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. Transferal 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 A severe episode of epileptic seizures had changed her from a bright, interactive two-year-old to a private, withdrawn child whose lack of social interaction was attributed, by her paediatrician, to autism spectrum disorder (ASD).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).
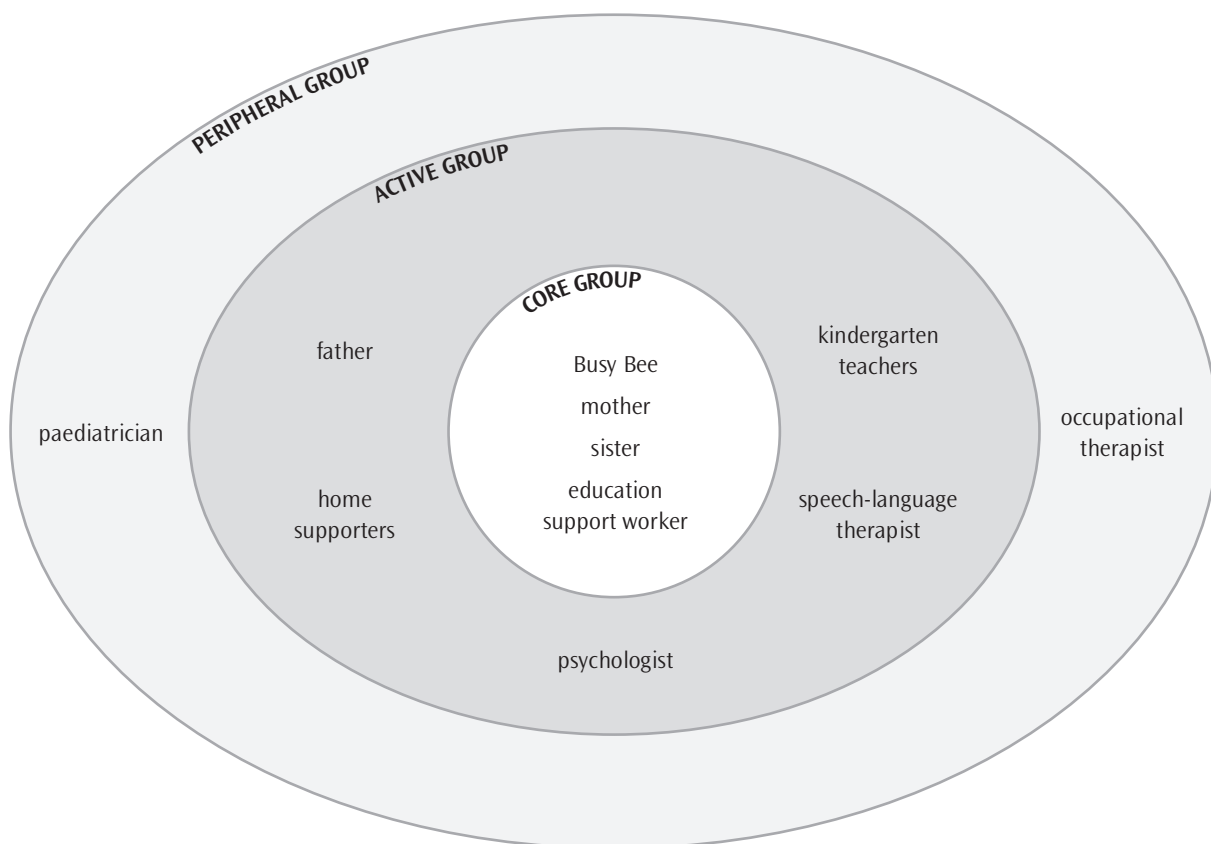

Figure 1: Degrees of community participation (Based on Wenger, McDermott & Snyder, 2002)

- 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.

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[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.

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[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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