

With Hindsight

An overview of the autism spectrum disorder participatory action research project

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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 flax-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 Practice* 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

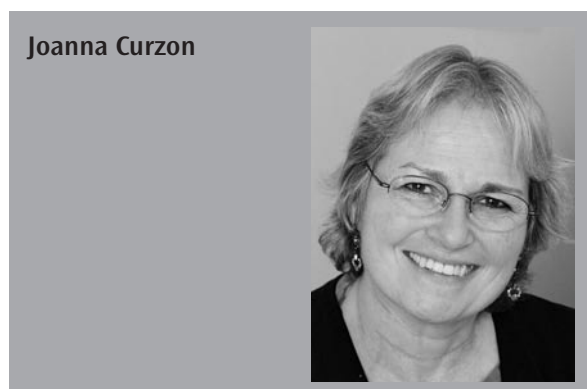
⁵ Meeting

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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AUTHOR PROFILE



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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