Parents Together: action research and advocacy support for parents with learning difficulties

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Abstract

This paper describes the work of *Parents Together*, a pioneering action research project that set out to support parents with learning difficulties in ways that were non-stigmatising, non-intrusive and responsive to their perceptions of their own needs. Based on an explicit model of parenting and social support, *Parents Together* used an advocacy approach to challenge discriminatory views of parents' competence and to lighten the load on families by reducing the environmental pressures that undermined them. The paper concludes by drawing out the wider lessons of the project for policy and practice. Pseudonyms have been used throughout this article.

Introduction

The number of parents with learning difficulties is unknown, though the numbers who are known to the health and welfare services are widely acknowledged to be rising steadily (Gillberg & Geijer-Karlsson 1983, Hoffman *et al*. 1990, Whitman & Accardo 1993, Ray *et al*. 1994, McGaw 1997). The reasons for this trend are complex and it is not easy to tell if more referrals really mean there are more parents. On the one hand, policies that reduce controls over the sexuality of people with learning difficulties might be expected to lead to more of them having children. The fact that increases in the number of parents have been reported in all countries that have moved towards services based on 'ordinary life' principles and community living appears to support this interpretation (Danish Ministry of Social Affairs 1996). On the other hand, families on the margins of competence might be finding it harder to manage in an increasingly competitive society. Greater intervention by the state in family life, closer surveillance of parents and their children and the widening of the child protection net (Thorpe 1995) may have brought more parents to the attention of the public services.

Whatever the reasons for the apparent increase in families headed by a parent or parents with learning difficulties, they now represent a sizeable population whose special needs for education, training and support have so far not been adequately addressed by the health and social services (Booth & Booth 1996b). Research has shown that parents too often receive a raw deal from the statutory services: the evidence points to high rates (40–60%) for the removal of children from the family home but low investment in the kind of services and supports that might enable them to bring up their children. A number of features of much professional work with parents serve to exacerbate their vulnerability:

- *The presumption of incompetence* – parents frequently experience discriminatory treatment as a result of the misplaced belief that their innate limitations make them unfit for parenthood (Booth & Booth 1993a, Booth & Booth 1994b).
- *Conflicting responsibilities* – there is a constant tension between the 'policing' and 'enabling' role of social workers. As Harris (1990) observes, families in difficulty 'typically turn to the very professionals who have the main statutory responsibility for child protection'.
- *A deficiency perspective* – practitioners tend to focus on people's deficits, and on what they cannot do,

so reinforcing their feelings of inadequacy and undermining their confidence (Booth & Booth 1993b).

- *Competence-inhibiting support* – parents are often deskilled by services that take over their responsibilities and put the practitioner in control (Booth & Booth 1993c).
- *Blaming the victim* – family and child care problems are too often ascribed to the limitations of the parents when they owe more to environmental pressures or to deficiencies in the support services (Booth & Booth 1996a).
- *Lack of trust* – many parents have had bad experiences of the services in the past and are often reluctant to seek or accept help, even when needed, for fear of where it might lead (Whitman, Graves, & Accardo 1989).

This paper provides an account of an action research project, funded by the Joseph Rowntree Foundation, that sought to avoid these pitfalls by working in partnership with parents in ways that gave priority to their own views of their needs (see Booth & Booth 1998).

Parents Together

Parents Together was set up as an independent network to provide advocacy support for people with learning difficulties who were mums or dads, expectant parents or thinking about having a baby. It was open to couples where one or both partners had learning difficulties, single parents with learning difficulties, parents who had had children taken into care, parents with dependent children, and parents whose children had left home.

The driving aims of the project were to:

- *enable* parents by creating opportunities for them to exhibit their competence;
- *empower* parents by improving their sense of control over their own lives;
- *enhance* parents' self-esteem;
- *extend* parents' social networks.

The end-goal was to make parents feel better about themselves and better able to look after their children.

Parents Together adopted a principled approach to working in partnership with parents drawing on the precedents and examples set by:

- *The self-advocacy movement* – especially the idea of people working together to find their own voice, speak up for themselves, challenge the identity they have been assigned and fight for their rights as full citizens (Williams & Shoultz 1991).

- *The citizen advocacy movement* – especially the idea of actively representing the interests of people with learning difficulties (in this case, parents) and helping them establish informal supports within their neighbourhoods (Butler *et al.* 1988).
- *The self-help movement* – especially the idea of people joining together to do something about their common problems and to enhance their sense of personal identity (Mullender & Ward 1991, Kurtz 1997).
- *The supported parenting model in the USA* – especially the idea that parents should be regarded as a resource (warranting support and investment) rather than a problem (Mandeville 1992).

Parents' involvement in the project was voluntary. All information received or shared was regarded as confidential (following the example of the Samaritans). All workers on the project had to be parents themselves (following the example of Home-Start and Parentline groups).

A model of support

Over the past decade, new initiatives in helping parents parent have begun to receive attention. Most of these are North American in origin, and most are designed as intervention programmes providing parenting training (see Tymchuk & Feldman (1991) for a recent review; also Ullmer, Kidd-Webster & McManus (1991) and Craft (1993)). *Parents Together* was based on a different approach. For most parents with learning difficulties, family life is constantly under threat (Whitman & Accardo 1990, Booth & Booth 1994c). Poverty, debt, unemployment, chronic housing problems, fraught relationships, the hardships of single parenthood, poor literacy and numeracy skills, personal harassment and victimisation all contribute to their vulnerability and add considerably to the risks of parenting breakdown. For this reason, as the experience of Project CAPABLE in Cincinnati has demonstrated, work with these families 'needs to begin with the problem of social support' (Espe-Sherwindt & Kerlin 1990). Unlike most intervention programmes so far, which have targeted the developmental needs of children born to parents with learning difficulties, *Parents Together* aimed at reducing the pressures on parents rather than developing parenting skills.

Parents Together was grounded on an explicit model of parenting and social support (see Figure 1) derived from original work by Tucker & Johnson (1989) adapted to take account of our own earlier research (Booth & Booth 1994c). In this model, *parental competence* is influenced by the *environmental pressures* bearing on the family and the *social support* the family receives.
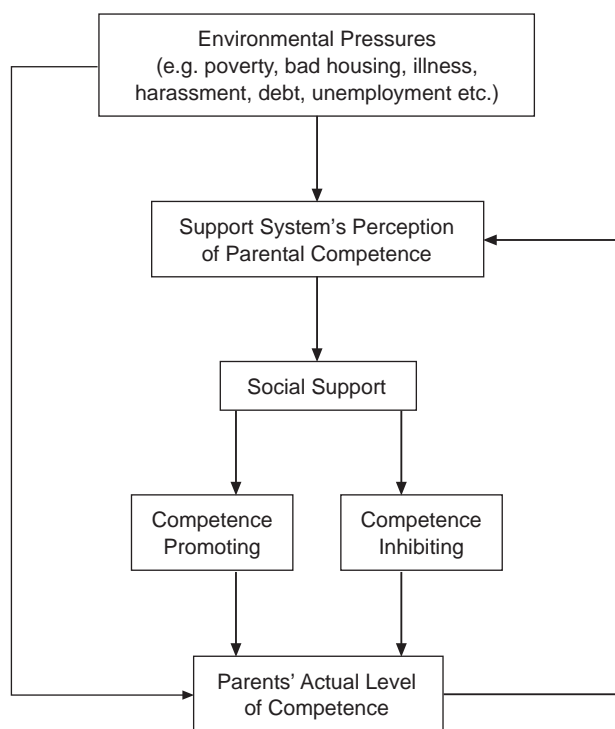
Figure 1 Ecological model of parenting and social support.

Environmental pressures exert both a direct effect on the parenting load and hence the parents' ability to cope, and an indirect effect by influencing how well they are seen to be coping and hence the type and level of support they need.

Social support impacts on parental competence for better or worse depending on whether it promotes or inhibits the parents' capacity to manage the parental task.

The parents' *actual level of competence* in turn feeds back to reinforce how they are perceived by the support system.

Drawing on this model, *Parents Together* set out to enhance parental competence in three ways:

- by reducing the environmental pressures on parents that undermine their ability to cope;
- by challenging discriminatory views of their fitness for parenthood, their ability to learn and acquire new skills or their capacity for love and affection;
- by supporting parents in ways that improve their confidence and encourage a sense of self-worth.

The action project

As an action project, *Parents Together* operated on two fronts:

- *Running support groups* – bringing together parents in order to share their experiences; to learn from

and support each other; to reduce isolation and loneliness; to combat stress; to encourage strengths and abilities; and to enhance self-esteem.
- *Outreach work* – developing the trust of parents new to the project; getting to know the parents better; maintaining contact with parents unable to attend the support groups; helping to mobilize community supports; accompanying parents to appointments with social workers, housing officials, schools, solicitors, etc.; offering personal support, mostly in parents' homes.

Other activities providing a bridge between these two parts of the project included:

- *Crisis advocacy* – for parents and families facing immediate problems that threaten to overwhelm them.
- *A telephone helpline* – for people wanting a worker to call, to cancel a visit, to off-load, a bit of advice or just to chat.
- *Parent-to-parent links* – bringing together parents for friendship or mutual support.
- *A resource network* – offering information and guidance on sources of practical help.

Who was involved

Initially, most parents were contacted through the health and social services. When the project was up and running, however, other means of getting in touch opened up and the names of families were put forward by, for example, solicitors and voluntary organizations. Some parents were brought along by those already in the project. *Parents Together* did not take referrals from practitioners. We were happy for them to put us in touch with people who might like to join but membership was voluntary and only for parents who wanted to take part. In other words, joining the project was a decision for parents, not for practitioners as referral agents.

Twenty-five families were involved in *Parents Together* between February 1996 and July 1997. These 25 families included 23 mothers with learning difficulties; three fathers with learning difficulties; two (single) mothers without learning difficulties; and 10 fathers without learning difficulties. The two mothers without learning difficulties were introduced by other parents to the support groups. They shared the same problems of isolation, powerlessness and vulnerability as the other parents. They did not receive outreach support.

Among the 25 families, there were six married couples, seven cohabiting partnerships, seven single mothers, four divorced/separated mothers, and one mother who was living with two men.

Nineteen families in the project had between them 35 children living at home. These children ranged in age from 0 to 24 years: 29 were under 11. A mother and five couples had no children at home with them. During the course of the project, two more babies were born, three mothers became pregnant, and one child was taken into care.

In addition, 18 children from these families had been fostered or adopted, three (now adult) children were living independently, six children were living with an ex-partner, and two children had died.

The project team employed on *Parents Together* was made up of four workers: one full-time (woman) with five years experience as an Adviser to a People First self-advocacy group, one half-time (woman) with experience of supporting low income families, and two people who were employed one day a week (a man whose own mother had learning difficulties and a woman with experience of teaching adults with learning difficulties).

Contact with parents

Conveying something of the extent of involvement with families is not easy. Contact with some families was greater than with others. People's needs shaped the frequency of their contact with their advocate. The length of home visits varied. The work done on behalf of families cannot be measured by the time spent with them.

Crudely, then, the figures on the frequency of communication between the families and project workers are:

- 653 contact meetings (including visits and support group sessions);
- 212 telephone calls to parents from advocates;
- 193 telephone calls to advocates from parents;
- 14 letters to parents;
- one letter from a parent.

Being responsive to parents' views of their own needs meant some made greater use of *Parents Together* than others. For example, one mother was visited 61 times, attended the support group 58 times and rang her advocate 48 times. By contrast, another mother, who was in the project for a similar length of time, was visited just 22 times, attended the support group once and phoned her advocate once. (As she was on the telephone her advocate was able to ring her 39 times to keep in contact).

Advocacy in action

Parents Together was conceived and carried out as a piece of action research. Lewin (1946), who is generally credited with introducing the term, described action research as a way of generating knowledge about a social system while, at the same time, trying to change it. In this process, the generation and analysis of data are fundamentally linked with action for change: there is 'a blurring of lines between "finding out more" and "doing something about" the issue or situation selected for investigation' (Hart & Bond 1995). Evaluation provides the loop through which fact-finding and practical problem-solving are bound together.

We adopted Beattie's (1991) 'portfolio' approach to evaluation (see also Hart & Bond 1995) which, in this case, involved systematic programme monitoring, the maintenance of a project diary and activity log, formative assessments of work in progress, and *posthoc* interviews with parents and their practitioners. Continuous and detailed recording of all encounters, actions and outcomes was maintained throughout the term of the project. This article draws on the evidence contained in these extensive records.

Examination of the portfolio of evaluation data highlights the many different ways in which *Parents Together* worked to support families. At one time or another, often simultaneously, the advocates acted as:

- a *witness* to the actions of officials and practitioners in their dealings with parents;
- a *buffer* absorbing some of the pressures on families by fielding or deflecting matters that might exacerbate their troubles;
- a *voice* making sure the parents' views were heard;
- a *go-between* helping to facilitate and improve liaison between families, practitioners and the services;
- an *interpreter* putting information into language that parents could understand;
- a *listener* enabling parents to share their worries, air their grievances or just talk things over;
- a *scribe* helping with letters and form-filling;
- a *problem-solver* helping parents to think things through, supporting them in their decisions, and ensuring that practitioners were alerted to options for helping families they may have missed;
- a *fixer* sorting out problems of service delivery caused by poor co-ordination, errors, oversights and bureaucratic inertia;
- a *conduit* channelling the lessons learnt in supporting one family for the benefit of another;
- a *sounding-board* encouraging families to have confidence in their own ability to cope by helping them to work things out for themselves;
- a *confidante* with whom confidential information could be safely shared;
- an *ally* unambiguously on the family's side, prepared to stand by them, and whose actions were always consistent with this stance;

- a *sleuth* tracking down and searching out information that would help parents achieve positive objectives;
- a *mentor* sharing knowledge and experience of life in the capacity of a supportive equal rather than an expert;
- an *observer* looking out for the early signs of stress, or changes in personal circumstances, that might impact on the parents' capacity to cope;
- a *mover and shaker* making things happen.

Parents' perspectives on their advocate

All but one of the families present at the end of the project who had received one-to-one advocacy support agreed to talk to someone from the project other than their own advocate (and with whom they had had no dealings) about what it had meant to them.

These parents overwhelmingly endorsed the practice principles followed by *Parents Together*: they liked the advocates' ways of working; they liked knowing that nothing was being done behind their back; they liked having copies of everything that was written about them; they liked having easy contact with their advocate; and they liked being listened to and treated with respect. Patricia summed up these feelings when she said:

I was very happy with the way she helped me. She was someone to talk to and she was great with Michael. I'd rather have her than a social worker. She was good. I could have a laugh with her, she didn't criticize me. She respected things we told her. I liked the confidentiality if we said anything about social workers. I think single parents would benefit from having someone like her. She was great.

Parents valued the roles played by the advocates ('She's done more than what anyone else has done'). All of them reported feeling better for having an advocate ('It was good to have someone on my side'), and all of them would have liked their advocate to have continued beyond the end of the project ('I would like Anne to continue, and the kids would'). Maureen and Ruby echoed the sentiments of the other parents when they spoke as follows about their advocate:

She was great with me. She helped me more than a social worker and was more useful than a social worker. It was good to talk to someone. I'm still waiting for a house and I would have liked her to have been here to help with that. She helped me more than anyone. We got on great with her and had some laughs. She was someone to talk to. She was company during the day. It was good to have help; it was good what she did. I would have liked her to have continued coming to see me and helping me. I wish she was still coming. (Maureen)

She explains to me what I don't understand, what Social Services are talking about. If I didn't understand what questions were she'd repeat it and explain it. She was brilliant. Helped me with debts. Had problems with money – still have problems. Calming me down when I get stressed. Any problems I tell her and she tries to help me. Trying to help us get kids back. She went to Court with me and Review meetings. That's why I want her back. Social worker's a cow. If I'm in bad distress I tell her and she tells me who to get in touch with. I've never had anyone better, not like her before. (Ruby)

These quotations reflect the overwhelmingly positive comments of parents (see Booth & Booth 1998 for a fuller account of what they had to say about the project). The only criticisms voiced by parents (2) were about advocates' level of involvement. One mother felt that her advocate 'got too involved in certain things' where another 'would have liked to have her around a bit more'.

Practitioners' perspectives on advocacy

Practitioners were invited to give their views on what impact, if any, the advocate's work had had on their clients, their own practice and on their agency. Some families in the project had no close involvement with a practitioner and there was no-one to ask. Comments were obtained by postal questionnaire from eight people who had been closely involved with parents in a professional capacity throughout the project.

All these practitioners felt their clients had benefited from having an advocate and all of them cited ways they too had benefited from the advocate's work. Most said that working alongside an advocate had prompted them to examine their own practice, though some had found aspects of the advocate's work unhelpful. Nearly all thought that a permanent advocacy scheme should be established. The following quotations are typical of the comments made by practitioners:

Excellent facility which needs to be on-going. The advocate's work was supportive and practical help given. The clients found the work done invaluable. They have begun to do some things for themselves. I would see the need for a permanent advocacy service to be offered to all clients with learning disabilities. (Social Worker)

The advocate dealt with areas which I would have found difficult having not had the necessary experience and allowed me to concentrate on other areas of need in the client's life. I felt that my client was getting help from the most relevant people. (The advocate's presence also) made me try to make sure that I carried out work promptly before I was reminded that something had not been done. (Community Nurse)

Initially, my clients having an advocate took some getting used to, feeling as if my work was being scrutinized. However

I actually found this useful, enabling me to reflect on practise. Throughout, I felt this to be beneficial to the clients concerned. It helped me enormously too. Giving clients support in areas that often I had little time to give to enabled me to work more effectively in relevant areas. Therefore meeting needs across a wider spectrum for the client. I felt they gained in confidence and learned a lot via role modelling. I felt they learned to have expectations of services, where previously they appeared to accept whatever was offered – appropriate or not. There needs to be long-term commitment to projects like this. (Community Nurse)

I felt generally positive about my client having an advocate, though some concerns. At first, I felt there was a very anti-professional stance and assumptions being made. This dissipated over time. The advocate's involvement proved positive when there, negative when it stopped. I have found contact with the project and its workers positive – hope it is groundwork on which to build more partnership to pursue support and empowerment of parents with learning difficulties. (Psychologist)

The practitioners owed no loyalty to the project. Their generally positive appraisal suggests they appreciated its value to the parents even when (as advocacy should) it made their work more difficult.

The support groups

Two separate advocacy support groups were run as part of the *Parents Together* project:

The City Group met 61 times (for $2\frac{1}{2}$ hours each session) in a city centre venue over a period of 18 months. During this time, 9 mothers, 3 fathers and 3 children attended meetings, of whom 5 mothers and 1 child turned up almost every week.

The District Group met 18 times (for $1\frac{1}{2}$ hours each session) in a local branch library, with adjacent crèche facilities, over a period of five months. During this time, four mothers with 10 children attended meetings of whom all but one mother and two children came regularly.

Parents from 13 of the 25 families involved in *Parents Together* came to group meetings at some time. The others did not attend for a variety of reasons:

- because the meetings clashed with other commitments;
- because they would have needed help with using buses;
- because they were frightened of travelling alone;
- because they lacked the confidence to attend; or
- because they were not interested.

Two workers generally attended every meeting. It was agreed from the start that they would adhere to an advocacy role in supporting the self-help aims of the groups. Particular importance was attached to three points:

- The role of the advocate as facilitator was to assist and support the groups but not to lead or take responsibility for the meetings. This did not mean standing on the edge of the group. It meant joining in and sharing without taking over.
- The parents owned the groups. After the first meeting, they decided who could join. No-one was invited without their consent.
- The agenda for the meetings should be decided (or left undecided) by the parents.

None of the parents had attended a support group before, nor any other sort of group in which they were in charge. During the course of the first few meetings, they decided on some basic ground rules about how the groups would operate:

- They agreed when to meet, how often and for how long.
- People could come and go whenever they wanted.
- What people said was private and must not be told to outsiders.
- Children under school age could attend with their parents.
- The groups were open to all parents (no mention was made in this context about the groups being for parents with learning difficulties).
- Everyone present should help set up the meeting and tidy up afterwards.
- A different person would lead the meeting each week.

What the groups did

Process

The parents were adamant from the beginning (contrary to the expectations and intentions of the workers) that they did not want outside speakers or any experts coming along to talk or join in group meetings. Their position was that if they wanted to know something, 'We'd do better to find out for ourselves and bring it back to the group'. Also the idea of sitting and listening did not appeal. They much preferred to do the talking themselves.

The workers, with the parents' permission, kept a record of what was said, what happened and what was decided at meetings. Initially, this was done for research purposes (as part of the monitoring of the action project). But as time went on it became an integral part of the workings of the group:

- People liked seeing what they had said being written down. They would often check that the

worker had noted it all or say, 'Have you got that down?' People seemed to gain confidence from feeling they had made a contribution.

- Latecomers could be brought up to date with what had gone on in the meeting using the parents' own language.
- It was useful as a reminder of where the group had got to in the previous meeting and what had been left over to do at the next.
- It was a way of continually re-affirming the parents' ownership of the group by demonstrating that the proceedings were driven by what they said.
- It served as a tangible sign that there was no hidden agenda concerning the business of the group.

Keeping the groups together and going meant keeping everybody involved and interested. Attention had to be given to group maintenance as much as to task performance. This was especially important whenever new parents joined a group. Relationships had to change to include them.

The groups had to handle some strong emotions. Painful feelings (anger, frustration, jealousy and grief among others) were generated within the groups and brought into the groups. These had to be dealt with in different ways. The initial response to problems in relationships between members was to leave them to sort things out among themselves. Observing and learning how to resolve such conflicts in a safe setting was a positive aspect of the work of the groups and contributed to greater self-awareness and assertiveness among members. If, however, these conflicts continued to the point where they upset others or threatened to split the group the worker would have to step in to calm matters, but always without taking sides. Painful feelings brought into the group were almost always caused by problems in family relationships or by system abuse. These feelings worked to bring the group together, mainly because others had invariably experienced them too. Sharing them with the group created opportunities for showing mutual support, and helped to free people from the sense of being alone in a hostile world.

Activities

Group sessions were not preplanned or designed with any purpose in mind other than to bring the parents together. From the outset, the aim was that the groups should be a resource for their members, and the parents would decide how they wanted to use them. Topics and tasks were carried over from one week to the next and, as the range of activities the groups were involved in grew, so the agenda of upcoming meetings filled

with things to do and decisions to make. Nevertheless, there is no sense in which the groups could be said to have followed a structured programme beyond the routine that emerged as they went along. Looking back, however, it is possible to see that group activities clustered under a number of headings.

The weekly newsround
At the start of each session, everyone, including the workers, talked in turn about things that had happened to them during the past week or since their last meeting. They raised some matter that was troubling them or had made them feel good or which they thought the group would be interested in hearing about. The newsround was very popular. Initially used as an 'ice-breaker' when the groups first formed and people didn't know each other, it soon became a fixture on the weekly agenda. Everyone made a point of always contributing. Some people wrote down their news so they didn't forget anything, and two even bought diaries for the purpose. Others got involved in things they might not otherwise have done in order to ensure they had something to report. The newsround served a number of purposes:

- it ensured everyone who attended meetings had their own slot on the agenda, a chance to speak, and to have people listen to them;
- it allowed people to get to know each other better, and to appreciate what they had in common;
- it gave everyone a stake in the group;
- it helped to identify issues of common concern;
- it provided an anchor for meetings and gave them a sense of cosy familiarity.

Discussion slots
Discussions usually took place spontaneously in response to parents' news, or questions, worries and concerns that emerged during the course of the meetings. A list of the topics raised by parents and discussed within the groups over the course of the project was kept in the project activity log and is shown below.

This list is instructive because it reflects the parents' priorities and their sense of who they are:

- it is not just about being a parent or bringing up children;
- it does not encompass the kind of concerns that usually feature in training programmes for parents with learning difficulties which are usually child-focused and skill-based;
- it shows the problems that figure prominently in their lives, and the things that interest them as

abuse	housing matters	**Table 1** Topics raised by parents and discussed within the groups
being pushed around	informal support	
benefits	jobs and job opportunities	
birthdays/treats and special occasions	leisure interests	
child removal	loneliness	
children	making new friends	
confidentiality within the group	male friends	
conflicts with neighbours	men who abuse	
contraception/pregnancy and birth	moving house – setting up home	
cooking	new clothes	
death and bereavement	New Year's resolutions	
disability	people from other countries	
education and enrolling at college	pets/animals and plants	
family and home	relationships	
fines/debts/money/finances	religion	
harassment/victimisation/burglary/crime	safety and self protection	
health – personal and children's	service provision and shortfalls	
holidays and trips	travel and mobility	
house decorating	unemployment	

parents, are probably the same as most families in need, and do not stem from their learning difficulties alone;
- the focus is on their place in the world, not on their limitations. What they looked for was help with the things that made their lives more difficult.

Outings

The groups organized five outings and held a joint meeting with a parents' group from another town. The outings were planned, organized and paid for by the parents.

Arranging the outings took up a lot of time in the groups spread over many weeks. They involved the parents in setting up a bank account, running a savings scheme, finding information about where to go, working out costs, sorting out transport, managing the children, and resolving all the differences that arose within the group about most of these issues! The outings were important because:

- the parents and workers enjoyed them;
- they were something to look forward to and to think about afterwards. As one parent said, 'We want some sweets in our life, not all sours';
- the fun was in the sharing. 'It was nice to go, even just going to McDonalds for a meal with others instead of sitting there alone with three kids. Kids could meet others too';
- they provided a lighter side to the groups.

Projects

Parents worked together on a number of projects on their own initiative arising from their ideas:

- they designed an invitation card for prospective members of the group;
- they produced a pictorial leaflet explaining what the group was about to accompany the invitation card, and also for distribution to practitioners and other outlets;
- they put together a small booklet advising families what to look for when moving house. This came about when a family in City Group was anxious about making a move, and asked the group for advice on what to do for the best. Members decided their pooled experience would be useful to other people needing guidance;
- They worked on a healthy-eating pictorial shopping list for people who couldn't read. Over a number of weeks, parents collected recipes and information, discussed a healthy diet and tested out ideas for a leaflet within the group.

Many of the benefits derived from these activities mirrored those listed above under *Discussion Slots*. In addition, these projects:

- made members feel the group was important in its own right, as a way of helping other families;
- gave people the feeling that they had something to contribute;
- allowed them to feel they could get things done.

Parents' assessments of the groups

All the regular attendees were given an opportunity to say what they thought about the groups. Some wrote down their comments, some got others to write for them, and some just spoke their mind. Without exception,

they all emphasized the positive benefits they had derived from belonging to their group: common among these were meeting and talking to other people, sharing problems and gaining confidence.

I liked meeting new people and getting on with them. I was always stuck in before. It was a break from the children. (Stella)

It's something to look forward to. It was nice to go … I knew one mum from seeing her at school. We see each other quite a lot now. I can talk to her about anything, better than my family. Like abuse. We talk about things. (Julie)

Because of group I am able to meet new people and talk with them. I'm more open. With going to that group I found it good. (Dilly)

The group helped me as it got me talking about my anger. When I talked about my daughter it made it seem as if she was there … It made me feel like a mum. (Tricia)

When a parent is talking in the group, and listening to what they are going through each week, and taking an interest in, and just by talking to new people, you think you're not the only one in the world with problems. (Catherine)

The group helped by supporting me and giving me someone to talk to … I get a lot out of talking to different people. Everyone has been good to me. Thank you all for being there. (Emily)

It's somewhere where we can be honest. (Eric)

I felt safe talking there and better after talking … The group is different, it's different because it's nothing to do with services. We sort out other people's problems. (Moira)

Everybody's been there to listen. I enjoy listening to other parents and what they've been through. It gets you away from family pressures, although I know they're still there. (Gillian)

Conclusions

This paper has described the work of *Parents Together*, an action research project which set out to use an advocacy approach to supporting parents with learning difficulties. In this concluding section we consider how far the project succeeded in achieving its aims and summarize the key lessons for practice that emerged.

In arriving at a summative assessment of project outcomes, it is necessary to link the information we have presented on the working of *Parents Together* – the process side of the project – to its original aims and ask how far it was successful in lightening the load on parents, challenging discriminatory practice and improving their self-esteem. In approaching this task, it is important to remember that action research of this

'empowering' type (see Hart & Bond (1995) for a useful typology) is more a matter of engagement than experimentation in which new learning comes more from hands-on experience than the application of scientific methods (Winter 1987). The general conclusions that follow come out of a critical appraisal of the evidence contained in the portfolio of information built up during the course of the project.

1 *The parents felt better for having an advocate but the advocates could do little to change their situation.*

   All the evidence – in terms of what parents said about the project, the record of their participation, practitioners' judgements and the experience of the advocates – shows that parents felt empowered by having an advocate to call on or a group to attend. At the same time, the advocates were aware of just how little they succeeded over the course of the project in doing anything about those things, like bad housing, victimisation, poverty, system abuse, which made life difficult for the parents.

2 *Advocacy cannot ameliorate parents' troubles, but it can act to prevent them being compounded by bad practice and competence-inhibiting support.*

   In terms of the model of support on which the project was based (see above), *Parents Together* had little success in relieving the environmental pressures on parents, but it did succeed in changing for the better the way in which the parents were regarded by some practitioners and the kind of support they received. Advocacy can successfully challenge specific instances of bad practice, but it cannot change the system that generates it. The goal should be to get the system working better to support families, rather than to get everyone an advocate.

3 *Without an adequate infrastructure of health and social services, advocacy alone is unable to relieve the environmental pressures that undermine parents' ability to cope.*

   One-to-one advocacy work with parents who have learning difficulties is like pushing string. The pressures on the parents and the problems they face are unremitting. At the same time, services geared to the needs of these families are missing and what services there are tend to be crisis-oriented, child-centred rather than family focused, unreliable, inflexible, uncoordinated and thin on the ground (Booth & Booth 1994a, 1996b). Consequently, there are few resources available for the advocate to mobilize in order to relieve the environmental strains on parents.

4 *Advocates were no more successful than the parents themselves over the longer term at dealing with the*

failings in the system. In both cases, individuals were worn down by the constant struggle to get anything done.

Life is tough for parents with learning difficulties. The pressures that bear down on them can weary their advocate too. An advocate cannot expect to change agency policies or practices that impact unfairly on families; make professionals like the parents or treat them with respect; undo the harm done by deficiencies in the services and support provided to families; shield people from discrimination and day-to-day harassment or change the attitudes that fuel their victimisation in the community. Squeezed between the scale of the problems parents face and the unavailability of appropriate services, advocates are easily pushed into taking on more than they can realistically hope to manage, with the attendant dangers of disillusionment and exit.

5 *The advocacy support groups were successful in helping people to work with their problems (if not resolve them) and to feel better about themselves, but support groups represent an extension of, rather than a substitute for, one-to-one advocacy.*

The advocacy support groups were more successful in converting effort into effect. They:

- got to more people for less advocacy time;
- allowed parents to meet each other;
- served as a platform for challenging discriminatory attitudes;
- boosted parents' self-esteem and confidence;
- provided opportunities for learning;
- brought some fun into people's lives.

But not everyone was able or wanted to attend a support group. Even the people who did regularly go along to the groups had some problems that were better addressed confidentially, on a one-to-one basis.

The advocacy approach adopted by *Parents Together* serves as a model of how to work in partnership with parents who have learning difficulties. Indeed, given that many of the factors undermining their ability to cope are the same as those that make it hard for people without learning difficulties to be good parents, the approach has implications for practitioners working in partnership with all families in need.

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