. This article and the companion piece were written based on this outline. Each team that has been directly quoted in the article has given permission for their words to be used in this way. Pseudonyms for children’s names and schools have been used throughout the article.

Four themes are explored in this article: teaming; engaging with participatory action research; attitudes; and the adults’ learning journey.

TEAMING

Ideas about teaming emerged powerfully from all of the projects’ reports. There was agreement that a team approach was paramount to supporting children and young people with ASD. Three sub-themes emerged: coming together (the make up of the team and collaboration); making it work (processes and activities that supported team work); and the values and culture of the team.

¹ For background to the ASD PAR project and demographic information about the teams involved, see the article *With Hindsight* in this issue.

Coming together

Over time both the teams and especially the team leaders have developed in confidence in leading their teams and in developing a shared understanding of these two particular children. The parents on the teams have also established a role for themselves... according to their own needs and style, and the teams have been sensitive to these preferred ways of working. Including the teachers fully in the decision making of the team has been complicated, given their other commitments. However, both teachers have demonstrated a greater understanding of the children and have been instrumental in facilitating greater inclusion of the children into the class and centre groups. (Local project team H.)

The team around the child

While most of the teams had been working together in some way prior to the ASD PAR project, their ongoing commitment as the team around a child or young person was a dynamic endeavour.

Engaging the whole team around the child was integral to developing a holistic picture of the young person, planning interventions, implementing strategies across settings, monitoring progress, and reflecting. Teams were emphatic that the support provided to children and young people was unquestionably enhanced by the involvement of the whole team.

The value of close contact and communication between and among team members has been demonstrated in this study... The "expertise" and specialty skills of all team members are respected. (Local project team A, sub-team 1.)

Discussions centred around Heidi's communication skills have been enhanced by the closer interactions between those working with her, when team members contribute important information about Heidi gathered from a variety of social and physical settings to add with their professional and personal expertise to the team's knowledge base and planning processes. (Local project team A, sub-team 3.)

Each project team was unique in terms of membership and how it was configured. While engaging the whole team was considered important, many teams discovered that this did not require each team member to contribute in the same way. Ultimately these differences in participation, perspective, expertise and knowledge of the child or young person were intrinsic to effective team work.

Each sub-group has functioned differently... Much of this is attributable to the actual dynamics of the teams themselves and the circumstances affecting the nature and depth of team members' individual involvement. (Local project team E.)

While the mother has the most in-depth knowledge of Esther, the team and its supporters have a wide knowledge and experience in both social skills development and in working with students on the ASD spectrum. (Local project team C.)

All members of the team contribute their separate roles and expertise. All are valued for their unique input and have an equal voice in meetings to discuss Elliot. (Local project team F.)

The place of the family

Many of the teams considered the place of the child or young person within the team and all reflected on the role played by the family or whānau² in the teaming process. There was agreement that the young person must be held at the centre and that the family's place in the team was paramount.

The research established the benefits of an open, ongoing relationship between school and family. Between "us" we represent two of the most important circles of support for the child. It makes sense that one should enlist the support of the other. In the busy world of family and school, time is not always made available for "sharing" and reflection. As a school we must structure this time into the system, the goal being to maintain an "ongoing conversation" with every family. (Local project team B.)

Our intervention has been moulded to suit Gina's needs as they have arisen, and the needs of her family. It has been such an integral part of the project to recognise the needs of her family as an essential component of our intervention. My initial vision was to concentrate on progressing through the PECS system... However, it quickly became apparent that when working with Gina there were so many other aspects of her being that impacted on her everyday life that were just as important. (Local project team A, sub-team 1.)

Collaboration

Notions of collaboration emerged repeatedly as teams reported on how they worked together. These reflections moved beyond the rhetoric of collaboration and revealed that working collaboratively was not always easy. Collaboration required some people to work in new ways; educators were challenged to truly understand the family's worldview; specialists shifted from the role of "expert" and families stepped up with increasing confidence to have their perspective come to the fore. For some teams this change was difficult despite their best efforts, particularly where an existing culture of how to work with families or classroom teachers prevailed.

Speech-language therapist and psychologist reflection: ... [The project] has created the opportunity for the voice of the parent and the teacher to be given equal weight and to drive the interventions. [We] share responsibility for finding all the answers – not needing to drive it as a professional. [We have developed] an insight into the larger context of the child in both home and school settings. (Local project team A, sub-team 2.)

Making it work

The teams described several factors that affected their team work. They were: time together, communication, understanding the roles played by team members, leadership, and support for the team.

² Immediate or extended family.

Time together

Spending time together was identified by all the teams as essential. This was not always easy where team members did not live in the same area, and where team members had competing priorities. Meetings where as many team members as possible could attend were considered very valuable. For some teams, it was not that these meetings were different from the usual meetings teams had (such as Individual Education Plan meetings) it was just that they were more regular. Regular informal meetings, even over the phone, were also useful.

The opportunity to meet together more often than the regular Individual Education Plan meetings has assisted us in becoming a more cohesive unit ... and we look upon our team meetings, whether planned or informal as being the most valuable aspect of our whole involvement in the project. (Local project team H.)

The parent and I usually had weekly contact either by phone or email to discuss the things that were working well, and to get some understanding of the things that were not suitable, and why ... More regular, frequent contact meant a quicker building up of the working relationship with all team members. (Local project team G.)

While research money was available to release teachers to attend to project-related duties, there was a shortage of relievers with the experience and skills needed to teach students with severe disabilities. Additionally, given the nature of ASD, the change of teachers and routines were issues of concern to project teachers and so made them reluctant to use release time. (Local project team E.)

Teams trialled several strategies to support their having time together. For example, meetings were scheduled well in advance or were held in the family home over a shared dinner. In some cases, the resources provided to each team for the project were used creatively to support teams to get together, such as releasing teachers for meetings during school time, and meeting families travel costs.

Once a term a dinner meeting was held at the parents' home outside of school/work hours ... so that all team members could attend ... Meetings led to feedback, reflection and developing new strategies. For the school it also facilitated a whole view of the child in his home context. (Local project team F.)

Communication

It is not surprising that a heightened commitment to communication, and an increased effort to share information among team members, was consistently reported to enhance team work.

Many teams adopted an open approach to communication, where the views of all team members had a valid place in discussions. In this climate, problem solving and decision making were cooperative processes.

... with the existing model of open and honest discussion, and the ongoing reflection on our work, it was a relatively simple process to introduce a cooperative

decision making model. This reinforced a willingness of all staff to speak openly about their actions and those of others and how we might change what we were doing to encourage and guide change in the students. This also led us into a willingness to critically review our programmes for each student. (Local project team C.)

Making sure that all team members "were on the same page" was considered vital for several teams who ensured that information was always shared. Teams reflected on the language used to convey information and found it essential to use everyday language, avoiding jargon where possible. As most teams had members from several different contexts, this meant using strategies such as group email messages and home-school communication books.

The home-school notebook travelled with students and was used on most days to keep parents informed of events and actions in their daughters' school lives. Most parents and caregivers were equally good at letting us know what was happening on evenings, weekends and holidays. (Local project team C.)

Roles within the team

While many teams reported a sense of equality in their team processes, team members clearly played different roles. Some teams found it useful to delegate roles that supported the mechanics of their project, such as managing the budget, organising meetings or acting as a conduit for information. It was clearly helpful for these roles to be articulated and for people to be aware of others' expectations. Often the roles played by people that supported team work, such as facilitating discussions, providing positive feedback and buoying the team's enthusiasm, evolved over time.

Although each of the teams has worked together for some time new ways of working and roles are required for the action research project. In the past, some members of the team were involved in keeping the rest of the team informed about what they were doing rather than in making shared decisions with each other. (Local project team H.)

Initially, meetings were facilitated by the resource teacher: learning and behaviour. The team quickly developed its own coherence and there was no longer a need for a facilitator. (Local project team A, sub-team 2.)

Leadership

Teams' conclusions on leadership were variable, with some reporting the benefit of a team member taking a leadership role, and others indicating the value of equality and joint processes to determine direction. For teams whose experience of participating in the project was marred in any way, particularly by issues at the national level of the project, leadership of a nurturing kind was important and was provided by various team members, including mentors. Several school-based teams found it valuable for someone from within the school's leadership structure to be involved or supportive of the project.

Positive, proactive leadership provides a climate where people will risk more and work further from their "comfort zones", as the potential for failure is seen as

part of the learning process rather than something that reflects badly on an individual. This means people are more willing to attempt tasks that might be a "stretch" personally. (Local project team F.)

Support from school leadership, in the form of ideas and validation, was an important aspect in the success of this project. (Local project team D.)

Support for the team

Some teams used support from specialists in a consultative fashion and all teams were supported by a research mentor or mentor team. Many teams acknowledged the benefit of the contribution and support provided by specialists and mentors. Providing a sounding board, bringing specialist knowledge or skills, maintaining the team's enthusiasm and facilitating discussions or workshops were all welcome contributions made by specialists and mentors.

The consistent approach of a tightly knit team, plus the support of other teachers and expert personnel, has been a model to emulate in the future. (Local project team F.)

The professionalism, knowledge and experience of the mentor team has been a crucial element in the success of this research project. The three mentors have contributed much more than they were contracted to provide. This is appreciated and acknowledged. (Local project team E.)

The values and culture of the team

It seems most dear to us that the PAR model relies heavily on mutual trust and respect if it is to work effectively. Staff need to be confident of speaking out openly at either focus group meetings or to the wider team. (Local project team C.)

The teams strived to operate in a climate where relationships were built on trust, respect and openness. Honesty, humour, and a sense of equality were also valued. Most teams discovered that disagreements and conflict were inevitable as they worked together, and moving forward constructively was supported by a trusting team culture that valued all team members and their contributions.

[The family] was prepared to try things outside their comfort zone because they felt the team had a profound understanding of the family and Elliot. This engendered even more trust than that which existed at the beginning of the project. (Local project team F.)

Some teams experienced changes in team membership during the project and brought new team members on board. These teams found it important to be aware of their team culture in this process. It was not just the child or young person that new team members became acquainted with, but the team around the child and their preferred way of working. Giving new team members a sense of "how we do things around here" was found to be an effective way of supporting their participation.

We improved our ability to include new team members and bring them into the group by just letting them observe the group process during the meetings at the family home. They joined in as they felt comfortable.

New team members commented they felt welcome, did not feel pressured to perform, and therefore felt comfortable to contribute quite quickly. (Local project team F.)

ATTITUDES

Many of the projects identified that the adults' attitudes made a real difference to how children and young people responded and the outcomes they attained.

Teams found themselves in a positive feedback cycle where a child or young person's success lifted the team, making the adults themselves feel successful. This in turn fostered families and educators who interacted positively with children and young people, and had optimistic expectations for these interactions. These attitudes and interactions only served to further enhance success for children and young people. As teams raised their expectations, children and young people surpassed them.

As a result of Dominic demonstrating that he can learn, staff have raised expectations of him. Staff have an increased awareness of his lateral thinking, interpretations and his association of ideas. (Local project team E.)

Roy's parents found it reassuring that there was a recognition that progress could be made. This acted as an incentive to raise efforts. It has raised the family's expectations of what Roy should/could do ... It has given the family a boost and motivated them to do more. (Local project team E.)

Some teams were mindful that high expectations must be both realistic and matched with the necessary support to succeed.

Teams not only raised their expectations, they shifted in how children and young people were regarded. They described young people positively, as valued, accomplished and included participants in family, centre, school and community life.

It has made me realise how cool people with autism are. (Local project team D.)

ENGAGING WITH PARTICIPATORY ACTION RESEARCH

All of the teams told compelling stories about their journeys as practitioner- and parent-researchers. While each team engaged in PAR in a way that suited their context, all teams reported on a process that was cyclical, passing through similar phases. Benefits and challenges of engaging with PAR emerged, as did some pragmatic considerations when embedding the process in the everyday lives of families and education settings. Sections within this theme are: defining PAR, PAR cycles and PAR in the real world.

Defining PAR

Wadsworth (1991) explains that action research 'is not research or evaluation done by some people that is hopefully followed by action by some other people – it is action which is evaluated and researched with a view to both identifying where it has "worked" and what to do if it can be improved by those who are parties to that action' (p. 5, italics in original).

While action research is generally illustrated as a cyclical process, the specific steps followed can be described in various ways. Wadsworth (1991) suggests that action researchers move through phases of reflecting, designing, field work, analysing and drawing conclusions, and then putting it into practice – which in turn activates another period of reflection and the cycle starts again. While all the ASD PAR teams worked in cycles, they moved through and interpreted the action research phases in ways that were meaningful for their teams and their contexts.

Teams discovered that the action research approach complemented how practitioners already worked in their day-to-day practice. Many of the processes and skills required for engaging in action research were well-honed by practitioners, such as observation, data collection and reflection.

The early phase of the research created pressure for teaching staff who saw the research as an “added extra” to their already busy teaching lives... There was a sense that they had to focus teaching practice around the project. After a settling in period, the action research was put into perspective and the project fitted around teaching practice rather than the other way around... [In fact,] teachers practice participatory action research as part of their daily work. (Local project team E.)

It is noteworthy that the ASD PAR teams were engaged in *participatory* action research. This meant that although they were supported by a research mentor, the intention was for practitioners and parents to take the driving seat as researchers, examining and ultimately improving their own activities. Some of the teams saw challenges to participants taking the lead role as researchers and expected that the mentor would take this role.

The pressures of time on very busy educators necessitate the need for an “outside” person to undertake the facilitation, coordination, data collection and report writing. Prior to the research project commencement it was assumed that this would be incorporated into the role of the mentor team. This was a misunderstanding... Future participatory action research projects [must consider] this issue. (Local project team E.)

In a climate where some teams were unsure of the status of ethics applications they had submitted, and communication from the national project team was absent or ambiguous about whether to commence or continue with their research activity, some teams began to question the status of their team’s work and grappled with how it differed from everyday practice.

As each of the facilitators was involved in providing a service to the target child outside the research project it was necessary to decide how this project would differ from the regular pattern of service. It became clear that this project would not cover all of the service delivery areas... The amount of detailed data collected and the reflection with the whole team would be other aspects that set the project aside from regular service delivery. (Local project team H.)

PAR cycles

The cycle of observation, analysis, planning, action and evaluation is more effective with the input of... team members from Heidi’s several environments (Local project team A, sub-team 3.)

Identifying the issue

Several teams reported the value of spending time in an initial period of reflection and discussion, to decide on and define which aspect of supporting the child or young person they would focus on.

[It] has become apparent that the planning, reflection and consideration of the logistics and guiding principles to get to the official start of the project [was] an action research cycle on its own. (Local project team G.)

All participants agree the research questions gave a focal point and that the time spent developing them at the beginning of the research project was essential. It was important to get them right. (Local project team E.)

Planning

Planning the “action” of PAR was seen by several teams as a vital step. Planning was described as a distinctly team process and having the input of all those supporting the child was considered important. Including the whole team in the setting-up phase meant everyone knew about and was committed to the plan, which in turn increased the likelihood of it being enacted by all team members.

There has been more discussion and consideration about the approaches to use and this has been helpful for all team members in becoming aware of what is happening and the purpose of the approaches. (Local project team H.)

Fieldwork

In the context of the ASD PAR projects, fieldwork happened in classrooms, centres, homes and the community, when teams put into action the plans they had developed. Fieldwork was purposeful and coordinated. Teams carefully observed and documented their practices, recording data to aid team discussions, reflection and subsequent refinement.

One of the major advantages of regular team meetings has been the opportunity to consistently monitor Heidi’s progress, to coordinate intervention strategies and to gain insights into her abilities as they are demonstrated in a wide range of natural settings. (Local project team A, sub-team 3.)

Staff have acquired a way of researching and evaluating their own practice. The cyclical nature of participatory action research was evident in this project when initial interventions were unsuccessful and new interventions had to be introduced. (Local project team D.)

[We] set up a system for personal reflection (diaries) and anecdotally recorded changes in relation to the goal [and] used the simplest form of recording possible: sticky notes on a grid...

	What we have seen	What we have heard	What we have felt
With familiar adults			
With unfamiliar adults			
With peers			
With siblings			
Other			
The process			

(Local project team A, sub-team 2.)

Reflecting

Wadsworth (1991) describes reflection as 'both an end and a simultaneous beginning when we stop, and metaphorically look back over our shoulder at what we are doing' (p. 5). Many teams found that setting aside time to reflect with others was an extremely useful activity. Reflecting on events or actions in the past was synonymous with planning what would happen in the future – teams asked themselves "why?" and then inquired "so what's next?"

In the time of our involvement with the project we have all grown in our confidence to reflect and be able to change our teaching approaches in accordance with what observations we have made. (Local project team H.)

Reflection allowed us to develop a strong and functional management plan for Esther's more challenging moments that all staff had input into and that all staff were happy with ... Short-term temporary decisions were made by senior centre staff, with an absolute understanding that these were provisional to give us time to reflect and discuss our options calmly rather than making decisions in crisis ... We [then] worked through several provisional plans with revisions and amendments before we were all happy with the outcome. The 'reflect, plan, action, reflect' cycle gave us a very powerful tool for managing this process. (Local project team C.)

Some teams reported the value of parents and practitioners engaging in private self-reflection about their own practice; a process facilitated by using reflective diaries and journals. For most teams, reflection was described as a group process that occurred in meetings as team members engaged in discussion.

PAR in the real world

Despite the frustrations and delays of the term, or because of them, we had come to appreciate the advantages of working in a real world model. A more traditional research approach would have been less able to handle the setbacks that action research saw as an integral part of the whole process. Certainly, we felt that the real world had intruded into our centre and had a major impact on the project. Some of the results were not positive, but we had had some pleasant surprises as a result of the difficulties. And we had learned a great deal about action research and about the impact of our actions on student outcomes. (Local project team C.)

Teams reported a range of real-life factors that impacted their ability to embed PAR in their context. Family commitments and priorities, geographical distance between team members, availability of communication technologies such as email, and the health of the children or young people at the centre of the teams all influenced teams' momentum in moving forward with PAR.

The most consistent factor that emerged as affecting teams' use of PAR was that of time. Time constraints imposed by participants' usual work commitments and busy lives meant making adequate time for the project difficult. The nature of how time is divided and used in the school year was also a factor. Participating in a nationally funded project, with its associated time restrictions, was also reported by teams as an issue.

In order for practitioners to reflect upon their practice, they must have time. This needs to be timetabled to ensure it takes place. Funding must be in place to do this. (Local project team D.)

The research project contract was for one year. The holiday periods and structure of the school year have a significant impact ... Over three months of the year was taken up in school holidays. One term was spent with proposal writing and planning. Two terms were devoted to solid research input. The final research term ... [was] such a busy time ... that the research focus could not be a priority ... This reflects reality. (Local project team E.)

THE ADULTS' LEARNING JOURNEY

While the teams focused on how best to support the learning and development of children and young people, their reports also gave an account of how the knowledge and skills of the team were enhanced by the project. Teams developed knowledge in several areas and reported a range of activities that enriched their learning, such as participating in workshops, attending a national ASD conference, engaging with mentors and specialists, reading literature and spending time together in discussion and reflection as a team. Acquiring knowledge *together* was a strong theme.

Enriching the adults' learning

The attitude and knowledge of staff also contribute to a supportive environment. They need to feel relaxed about taking the time to know the students and to build relationships with them, as well as gaining an understanding and knowledge of autism. (Local project team D.)

Some teams highlighted that those supporting children and young people need a good understanding of ASD and appropriate support strategies. Other teams emphasised the need to learn from the child and developed an understanding of ASD in terms of how it impacted the individual they supported.

Many teams found it valuable to learn about PAR.

The most obvious area of ongoing support provided by the mentors was around the research process itself. This is because the local project team members were very familiar with the students involved in the study and also

with the factors associated with ASD. However, they were not as familiar with the concept of action research and all that this entails... As the project progressed, the confidence of team members to undertake action research grew. (Local project team E.)

It was evident that as teams developed knowledge and skills, their confidence grew, which in turn enhanced the support they provided to the children and young people.

Teachers and teachers' aides are more confident in their knowledge and practices – this has had a relaxing effect upon the students. This has resulted in teachers using different strategies for different students, which is a very learner centred and individual approach. (Local project team D.)

All teachers reported they felt much more confident about making judgements about appropriate elements of programming because of their increased understanding. (Local project team G.)

Learning together

The major strength of the research project was that all those involved increased their knowledge and skills. Students' communication and computer skills were developed while parents, teachers, teachers' aides, mentors and other professionals increased their knowledge of action research, ASD and effective teaching and learning strategies. In addition, the action research process facilitated a supportive learning community, led to increased communication and collaboration between teachers and parents and, if the findings from the research are broadly disseminated, it has the potential to benefit the wider ASD community. (Local project team E.)

Complex and reciprocal learning relationships existed within teams. Mentors supported teams' use of PAR while learning about the lived experience of ASD from families and educators. While supporting young people's learning, teams learned *from* their children and students – gaining ever deeper insights into what "having ASD" meant. Whole teams developed a profound understanding of all team members' perspectives and situations.

The project provided the mentors with many opportunities to increase their knowledge and skills in the area of ASD and action research. In particular, the mentors appreciated the opportunity of working with and learning from the teachers at Renga Renga School. This reflects the benefits of collaborative partnership, where team members learn from each other. (Local project team D.)

The notion of a learning community was evident for several teams who reported that knowledge was shared and acquired together. Teams did not only learn from each other, they learned with each other. Traditional professional learning and development opportunities, such as workshops and conferences, were significantly enhanced when several team members if not the whole team attended together. New information was embedded and made real as teams engaged in discussion and reflection, and related their learning to their context.

During this workshop, teachers had the opportunity to brainstorm and discuss ideas... Teacher feedback indicated that this was invaluable for all participants and highlighted the benefits to all of professional collegial sharing. (Local project team G.)

The team was strengthened and empowered by learning and socialising together. Each person took different elements out of the learning experience according to their need and role. (Local project team F.)

CONCLUSION

An "outsider's" analysis of project reports (some four years post the project's conclusion) could never claim to fully capture the complete story of a journey as complex, valuable and demanding as engaging in PAR about supporting a child or young person with ASD. However, sharing the consistent and powerful findings generated by those who stepped up to participate in the ASD PAR project, serves to acknowledge the work of those teams and provides others who do similar work with insights to affirm and enhance practice.

On the face of it, the findings of the ASD PAR project reported here may not seem such new ideas to those supporting children and young people with ASD in New Zealand. Indeed, few would challenge the importance of team work, positive expectations and attitudes, building capability, and reflective practice. Yet, there is a depth to these findings, particularly worthy of discussion on two fronts.

Firstly, it is interesting to note that the ASD PAR teams themselves espoused many of these tenets of effective practice in their proposals and early reports, prior to actually commencing work on the project. This raises the question of whether their work and efforts during the project served only to affirm what they already knew and were already doing. In some instances, it seemed this was the case. At the start of the ASD PAR journey most teams reported that they already worked collaboratively, had existing expertise in ASD, respected the perspective of the families and whānau, and regarded children and young people as positive contributors. However, they also reported that the process of engaging in PAR still brought about deep learning and real shifts in practice. The process called on teams to be purposeful in how they planned, analysed and reflected on their practice, and teams' own descriptions of this process revealed a movement from the rhetoric to reality of effective practice. Three very powerful examples of teams who underwent this shift in thinking and practice appear in this journal, in the articles *Learning from Each Other*, *Making Assumptions vs. Building Relationships*, and *Building Communities of Support*.

The second point of note is the sheer degree to which teams chose to report on aspects of teaming, learning, attitudes and reflection. One might assume that teams' reporting was weighted more heavily towards findings about specific interventions than the findings described here. This was definitely not the case. Teams reported as much and often more so about the interactions and attitudes of the adults in the team than they did about the specific support provided

to children. Many teams concluded that the way in which the adults worked together and supported each other had as much impact on success as the specific strategies used by these adults when supporting young people. This further underscores that teams were not playing lip service to notions of team work, capability building or reflection. They were what teams did, as they lived the experience of effectively supporting a child or young person with ASD.

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What Works for One

Practice considerations for supporting a child or young person with autism spectrum disorder, drawn from participatory action research

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ABSTRACT

This article is an analysis of the reports submitted to the Ministry of Education by teams and mentors who took part in the autism spectrum disorder participatory action research (ASD PAR) project. The key findings highlight the importance of: individualised support based on a sound knowledge of the child or young person; strategies targeted at the child's environment and the people within it as opposed to addressing perceived within-child challenges; and interventions thoughtfully linked to outcomes and carefully implemented in accordance with the culture and context of the child and the team.

Keywords

Action research, autism spectrum disorder, ecological perspective, effective practices, intervention strategies, participatory action research, reflection, student participation.

INTRODUCTION

All students are different and need to be treated that way – what works for one does not always (if ever) work with others. (Local project team D.)

In the reports submitted to the Ministry of Education by the nine teams who took part in the autism spectrum disorder participatory action research (ASD PAR) project¹, each team told their story of how best to support a specific child or small group of children with autism spectrum disorder (ASD). The companion article published in this issue, *What We Did*, outlines the permission process for using teams' reports, and the methodology used to analyse them. *What We Did* also describes the themes that emerged about working and learning as a team, the influence of attitudes, and the process of using participatory action research (PAR). This article focuses on the specific findings about strategies to support children and young people with ASD. The themes are discussed in three sections: child at the centre, the child's world, and putting it into practice. Pseudonyms for children's and adults' names have been used throughout.

CHILD AT THE CENTRE

I have become more aware of how Alex thinks and feels and how he sees the world. I can see the differences between how I see the world and how he does. I have

been able to make small changes over long periods of time, which has resulted in significant changes that make a huge difference for our family. (Local project team A, sub-team 2)

There are two sub-themes in this section: knowing the whole child, and using the child's interests for motivation and learning.

Knowing the whole child

The importance of truly knowing the individual child or young person was highlighted by all the teams. While many teams were working towards a goal or outcome in a particular area, such as communication, they did not lose sight of the whole child. Teams worked to understand children's and young people's unique profiles, their nuanced way of indicating their preferences and dislikes, their habits and personalities, and their ways of being in different settings. Teams spent time discovering what motivated the child or young person, learnt to appreciate their sensory preferences and imagined how they viewed the world.

We talked about any physical signs Dean might show to indicate he was relaxed in a certain situation. Taking his seatbelt off voluntarily, getting out of the car, and taking off his shoes were all perceived to be signs that he was relaxed. (Local project team H.)

For teaching participants there is now a stronger commitment to begin by assessing their ASD students' prior knowledge, valuing it and using it to inform their future planning and teaching, while always keeping the student and their unique perspectives at the centre. (Local project team G.)

Several teams found that the best way to develop a complete picture of the whole child was for the team to pool what they knew of and observed about the child in different contexts.

The contributions of team members towards assessments are invaluable. Observations of Heidi's social interactions at home, in the classroom and the playground have given comprehensive insights into her capabilities, which may not all be seen in any one setting. (Local project team A, sub-team 3.)

Other teams found that building a relationship with the child or young person was the best way to truly understand their perspective.

¹ For background to the ASD PAR project and demographic information about the teams involved, see the article *With Hindsight* in this issue.

Instead of giving staff a plan of how they need to work with students new to them, they are told that they need to get to know the students first and build relationships with them. (Local project team D.)

Teams acknowledged that taking time to look at the world through the eyes of the young person led to a greater understanding of their perspective, and ultimately practices that improved outcomes

We acknowledged that this was a very successful visit ... The only variable that had changed was the fact that we had taken the time to write Dean two stories to explain what an airport was and why people go to an airport. It made us realise that we cannot take for granted that Dean will understand or perceive places as we do. (Local project team H.)

The student's actual view of the world needs to be understood and not assumed ... All the teachers acknowledged the importance of understanding their students' unique differences in cognition and the value of being able to walk a little way in the shoes of the students with whom they work ... Several teachers realised that their assumptions about the students had led them to miss teaching opportunities in the past. (Local project team G.)

Using the child's interests for motivation and learning

Many teams recognised that an important aspect of understanding what "made their child tick" was learning to understand what interested the child and using these interests to motivate them and enhance their development.

It was fascinating looking at it from her view – keeping our minds open for opportunities to use her interests to progress her learning. Seeing her interests as valid rather than "getting back to the programme". I can see now that just using interests as a motivator may be limiting. (Local project team G.)

New resources I tried to introduce, which I thought might link with Gina's current abilities, often had no interest to her. I found that it was easier to attempt introductions of small extensions to her current interests ... I had to take the lead from Gina. (Local project team A, sub-team 1.)

By taking the child's perspective, appreciating the child's special interests and considering the whole child, teams focused on what the child was able to do, their many skills and what they were good at. This proved an excellent starting place for extending their learning and development.

Hone showed a positive response too in terms of engagement and motivation, and enjoyed being able to use and share his areas of strength and expertise in his school work. (Local project team G.)

THE CHILD'S WORLD: SOME PRINCIPLES FOR EFFECTIVE SUPPORT

We constantly scanned the literature for new ideas and took those we could use. We did not follow new concepts slavishly, but used the ideas in ways that suited our child, our situation and our culture. (Local project team F.)

The following seven sub-themes are discussed within this section: individualising programmes, focus on changing ourselves, adapting activities and the environment, preparing for transition and change, real-life settings, involving peers and siblings, and benefits for all.

Individualising programmes

A clear theme that emerged was that teams developed highly individualised programmes of support. They used their in-depth knowledge of the child to individualise every facet of the support provided.

The specific team culture and the context in which teams were working also affected how support was individualised. For some teams, family preferences and aspirations were deemed a particularly important factor in determining directions, goals, approaches and strategies.

Our long-term goal of increasing Esther's willingness to communicate with others in her environment, and thus to open greater possibilities for inclusion, was kept firmly in front of us by the family. On 21/11 her mother wrote: 'Thank you for the newsletter. The waka ama² participants did so well ... I would like Esther to be involved in waka ama and surf lifesaving mainly because she comes from a very sporty whānau³ and she is so strong. (Local project team C.)

focus on changing ourselves

Many teams discovered the benefit of shifting the focus away from changes within the child to changes within *themselves*. They recognised that improved outcomes for children and young people were determined by the attitudes, interaction styles and behaviours of the people who support them.

The greatest changes documented have been to team members themselves as they have altered the way they interact with Alex. This has in turn had an impact on the way Alex communicates with us. Bridges have been built that have strengthened mutual understanding. (Local project team A, sub-team 2.)

A supportive environment is one that does not just focus on making changes within the student. It focuses on making changes to the practices of the professionals and the environment. (Local project team D.)

Adapting activities and the environment

Much like teams discovering that it was their attitudes and behaviours that required adapting, and not the child's, they also found that making adjustments to the physical setting and how it was arranged and managed, and learning activities and how they were set up and presented, had positive spin-offs for young people.

To encourage the changes in behaviour we wanted, we would have to alter some of the structures and routines of the centre. This was the most difficult step to take. We found that it is not just students who have autism who cling to structure and routine; as a staff we were equally dependent on it for a sense of stability and safety. (Local project team C.)

² Outrigger canoe.

³ Immediate or extended family.

Preparing for transition and change

The concept of "transition" was acknowledged as encompassing a broad range of experiences, from shifting between activities in the classroom, to making the move from school to the workforce. Many teams reported that experiences involving transition or change, such as altered routines, new situations and novel events, were particularly tenuous for the young people they were supporting, and yet could not be avoided.

The research also highlighted the fact that "transitions" during a child's/family's life are fraught with pitfalls. Unless these times are handled carefully, years of energy and progress can be undone. (Local project team B.)

Many teams found that preparation, pre-planning and support were vital in times of transition and change.

It is also apparent from Maxine's journal (Alex's mother) and from comments by Toni (Alex's teacher) that preparation for transitions is a parallel process to other interventions. Maxine noted that she prepares Alex ahead of time for riding for the Disabled, going to stay with relations, shopping, or interactions with friends. Toni reported that she is more conscious of impending change in the classroom, and makes sure that she informs Alex when a relief teacher will take the class. Preparation for changes in the bus timetable and for the class camp were discussion points at team meetings. (Local project team A, sub-team 2.)

Real-life settings

Teams discovered that real-life activities, routines and situations, be they in the education setting, at home or in the community, were the ideal location for children and young people to learn and practice new skills.

Meetings in Gina's home doubled as social events, allowing picture exchanges to be used around desired food items, including her drink bottle and vegetable chips, especially following her afternoon sleep, when she was hungry. (Local project team A, sub-team 1.)

A number of teams learned that to ensure children and young people were able to use their knowledge and skills across settings and throughout their day, team members in all environments had to use consistent strategies and supports. However, some teams found it challenging to guarantee this level of consistency.

Using similar strategies to those used in the research on the computer, Dominic has been able to successfully practice some targeted skills, eg, turn-taking in physical education. (Local project team E, sub-team 3.)

When working on developing new skills, teams built on existing effective practice by starting with strategies that had been successful in the past.

We believed that the most effective [approach to] action research was one where the existing systems are used as the basic framework, with additional questioning primarily designed to explore current practices and determine their strengths and/or areas for refinement. (Local project team F.)

Timing for tackling new skills was considered a particularly important factor by some teams, highlighting that it was important to ensure readiness in the child and the team.

Prepare the ground then seize the moments. Where the child initiates, go with the flow. It appeared to us that Elliot thought about and/or watched some activities for a long period of time before he participated. Our challenge was to be ready to support new experiences when he expressed an interest. (Local project team F.)

Involving peers and siblings

Many of the teams identified the invaluable role played by peers and siblings. Some children and young people at the centre of the teams were very motivated to be with and interact with their peers and appeared to respond particularly well to other young people in their environment.

By term's end it was apparent that even if Esther was not responsive to us she was responsive to peers. We also found that we didn't have to institute special procedures to encourage the other girls to respond, as many responded to her naturally as part of their day ... Additionally, she was able to watch the other girls and learn routines from them ... This became very dear during the physical education lessons when, without us guiding her, Esther watched the other girls in the class getting balls and racquets and went up to get her own. By the end of the term, with a little adult prompting, she would put her gear away in the correct place with the other girls at the end of the lesson. (Local project team C.)

Allowing children to learn from peers gradually became more and more significant throughout the process. Elliot gradually became aware of his peers and wanted to interact with them on an increasing number of occasions eg, he wanted to be part of a reading group rather than read on his own. (Local project team F.)

Benefits for all

Most of the local project teams found that the approaches they were using to support an individual child or small group of children had much wider applicability.

Although the project only involved three students, teachers commented that they would use the findings to support other students with ASD in their school. (Local project team E.)

We found that many of the practices we used for Elliot were, in our view, beneficial for all children in the classroom. These were things such as regular routines, visual timetables, clear simple instructions, regular monitoring of the progress, and specific objectives for the child's progress. (Local project team F.)

PUTTING IT INTO PRACTICE: STRATEGIES FOR SUCCESS

A range of specific strategies and approaches were used by the local project teams. Teams did not attribute their successes to the use of a single approach or strategy. A dedication to teaming and the use of PAR meant that strategies were carefully selected, planned, implemented, fine-tuned and adapted.

The strategies used by the teams are described below under the following outcomes

- being with others
- communicating
- regulating self
- engaging in learning
- making a contribution.

This clustering of strategies emerged as the teams' reports were analysed. Links can be drawn from these outcomes to the strands of *Te Whāriki* (Ministry of Education, 1996) and the key competencies in *The New Zealand Curriculum* (Ministry of Education, 2007).

Being with others

Several teams found that an important aspect of supporting children and young people with ASD to be with others, was ensuring that others were supported to interact effectively with the child. Strategies used by local project teams included:

- With the family's permission, talk to classmates and siblings about the child's unique ways of interacting and communicating and suggest some effective ways to respond to the child.
- With the family's permission, inform the whole staff about the strategies being used to support the child, to ensure these strategies are used in any interaction the child has with teaching staff.

A whole-school approach is vital. All staff must be able to interact appropriately and confidently with Elliot in the playground and in the classroom, if required. If Elliot has a new teacher every year, the myth of "difference being dominant" lessens, and he will form strong relationships with a range of different teachers. (Local project team F.)

Strategies used by teams that involved peers and siblings included:

- Capitalise on the child's positive response to peers by setting up a buddy system in the classroom or playground.
- Consider the buddy systems carefully – the best buddy may be an older child, a child with a similar cultural background, or the same child for a long period of time to ensure consistency for the child with ASD and giving them time to develop a good relationship.
- Allow children with ASD to see new tasks or activities first modelled by peers or siblings before they are asked to do them themselves, and give them the option to "pass" and take their turn later.

Communicating

Most of the teams in some way worked towards enhancing children and young people's communication.

Teams that successfully implemented the Picture Exchange Communication System (PECS) reported powerful examples of what happens when young people are provided with a means to initiate interactions and communicate with others in their environment.

Esther was actually better at [using PECS] than we were at working out what she wanted. After several days of showing us a photo of herself and some other students and pointing to one corner of it, only to be praised for recognising herself, one staff member realised that the TV and video were tucked away in the corner [of the photo]. What we had focused on, the people in the foreground, had not attracted Esther at all. She had focused on the small video, half hidden, tucked away in a dark corner. (Local project team C.)

Teams that worked with children and young people with emerging communication skills discovered the benefit of setting up situations in the environment or sabotaging familiar routines in a way that enticed the child to communicate.

A recently established routine between Gina and the other kindergarten teacher, involving Gina's favourite resource, has intensified their social relationship. The teacher began to tease her by tipping the bead/blocks out from the tote tray, or removing the tote tray of beads from her and hiding it somewhere. When Gina looked for and followed her to reclaim it, it was returned, eventually by exchanging it for the appropriate PECS card. This promoted closer attention to the teacher's whereabouts and activities, more eye contact, and closer communication to regain the tote tray. (Local project team A, sub-team 1.)

Some teams used Gutstein and Sheely's Relationship Development Intervention Tracking Form (2002) to both assess and monitor their child's communication and socialisation. They found the tool complex but useful, as a means to promote discussion between the team members and to develop a full picture of the child in different settings.

Several teams acknowledged that communication is a two-way process. These teams focused on the adults adapting their communication styles with positive results. They reported that by sharing the responsibility for successful interactions and making changes to how the adults communicated, the children were able to understand and participate in interactions. These "adult change" strategies used by the teams included:

- Make more comments and ask fewer questions
- When asking questions, make them specific
- Wait longer for responses and be comfortable with silence when working together.
- Use fewer words when communicating, for example, one-word instructions
- Experiment with different tones of voice – the child may respond better to some than others.

I have changed the way I approach Alex now, not asking as many questions, as I found this is what I constantly did, and I gave him more time to process the questions and answer. I also found I shied away from giving him responsibility or tasks, which I am now starting to introduce and he is coping really well. (Local project team A, sub-team 2.)

Regulating self

Many teams identified that the world was a confusing and stressful place for the child or young person they were supporting. They also identified that once stressed or dysregulated, children and young people often became unavailable for learning and interacting. Therefore, supporting children and young people to remain well regulated was an important focus.

The following strategies were used by the teams to support children and young people's regulation and to "keep them in the zone" for learning and being with others.

- Observe the child and find out how they show they are getting tired, feeling stressed or becoming over- or under-stimulated. Watch for these signs so strategies can be put in place.
- Find out what it is that keeps the child "in the zone", and allow the child to access these activities or supports.
- Consider what it is that stresses the child and attempt to set up environments and experiences in ways that minimise stressors.
- Ensure the child has opportunity for down-time and breaks in their day, both during and after school. Respect the child's need for these breaks.
- Plan for down-times. Some children may prefer to have their down-time in a particular place within the home or school, or space within the centre or classroom.
- Integrate physical activities into learning. Some children may find lots of physical activity particularly calming, or may focus better after periods of being active.
- Negotiate or set times for tasks. Some children may find time pressure particularly unnerving – ensure they have enough time and know how much time they have to complete tasks.
- Consider the sensory demands of environments and activities, and the child's own sensory preferences. Make modifications to accommodate.
- Alleviate distraction from sounds. Music or headphones support some children to keep focused during activities as they screen out distracting noises.
- Consider that the child's actions, such as running away, making a lot of noise or leaving work incomplete, might be them telling you that they are dysregulated and just not able to do any more.

The main ways Elliot seems to de-stress are through plenty of physical activity, eg in the playground at lunchtime with buddies, via sympathetic adults he can talk to if he has concerns, and by ensuring he has adequate "relax time" at home after school. With these strategies, we have experienced very little overload behaviour this year. (Local project team F.)

Some teams found that providing the child with a sense of order, often with the use of visual strategies, was a useful way to support their regulation.

Both Alana and Vincent had a visual timetable containing their programme for the day. This acted as a stress preventer. Visual strategies were also used

when the students did become stressed – by taking the students back to their timetable to remind them of what should be happening. (Local project team D.)

New experiences or changes to routines were identified by several teams as having a dysregulating effect on children. Teams acknowledged the need to prepare children for these changes with a range of strategies.

- Prepare children for changes to school and classroom routines, such as relieving teachers and changes to library days.
- Use a timer as a way of warning a child about how long until an event or activity finishes.
- If a change is avoidable, ask the child how they would like the change managed.

If people don't communicate in a way that the students understand, this can cause stress to them. For example, one day Vincent wasn't told that he couldn't go to work experience because the person there was too busy to take him. It was discussed amongst the staff but not explained to Vincent. When Vincent was told to get his togs for an alternative activity at the swimming pool he became very upset and stressed ... By using visual strategies and Social Stories™, giving clear information and giving time to process information, this stress can be reduced. (Local project team D.)

Social Stories™ were used successfully to prepare children for unfamiliar social experiences. Ultimately, this strategy supported children's ability to stay well regulated during these events.

Social Stories™ are a useful tool to prepare Dean for:

- the sequence of events
- any potentially negative aspects (we learnt to be much more honest about these)
- reassurance that there would always be support or an "out"
- cognitive understanding about the function of places and situations
- either expected or unexpected changes.

(Local project team H.)

Once the team had agreed to develop a set of Social Stories™, team meetings were used to gather as much information as possible ... The resource teacher, learning and behaviour and speech-language therapist collaborated to draft the stories, which were then checked with the rest of the team before being shared with the child. Each Social Story™ involved a number of re-writes. The team attempted to ensure that the stories were as accurate as possible, and based on the child's perspective and not on assumptions. (Local project team A, sub-team 2)

Engaging in learning

Several teams found that children and young people's engagement in learning was affected by the learning environment itself. Teams discovered that it was the role of the educator to adapt the learning environment to suit the child, and not the other way around. Teams employed a

range of strategies that acknowledged how confusing and stressful education settings were for the child or young person they supported. Many of these are listed previously in the "regulating self" section. Other strategies included:

- Consider how group size within classrooms and centres affects a child's learning and interaction. Small group work before and following a whole class activity may be beneficial, as it provides prior warning for new topics and creates repeated opportunities for learning.
- Some centre and school activities can cause sensory overload for children and young people; particularly activities that involve close physical contact with many other children, such as attending assembly or sitting with many other children on the mat. Special considerations may be necessary for these times.
- Consider how the child's physical place in the learning environment affects their engagement. Working too close to the front of the room, beside a bright window or working in a place removed from their peers could all affect an individual child's engagement in learning.

We moved Esther's desk from a corner, where she had sat since she started at [the school] and where she felt safe and secure, to the main group in the middle of the room. She, and some staff, would occasionally move it back, so eventually we replaced the space with two comfortable lounge chairs. Despite these minor returns to the past, Esther accepted the move well. Soon she went directly to her "new" desk as soon as she arrived at school and worked there happily all day. We noticed that as soon as she was facing the main part of the room, she became far more interested in what we were all doing. She started to seek staff out far more regularly. She started to seek and use classroom equipment for herself... Eventually we saw the first instances of Esther choosing to involve herself [in] activities with the other girls. (Local project team C)

Team members are becoming more aware of Heidi's learning style and abilities. Her position in class is monitored by teaching team members, who note that she is less distracted by her surroundings during circle time if sitting on a chair and not on the floor. (Local project team A, sub-team 3.)

Some teams successfully used school-based learning opportunities to support children's understanding about the wider world, such as travelling on a plane or the death of a family pet. Other teams discovered the power of shaping school-based learning around the child's world, by adapting teaching to their preferred ways of learning and incorporating their area of special interest into learning activities.

It was decided to focus on an individualised school programme around the topic of flight, namely planes and airports. Trips and visits would be scheduled as part of our weekly community programme. The experiences gained, any photographs taken and a library of books borrowed around the topic would become the focus of Dean's reading and written language programme. It was

decided to find a toy airport to be used for the purpose of imaginative play around the airport theme. (Local project team H.)

The teacher decided to plan an integrated learning programme around Usha's interest in balloons. She used a clear file folder, with an activity for each page, instructions and supports for work, which would systematically be replaced by completed student work. (Local project team G.)

Several teams discovered opportunities and constraints afforded by technology. Computers were successfully used by some teams as means of presenting information, as a way of providing children with some down-time, and as a reward.

Making a contribution

Several teams worked towards ensuring the child or young person they supported was given every opportunity to contribute to centre, school, family or community life. Supporting participation in school events, such as sports days and camps, and family events, such as travelling a long distance for a family celebration, required teams to acknowledge how potentially unsettling these events could be for the young person at the centre of their projects. Respecting this and putting considerable effort into preparing for these events reaped positive rewards for the children and young people and those around them.

[We] increased liaison with home in preparation for school camp, and increased preparation time and class discussion prior to camp about what would happen, where they would sleep, what they would eat, the timetable for activities etc. (Local project team A, sub-team 2.)

Many of the specific strategies teams used made sure the child or young person at the centre of their project had the opportunities and the necessary support to be successful. To ensure that children and young people made a successful contribution, teams adapted tasks and activities in the following ways:

- Show the child how to do a task or activity before asking that they try it – talk about what you are doing as you do it and give the child a chance to observe.
- Allow the child to try new tasks or activities several times before you expect success.
- Allow the child opportunities to "rehearse" a task, activity or conversation before expecting them to carry it out in a group.
- Provide the child with visual cues that show the steps of a task or activity that can be referred to as they do it.
- Carry out a task or activity simultaneously alongside the child with the same resources as they are doing it.
- Reduce the number of variables in an activity or the demands the task place on the child, for example, in a choosing task, reduce the number of choices being offered.
- Break new tasks or activities into small steps and work on just one small step at a time.

A psychologist developed a series of commonsense sequential programmes that gradually ensured Elliot met small, incremental expectations. For example, coming outside for physical education lessons, and then slowly participating for longer periods of time during the lesson. The psychologist's programme involved clear, simple expectations with specific, consistent consequences and meaningful rewards. (Local project team F.)

Some teams found that at times they offered too much support and were careful to ensure that adult prompting was gradually phased out as the child became proficient at a task or activity. They discovered that having high expectations of the child and providing an opportunity to achieve were the best ways to encourage the child to successfully make a contribution. Encouraging, and then acknowledging, a child or young person's success was also important.

CONCLUSION

The importance of holding the individual and their uniqueness at the centre of the support provided emerged as the prominent theme about supporting a child or young person with ASD. Teams were in agreement that individualised programmes were essential and could only be arrived at from a place of deep understanding about the child or young person, their blend of strengths and preferences and their views of the world. This finding supports the "no one approach for people with ASD" principle endorsed elsewhere (eg, National Research Council, 2001).

A distinctly ecological approach was evident in the teams' work. Children and young people were always considered in conjunction with the environments in which they lived and learned, and the communities they were a part of. Consequently, difficulties that children faced were not seen by teams to be within-child issues, but matters of concern for how the environment was set up and for how those within that environment interacted with the young person. This explains why many of the "interventions" used by teams were not levelled at change within the child, but focused on the child's world by adapting the environment, the task and the interaction style of adults and other children. This approach works from a social philosophy of disability and was found by teams to greatly enhance effective support.

The outcomes for children and young people that teams chose to work towards were generally not skill-based nor bound to certain tasks or contexts. They focused on goals that would support a child's participation, and the child's enjoyment of life and learning, in home, school, centre and community contexts. The specific strategies and approaches employed by teams as they worked towards outcomes were carefully selected, planned, implemented and adapted. This process was supported by the teams' commitment to collaboration and the reflective practice that underpinned their use of PAR.

The combined work of the teams revealed the complex relationships that exist between the outcomes being sought for young people and the paths taken by the teams to get there. Similar kinds of strategies were used to support a

range of learning or social outcomes, with teams discovering that supporting development in one area often led to positive changes in other areas. Teams did not attribute their successes to the use of a single approach or strategy. An individualised combination of strategies, targeted at the child's world, and thoughtfully implemented in the context by the team around the child, were what teams agreed worked for them.

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AUTHOR PROFILE



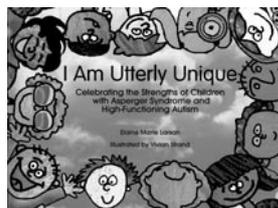
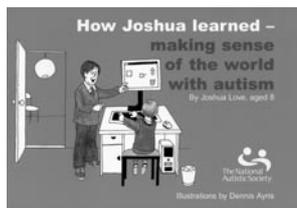
Anna Kelly

Anna currently works in the Professional Practice Unit in the Ministry of Education, Special Education. At the time of writing this article Anna's role within this team saw her contribute to a range of national autism spectrum disorder initiatives. Anna has previously worked as a speech-language therapist and is currently a facilitator for 'tips for autism' team professional development.

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Kairaranga Book Reviews



MOZART AND THE WHALE: AN UNEXPECTED LOVE STORY

Jerry and Mary Newport

It is hard to describe what this book is, and even harder to say what it isn't. Supported by co-author Johnny Dodd, Jerry and Mary Newport, who both have Asperger syndrome, take the reader on a journey through their remarkable lives. Each shares their dramatic experiences as individuals and as a married couple, Mary through the eyes of a gifted composer and artist, and Jerry as a brilliant mathematician. They both have extraordinarily high IQs and both have experienced traumatic life events that would challenge the sanity of anyone – Neurotypical or Aspie. It is little wonder then that both have also experienced depression, and both attempted suicide at different times.

They tell their stories in first person, weaving them together in a not-so-orderly fashion, jumping from one timeframe to another and from one person to another in a way that was sometimes, at least initially, a little confusing. This was a good thing. Their stories are genuine, and as I read I had a real sense of being in the company of people who have autism or Asperger syndrome and who perhaps do not quite know what is going on. One comes to enjoy these wonderfully eccentric people, their differences and their ordinariness, and the struggles they have had because they have Asperger syndrome, and because they are human.

It was this mix of extraordinariness and ordinariness that intrigued me. The way I moved between thinking, "Wow – is that what it's like!" to "Yeah, I know what that's like!" Mary and Jerry have managed to take the reader through a series of moments in their lives, and to vividly describe the trauma or the joy they experienced at those times.

They married soon after their "love at first sight" meeting but the marriage was short lived. The back cover suggests their marriage 'blew apart under the strain of a media circus that saw them become "superstars in the world of autism"' – I didn't really see it that way. Sure, that added to the stress of their already very complicated existence. But I was more struck by their description of interpersonal interaction that might have been typical of other more "ordinary" couples. As the pair shared the way in which they came to understand and empathise with each other and to rebuild their marriage, they were giving a dear message to all of us – a relationship needs work, and we need not only to tolerate, but to value what is important to the individuals we love. They demonstrated

how acceptance and understanding can lead to love, and how being loved can lead to internal peace. Not only "couple love", but also "human love".

In his foreword Professor Tony Attwood suggests *Mozart and the Whale* 'is much more than a simple love story and I now feel that's a bit of an understatement. It is a warm and wonderful treatise in human interaction with two amazing people who had significant personal barriers to overcome before they were in a space to give and receive unconditional love. The book is happy, sad, funny – I enjoyed the description of the cockatiel chasing the dog, chasing the cat, chasing the iguana, chasing the cockatiel – and very serious. In the final chapter, the pair offers some philosophical views about autism and Asperger syndrome. I'll leave it to you to read Jerry's theories on why there are more males with autism than females, and Mary's ruminations on people with autism as prototypes for a new kind of human. This is a great book!

REVIEWER PROFILE

Daphne Rickson

Daphne is a Music Therapy Lecturer at the NZ School of Music. She has experience of autism in her family and in her extensive music therapy work in education settings. She has been a regular contributor to Autism New Zealand conferences and has published papers in this field. Daphne participated in the Ministry of Education autism spectrum disorder participatory action research project as a team mentor.

BIBLIOGRAPHIC DATA

Title: Mozart and the Whale: An Unexpected Love Story

Authors: Jerry and Mary Newport

Publisher: Allen & Unwin

Date of Publication: 2007

ISBN: 9781741146844

RRP: \$35.00

A REVIEW OF CHILDREN'S BOOKS ABOUT AUTISM SPECTRUM DISORDER

There is an extensive selection of children's books about autism spectrum disorder (ASD). As well as a range of different forms, for example, picture books and workbooks, the books often have different purposes, such as

- books to promote understanding and acceptance for peers and/or siblings
- accounts by parents, friends or siblings who have written about a particular child with autism to share with others
- children's novels where one of the characters has ASD or some similar traits
- picture books or workbooks for children with autism either to help them understand an aspect of ASD (such as making friends or dealing with frustration) or for parents to help their child to understand their diagnosis when they are tackling disclosure issues
- some first-person accounts by young people who have experienced ASD
- a few books that promote or celebrate the particular perspective and skills of those on the spectrum.

The books also take different approaches to how they try to appeal to their audience and illuminate ASD. Some use the traditional "triad of impairment" model (ie, difficulties communicating, socialising and thinking flexibly) that is often presented to adults, but simplified for a younger audience. In others, the authors have built some characteristics or observable behaviours into everyday situations and tried to explain their cause or antecedent. Some – particularly the fiction titles – use a character who has particular traits as the messenger.

One thing that struck me is that (as in real life) it is very hard for the books to explain ASD and what it means, without portraying a stereotype. It is so hard to capture the unique way that ASD affects each person and many of the books (unsurprisingly) fail to do this. It is also disappointing that most of the books fail to celebrate the strengths and unique perspectives of people with ASD and tend to focus on the difficulties and concerns. Ironically, the fiction books sometimes give the most rounded accounts because they have the opportunity to explore many aspects of their characters in different situations.

I asked Autism New Zealand to recommend a few titles from their bookshop and library. They sent a selection of children's books that covered quite a few of the categories above. The bibliographic information for each book is provided at the end of this review.

These first three titles are about relationships between a young person with ASD and their sibling or friend:

- *My Brother is Different* is written from the perspective of an older sister explaining some of her brother's behaviour. It uses simple language and illustration and covers a variety of situations where her sibling might act differently to other children. A strength of this book is that it is written in a matter-of-fact way from the perspective of a child who is dealing with everyday

realistic situations. However, I felt it was a bit negative – with no positive aspects or situations portrayed about the (nameless) brother.

- *All About My Brother* is written and illustrated by Sarah – the eight-year-old sister of Evan. In the book she says that 'Mom gave me the idea to write this book because kids need to learn more about autism. I am the expert in my classroom on autism.' Sarah's story is great. She talks about all her family and it is a realistic but positive account of life with Evan. I loved her closing sentences 'I want Evan to have fun and be happy. If playing with sticks is what makes him smile, then he should be able to play with sticks.' Her pictures are also fabulous, but the overall layout and font do not entirely do justice to them. Recommended.
- *My Best Friend Will* is written by Will's friend Jamie with the help of her teacher. It uses black and white photographs which illustrate aspects of his daily life and likes. The photos are great and it is a very balanced account. However, I found the book a little confusing as it frequently changes tack in its perspective between being about Will, his friendship with Jamie, and autism. While it does an accurate and sensitive job of each of these, by not integrating them better, I found the flow was lost and it was hard to keep interested right to the end.

Two titles that aim to educate peers and siblings:

- *Everybody is Different: A Book for Young People who have Brothers or Sisters with Autism* is a book for children, from perhaps eight years old with adult reading support, which explains the characteristics of ASD. It answers some questions about some common "odd behaviours" such as language, eye contact, echolalia, flapping and other repetitive behaviours, aggression and self-harm. It also has a chapter about therapies and another about issues that are common to many siblings and concludes with a glossary of terms. Again, the text is accurate and at a good level for the intended audience.
- *All Cats have Asperger Syndrome* is a book that outlines many of the characteristics of children with Asperger syndrome and illustrates it with pictures of ... cats! Perhaps some of my own traits are too close to the surface here and I am being a little too concrete, but I didn't get it. The pictures are lovely (if you like cats) and I know that many others do get it and it is not only very popular but was short-listed for the Children's Book Council of Australia awards in 2006.

One of the books is aimed at the young person with ASD:

- *How Joshua Learned: Making Sense of the World with Autism* is a "self-help" book intended for young people with ASD. The author, Joshua, is an eight-year-old New Zealand boy and the book is written from his perspective. Each page starts with 'When I was little, I didn't ...' and the following page outlines what his Mum and Dad had done to help him learn and participate. For example, they used a chart for choosing what shoes to wear and sung a song to remember the

sequence of getting dressed. I really liked this book. The situations and their solutions are very appropriate and respectful and it has a really positive message. However, the book is a little too long (it could have conveyed its message with about 24 pages rather than 46) and the layout and illustration is a little old-fashioned.

The final two books are picture books in their more traditional sense and the most notable for their layout and illustration:

- ***I am Utterly Unique: Celebrating the Strengths of Children with Asperger Syndrome and High-Functioning Autism*** is an alphabet book. The full title is important, because while it does just what it says (with some fabulous illustrations), the portrayal is definitely of higher-functioning children. My personal favourite was 'I have Precise Pronunciation'. This would be a great book to read with a young person with ASD to share some information about their unique qualities with them.
- ***Looking After Louis*** would be a great book for a junior school classroom to illustrate to children why a peer might not always have to do the same things or follow the same rules as the other kids. Louis' quirks (including his echolalia) are described throughout the story in a very natural and endearing way through the voice of one of his peers. The pictures characterise him as interesting and full of life. Perhaps because of the genre, many of the children's stories about ASD are told from the perspective of the writer. This book is unusual and refreshing because it uses the peer's perspective to take the reader into account, which makes the story all the more appealing. My personal favourite from the selection.

All of these titles are available from the Autism New Zealand bookshop, tel: 0800 AUTISM (288 476) or www.autismnz.org.nz/shop/index.php.

REVIEWER PROFILE

Keryn Mells

Keryn Mells is a primary-trained teacher and a parent of a young person with ASD. She developed and coordinates the 'tips for autism' professional development. She is a member of the Ministries of Health and Education ASD Reference Group and has contributed to a number of publications and conferences. She was also a mentor for one of the autism spectrum disorder participatory action research projects.

BIBLIOGRAPHIC DATA

Title: My Brother is Different
Author: Louise Gorrod
Illustrator: Beccy Carver
Publisher: National Autistic Society
Date of publication: 1997
ISBN: 1-899280-50-2
RRP: \$26.00

Title: All About My Brother
Author and illustrator: Sarah Peralta
Publisher: Autism Asperger Publishing Company
Date of publication: 2002
ISBN: 1-931282-11-0
RRP: \$30.00

Title: My Best Friend Will
Authors: Jamie Lowell and Tara Tuchel
Publisher: Autism Asperger Publishing Company
Date of publication: 2005
ISBN: 1-931282-75-7
RRP: \$45.00

Title: Everybody is Different: A Book for Young People who have Brothers or Sisters with Autism
Author: Fiona Bleach
Publisher: Autism Asperger Publishing Company
Date of publication: 2002
ISBN: 1-931282-06-4
RRP: \$28.00

Title: All Cats have Asperger Syndrome
Author: Kathy Hoopmann
Publisher: Jessica Kingsley Publishers
Date of publication: 2006
ISBN: 1-843104-81-4
RRP: \$34.00

Title: How Joshua Learned: Making Sense of the World with Autism
Author: Joshua Love
Illustrator: Dennis Ayris
Publisher: National Autistic Society
Date of publication: 2007
ISBN: 1-905722-34-6
RRP: \$25.00

Title: I am Utterly Unique: Celebrating the Strengths of Children with Asperger Syndrome and High-Functioning Autism
Author: Elaine Marie Larson
Illustrator: Vivian Strand
Publisher: Autism Asperger Publishing Company
Date of publication: 2006
ISBN: 1-931282-89-7
RRP: \$49.90

Title: Looking After Louis
Author: Lesley Ely
Illustrator: Polly Dunbar
Publisher: Frances Lincoln
Date of publication: 2004
ISBN: 1-845070-83-6
RRP: \$18.95

TEN THINGS EVERY CHILD WITH AUTISM WISHES YOU KNEW

Ellen Notbohm

This easy-to-read book signposts the journey of autism beautifully as it weaves together the threads of practice and theory. It brings to life the usually unheard voice of the child, who, by virtue of their disability, is unable to express and advocate for themselves.

Drawing on both her personal experience and knowledge of autism, the author's anecdotes and stories provide a compelling yet sensitive message. The notion of only ten things to remember does not detract from the information being presented as factually concise yet real and compassionate.

The ten things are described simply and succinctly and serve as a reminder of the basic tenets of acceptance of difference and diversity. It is a book about crossing barriers and making connections, and one of the barriers it breaks through is with the reader, connecting us with life as seen through the eyes of a child who has autism.

Our understanding of autism has a crucial impact on a child's ability to successfully navigate a world that by the very nature of their disability is foreign to them and ultimately impacts on their journey to become a productive independent adult.

This uplifting read provides invaluable, easy-to-understand knowledge and insights into the autism experience. The book will inspire and motivate those who are working and/or living day-to-day with children on the autism spectrum and offers useful information on how these children communicate, learn and succeed.

REVIEWER PROFILE

Vanesse Geel

Vanesse is a psychologist working in the Early Intervention service at the Ministry of Education, Special Education (GSE), specialising in working with young children who have autism. Vanesse is also consultant to Acorn House – a support group for parents of children with autism.

Vanesse has a passion for research and developing new initiatives for children who have autism in inclusive early childhood education settings.

BIBLIOGRAPHIC DATA

Title: Ten Things Every Child with Autism Wishes You Knew

Author: Ellen Notbohm

Publisher: Future Horizons

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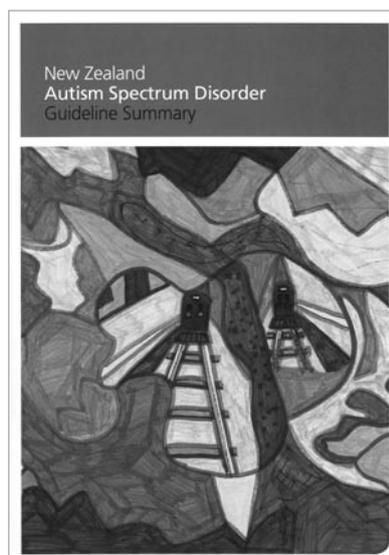
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Want to Know More?

Enclosed with this special issue of *Kairaranga* you will find a copy of *Autism Spectrum Disorder: A Resource for Teachers* and the *New Zealand Autism Spectrum Disorder Guideline Summary*.

Although aimed at teachers, the popular booklet is also useful for other people supporting children and young people with ASD, including parents and specialists. It introduces some of the challenges faced by youngsters with ASD, some of the characteristics of the disorder, and practical strategies for support. This booklet was originally developed in consultation with representatives of the Ministry of Education's Autism Spectrum Disorder Reference Group in 2000. Since then it has been revised and reprinted several times and this most recent version was updated and reprinted this year. To request complimentary copies of this booklet, email: asd.mailbox@minedu.govt.nz

The *New Zealand Autism Spectrum Disorder Guideline* was released in April 2008. The guideline has been five years in the making and has had impressive input from overseas and New Zealand researchers and experts, individuals with ASD, parents of children with ASD, and medical, educational and community providers. It's a great accomplishment to have a single, credible source of overseas and New Zealand evidence, experience and practice in one place. It is intended that the information in the guideline is used to help improve the advice, support, services and care for people with ASD, and their families. A copy of the *Guideline Summary* is included with this issue of *Kairaranga* along with a pamphlet for requesting copies of the full guideline and a Māori translation of the summary. Copies can also be ordered by phoning 0800 ASD 222 (273 222). The guideline can be downloaded from www.moh.govt.nz/autismspectrumdisorder



Submission Guidelines

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- *Kairaranga* considers the following education related papers as written documents
 - Practice Papers** – Papers celebrating effective practice and implementation of programmes. (Up to 2,500 words).
 - Position Papers** – Papers outlining a writer's view on a current educational issue. (Up to 2,000 words).
 - Research** – Papers summarising research studies involving quantitative and/or qualitative analysis of data, or reviews of the literature. (Up to 3,500 words).
 - Storyed Experience** – Papers reporting the experiences of children, parents, caregivers, teachers, support staff and professionals in various learning settings. (Up to 1,500 words).
- *If you have the kernel of an idea that doesn't quite fit the above please email kairaranga.journal@minedu.govt.nz and you will be connected with one of our editors who will support you on your road to publication.
- An abstract of not more than 150 words should be submitted along with each article.
- Articles sent as hard copy should be on numbered, separate and single sided sheets, with double line spacing. Articles can also be emailed to kairaranga.journal@minedu.govt.nz. Figures or graphs, illustrations and diagrams should be sent separately as tiffs, eps or jpeg files, as well as being embedded in the text of a word processing document. A disk or email version should be saved in Microsoft Word with the filename extension .doc.
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- *Kairaranga* will retain copyright of all articles published.
- Articles submitted to *Kairaranga* should not have been published with exactly the same format or content elsewhere.
- Authors are asked to submit a 50 word personal profile of themselves, their organisation, and/or other affiliations for reader interest.

PEER REVIEW PROCESSES AND GUIDELINES

- *Kairaranga* is a journal evolving through work submitted across the education sector. Peer review involves constructive feedback on your written contribution. The suggestions made will help you in editing your final piece of work.
- The peer review process for *Kairaranga* is "blind". This means that neither the name of the author nor the name of the reviewer will be known to each other.
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 - Feedback is given to the author.
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 - b) minor editorial revision by the author.
 - c) revision of content by the author and modifications based on this review.
 - d) not accepted for publication
- When papers are declined reasons will be given and resubmission may be possible.

Submissions for Volume 10, Issue 1, 2009

Deadline: December 1st, 2008

Submissions for Volume 10, Issue 2, 2009

Deadline: April 1st, 2009

Send to: kairaranga.journal@minedu.govt.nz



GUIDELINES FOR REVIEWS OF TEXTS, RESOURCES AND PROGRAMMES

- Reviewers are asked to submit a 50 word profile of themselves, providing their professional details and affiliations at the end of the review. This information may also be submitted as part of the review.
- Reviewers will take responsibility for the appropriate and correct use of people, places, companies, publishers, etc.
- Reviews will become the property of *Kairaranga*.
- Reviews will reach the *Kairaranga* address by the date published on the letter of invitation.
- Abridgement of the review will be at the discretion of the Editorial Board.
- We are looking to explore many varied and potentially contradictory views on issues relating to educational practice which may be included within the texts, resources or programmes. This should result in views being expressed that do not necessarily reflect the opinions of the Editorial Board.



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