

Advocacy for parents with learning difficulties

Parents Together was an action research project run by Wendy Booth and Tim Booth of the Department of Sociological Studies at the University of Sheffield. The project set out to support parents with learning difficulties in ways that were non-stigmatising, non-intrusive and responsive to the parents' views of their own needs. Parents had individual advocates and were also invited to attend advocacy support groups; 25 families were involved. The key lessons to emerge were:

f The parents felt better for having an advocate and valued the many different roles their advocate played. Many wished that the scheme could have continued beyond the end of the project.

f Practitioners felt their clients had benefited from having an advocate. Again, many would have supported an extension of the project. They also felt that working alongside an advocate had prompted them to examine their own practice.

f Advocacy support groups were successful in helping people to work with their problems (if not always resolve them) and to feel better about themselves. However, not everyone was able or wanted to attend a support group and some problems were better addressed, confidentially, on a one-to-one basis.

f The researchers conclude:

- Support groups represent an extension of rather than a substitute for one-to-one advocacy.
- Advocates can act to prevent the difficulties parents face from being compounded by bad practice and inadequate support but were no more successful than the parents themselves over the longer term at dealing with the failings in the system.
- Without an adequate infrastructure of health and social services, advocacy alone is unable to relieve the environmental pressures that undermine parents' ability to cope.

Background

Parents Together was set up as an independent support network for people with learning difficulties and their partners who are parents, expectant parents or thinking about having a baby. Its overriding purpose was to work in partnership with parents to support them in ways that were non-stigmatising, non-intrusive and responsive to the parents' own views of their needs. The guiding aims of the project were to make parents feel better about themselves and better able to look after their children.

The project aimed 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; and *extend* parents' social networks.

Parents Together set out to enhance parental competence by:

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

The *Parents Together* approach to working in partnership with parents drew on the precedents and examples set by the self-advocacy movement; citizen advocacy; the self-help movement; and supported parenting programmes in the USA.

Advocacy in action

Advocates worked to support families in many different ways. At one time or another, often simultaneously, advocates acted as:

- a *witness* to parents' dealings with officials and practitioners;
- a *buffer* by fielding or deflecting matters that might exacerbate stress;
- a *voice* making sure parents' views were heard;
- a *go-between* improving links between families and services;
- an *interpreter* putting information into language that parents could understand;
- a *listener* enabling parents to talk things over;
- a *scribe* helping with letters and forms;
- a *problem-solver* helping families think things through;

- a *fixer* sorting out problems of service delivery;
- a *conduit* channelling the lessons learned 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;
- a *leuth* tracking down and searching out information;
- a *mentor* sharing general knowledge and experience;
- an *observer* looking out for early signs of stress;
- a *mover and shaker* making things happen.

Parents valued the roles played by the advocates. All the parents reported feeling better for having an advocate, and all of them would have liked their advocate to have continued beyond the end of the project:

"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 [advocate] and she tells me who to get in touch with. I've never had anyone better, not like her before." (Ruby)

The parents endorsed the practice principles followed by *Parents Together*. They liked: the advocates' ways of working; knowing that nothing was being done behind their back; having copies of everything that

was written about them; having easy contact with their advocate; and being listened to and treated with respect.

"I was very happy with the way she helped me ... I'd rather have her than a social worker. She was good. I could have a laugh with her, she didn't criticise me. She respected things we told her. I liked the confidentiality if we said anything about social workers." (Patricia)

Practitioners too felt their clients had benefited from having an advocate; only two did not report any positive changes in their client as a result of the advocate's involvement. Most said that working alongside an advocate had prompted them to examine their own practice, though some also found aspects of the advocate's work unhelpful. Nearly all thought that a permanent advocacy scheme should be established.

"The advocate listened to our client and made requests on her behalf to [social services]. Some of these requests challenged the systems in place ... this can be very positive in helping us examine our practice." (Social Worker's Team Manager)

"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)

"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. People were just gaining confidence, trusting and tentatively making friends when everything stops." (Community Nurse)

The support groups

The advocacy support groups were more successful than one-to-one work at 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; and brought some fun into people's lives:

"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. I met new people and it helped me express my views and it was all confidential. It was good to talk to others, it got rid of some frustrations. It made me feel like a mum. The group helped me talk my problems through. It filled Mondays up for me and was something to look forward to. I made friends. It made me realise that I wasn't on my own, there are others in similar situations." (Tricia)

"Everyone supported each other and we are friends. Getting into the group stopped me looking at four walls. I found the group and having an advocate useful for all the information. I believe the group helped everyone that came. I felt guilty sometimes bringing my son to the group as I knew that Moira and Gillian couldn't bring their children. 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)

But not everyone was able or wanted to attend the 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. For this reason, support groups represented an extension of rather than a substitute for one-to-one advocacy.

The limits of advocacy

Life is tough for parents with learning difficulties. 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, unco-ordinated and thin on the ground. Consequently, there are few resources available for the advocate to mobilise.

Advocates were no more successful than the parents themselves over the longer term at dealing with the failings in the system. 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; make good 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. Equally, an advocate cannot erase past hurts or ensure a future free from distress. In both cases, individuals were worn down by the constant struggle to get anything done.

Conclusion

The researchers conclude that without an adequate infrastructure of health and social services, advocacy alone is unable to relieve the environmental pressures on parents that undermine their ability to cope. If advocacy cannot ameliorate parents' troubles, however, it can act to prevent them being compounded by bad practice and inadequate support. The project did succeed in improving the way in which parents were regarded by some practitioners and the kind of support they were given. However, this conclusion should not divert attention from parents' real needs. The goal should be to get the system working better to support families rather than to get everyone an advocate.

About the study

As an action project, *Parents Together* operated on two fronts: running support groups and one-to-one advocacy and outreach work with parents. Other activities providing a bridge between these two parts of the project included: crisis advocacy; a telephone helpline; parent-to-parent links; and a resource network.

Twenty-five families were involved in *Parents Together* between February 1996 and July 1997. These 25 families included 23 mothers with learning difficulties and 3 fathers with learning difficulties. Nineteen families in the project had between them 35 children living at home. In addition, 18 children from these families had been fostered or adopted; 3 (now adult) children were living independently; and 6 children were living with an ex-partner.

How to get further information

A full report of the project, *Advocacy for parents with learning difficulties: Developing advocacy support* by Wendy Booth and Tim Booth, is published by Pavilion Publishing in association with the Joseph Rowntree Foundation (ISBN 1 900600 80 3, price £13.95 plus £1.50 p&p). It is available from Pavilion Publishing (Brighton) Ltd, St George's Place, Brighton, East Sussex, BN1 4GB; Tel: 01273 623222, Fax: 01273 625526, e-mail: pavpub@pavilion.co.uk, website: www.pavpub.com/.

The following *Findings* look at related issues:

- A survey of group-based parenting programmes, Jan 96 (*SP91*)
- Housing, support and rights of people with learning difficulties, Mar 96 (*SC81*)
- Further education for people with learning difficulties, May 96 (*SC85*)
- Supported employment for people with learning difficulties, May 96 (*SC86*)
- Involving people with learning difficulties in staff recruitment, Sep 96 (*SC91*)
- Parenting in the 1990s, Oct 96 (*SP106*)
- Growing up with parents who have learning difficulties, Apr 97 (*SP113*)
- Direct payments for people with learning difficulties, Aug 97 (*SC96*)
- 'Low support' options for people with learning difficulties, May 98 (*F528*)
- Supported living and supported employment: opening up opportunities to people with learning difficulties, Jul 98 (*F728*)

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