

## **The Benefits of Mutual Support Groups for Parents of Children With Disabilities<sup>1</sup>**

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*This study examined what parents of children with disabilities and special needs found helpful about belonging to mutual support groups. Quantitative data (based on 56 parents from 6 groups) indicated that members found the groups very helpful and were very satisfied with the support they received from their groups; they also described the groups as high in cohesion, expressiveness, task orientation, and self-discovery. A grounded theory analysis of focus group data (based on 43 parents from 5 of the groups) indicated that such support was helpful in three broad domains: (1) the sociopolitical, which involved developing a sense of control and agency in the outside world; (2) the interpersonal, which involved a sense of belonging to a community; and (3) the intraindividual, which involved self change. A central theme of identity change emerged as superordinate to these three categories.*

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**KEY WORDS:** mutual support groups; self-help; parents; children with disabilities.

This study aimed to investigate what parents of children with disabilities and special needs find helpful about mutual support groups. An increasing

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number of parents of children with disabilities are participating in mutual support groups, usually in addition to seeking help from professional agencies (Russell, 1997). Studying what they find helpful will advance knowledge in the area of mutual support, may inform professionals about parents' needs and how to improve professional practice, and may help mutual support organizations to discover more about—and maximise the benefits of—the activity in which they are involved.

Although having a disabled child does not inevitably lead to difficulties, a substantial body of literature documents the stresses that many parents experience. In addition to feelings of grief, loss, and guilt, parents commonly experience psychological, social, and political consequences such as isolation and social marginalization, stigmatization, and disempowerment (Byrne, Cunningham, & Sloper, 1988; Pahl & Quine, 1987). Other common problems include financial worries, stress, and ill health (Glendinning, 1983; Pahl & Quine, 1987; Parker, 1985; Singhi, Goyal, Pershad, Singhi, & Walia, 1990). One important coping resource is social support, including practical help, information, and emotional support (Byrne *et al.*, 1988; Quine & Pahl, 1991), which can, among other functions, encourage feelings of normality (Barrera & Ainlay, 1983). Although professional help is available through a variety of agencies, these typically focus on medical treatment and special education provision (Glendinning, 1983); often no single profession or agency shares the whole picture (Hollins, 1985). Given the limited nature of support from professional agencies and the social isolation commonly experienced by parents, support from parents in similar situations has significant potential to be helpful (Brown & Hepple, 1989; Linder, 1970; Pahl & Quine, 1987; Woods, 1981).

Mutual support has many potential benefits (for reviews see Levine, 1988; Lieberman, 1979; Orford, 1992). These include promoting a psychological sense of community, providing emotional support, providing role models, conveying a powerful ideology, providing information, offering ideas about ways of coping, giving the opportunity to help others, providing social companionship, and promoting a sense of mastery and control. However, very little empirical research has investigated the benefits or outcomes of mutual support groups and what factors may be associated with outcome. In one of the few well-designed empirical studies, Maton (1988) found that two clusters of variables were associated with participants' well-being and perceived benefits of the group: social support (giving and receiving support, and the development of friendships) and organizational characteristics of the group (role differentiation, order and organization, and leader capability). A more recent study of support groups for families of adults with mental illness (Heller, Roccoforte, Hsieh, Cook, & Pickett, 1997) found that members perceived two major types of benefits: increased information and

improved relationships with the ill relative. As in Maton's study, giving and receiving support were associated with perceived benefits.

Maton (1993) argues that because group characteristics have the potential to influence the outcomes of mutual support groups, attention should be paid to measuring variables at the group level of analysis. Social climate, or group environment (Moos, 1986)—that is, the social and environmental characteristics of a setting—represents a cluster of such group-level variables. Social climate is a useful way of describing the key characteristics of mutual support groups and other social environments such as psychotherapy groups (Moos, 1996; Toro, Rappaport, & Seidman, 1987). For example, Toro *et al.* (1987) found that mutual support groups differed from psychotherapy groups on a number of different dimensions of perceived social climate: mutual help members rated their groups as higher in cohesion, leader activity, structure and task-orientation, and fostering independence, and lower in encouraging expression of feelings and flexibility in changing the group's activities.

To what extent the existing literature on mutual support groups can be applied to groups for parents of children with disabilities is unclear. Most of the literature is based on adult mental health and the dependencies; furthermore, there is relatively little research on the benefits of "one step removed" groups (Gottlieb, 1982), that is, groups for those caring for a person with the primary "problem." There are descriptive accounts of mutual support groups for parents of children with disabilities and special needs (Linder, 1970; Woods, 1981), but these do not provide a systematic analysis of parents' experiences of the benefits of belonging. Some studies have investigated mutual support groups for bereaved parents and have concluded that such groups help parents through emotional support and existential changes, although they do not affect their psychosocial functioning (Videka-Sherman, 1982; Videka-Sherman & Lieberman, 1985). It is unclear, however, to what extent the benefits of groups for bereaved parents resemble or differ from the benefits of groups for parents of disabled children.

The main aim of the present study was to provide a systematic description of what parents of children with disabilities and special needs find helpful about mutual support groups. It follows Goldklang's recommendation (Goldklang, 1991) for more descriptive, formative, and process-focused research on mutual support groups. This is an area in which theory generation research is appropriate, as existing theory is incomplete (Henwood & Pidgeon, 1992). Hence the emphasis of this study was on discovery and description, using the grounded theory approach (Rennie, Phillips, & Quartaro, 1988; Strauss & Corbin, 1990).

The study also addressed three subsidiary questions in order to provide a context for the parents' descriptions of the groups' benefits: (1) Overall,

how helpful did the parents find the mutual support groups? (2) How did they perceive the social climate of the groups? (3) What were the relationships (if any) between group climate and helpfulness? Quantitative methods were used to address these questions, alongside the grounded theory procedure.

## METHOD

### Participants

The study was conducted in collaboration with a national charity in the UK, Contact a Family, whose aim is to encourage mutual support between families of children with disabilities and special needs. Twelve affiliated mutual support groups were identified in Greater London, and each of these was sent a letter inviting them to take part. Six groups agreed to participate in the study. One agreed but then cancelled the arranged meeting, two chose not to participate, and three did not reply to the invitation. As no information was available on nonparticipating groups, it is not known whether or how they differed from groups who chose to participate.

The six participating groups were made up of 56 individuals. All groups were parent-run (there were no professional facilitators or leaders), with meetings lasting for about 2 hr. Three of the groups met in local community halls and three in members' homes. Information about each group is presented in Table I. Of note is that four groups consisted only of mothers.

The 56 participants consisted of 52 women and four men. Ages ranged from 27 to 58 years, with a mean of 39 years. Forty-three participants (77%)

**Table I.** Characteristics of the Groups

Group	Participants	Target population	Stated aim	Age of group	Frequency of meetings
1	11 mothers	All special needs	Informal support, organising activities	21 years	Biweekly
2	6 mothers, 1 father	Dyspraxia	Information, outside speakers	18 months	Bimonthly
3	4 mothers, 3 fathers	All special needs	Organising activities	10 years	Monthly
4	13 mothers	All special needs	Toddler group (for parents, children, and siblings)	2 years	Weekly
5	11 mothers	Autistic spectrum disorders	Informal support, occasional speakers	5 years	Biweekly
6	7 mothers	Autism	Informal support	5 years	Monthly

described their ethnicity as British or White; six (10%) as African, Caribbean, or Afro-Caribbean; two (4%) as Irish; and one (2%) as American, with information for the remaining four (7%) missing. Forty-three people (77%) described their religion as Christian, eight (14%) as having no religion, and one (2%) as Buddhist, with information for the remaining four (7%) missing. Sixteen participants (29%) described their occupation as housewife, carer, or mother; 15 (27%) were in professional occupations or had partners who were; 9 participants (16%) or their partners were in skilled occupations; 5 participants (9%) or their partners were self-employed; 3 (5%) were students; and 3 participants (5%) or their partners were in unskilled occupations, with information for the remaining 5 (9%) missing.

The mean length of time for which participants had been members of their groups was 3.9 years ( $SD = 4.4$  years, range 0–21 years). Participants had between one and eight children, with a mean of 2.5 and a mode of two children. The mean age of children with special needs was 9 years ( $SD = 5.5$  years, range 1–26 years). Sixteen parents (29%) had children with a specific learning difficulty, dyspraxia, attention deficit disorder, or speech delay; 15 (27%) had children with a severe or profound mental or physical disability or both; 14 (25%) had children with autism or disorders on the autistic continuum; and 6 (11%) had children with moderate learning disabilities, with information for the remaining 5 (9%) missing.

### Procedure

The first author telephoned the named parent co-ordinator of each group and arranged one visit to each group. At this visit the purpose and method of the study were explained; all parents present then completed questionnaires about their experiences (for full details, see Solomon, 1997), before taking part in a focus group discussion exploring their experiences of belonging to their mutual support group. At the end of the visit, each group was told that they would receive a summary report of the findings, which they could use for their own purposes, for example, to support local funding bids. No further visits to the group were made.

### Measures

*Overall helpfulness* was measured by a single-item measure adapted from Elliott and Wexler's Session Impacts Scale (Elliott & Wexler, 1994). It asked "Please rate how helpful or unhelpful to you the group is overall." The response scale ranged from 1 (*extremely unhelpful*) to 9 (*extremely helpful*), with a neutral midpoint (*neither helpful nor unhelpful*). This measure has

been found to be highly correlated with other, more complex, indices of helpfulness (Stiles *et al.*, 1994).

*Satisfaction* was assessed using four of the eight items of the Client Satisfaction Questionnaire (CSQ-8; Larsen, Attkisson, Hargreaves, & Nguyen, 1979). This was originally designed for clients of health services, and was adapted for the present study. A sample item is "To what extent does the group meet your needs?" with responses on a four-point scale (1 = *none of my needs are met*, 4 = *almost all of my needs are met*). The four items were aggregated into one scale (coefficient  $\alpha = .76$ ).

*Group climate* was assessed using four subscales of the Group Environment Scale (GES; Moos, 1986): cohesion, expressiveness, task orientation, and self-discovery. The selection of these subscales (made necessary by time constraints) was based on conceptual grounds and relevancy to the study population. Cohesion, expressiveness, and self-discovery seemed to be the central dimensions that correspond to conceptual accounts of "curative factors" in mutual support and psychotherapy groups (e.g., Yalom, 1975). Additionally, task orientation seemed particularly relevant because it was anticipated that the parent groups would vary in the extent to which they endorsed this aim. The remaining subscales were eliminated because they were either inappropriate (e.g., those pertaining to leader characteristics) or seemed less relevant (e.g., anger and aggression) to this setting and the aims of the study. All items on the GES are answered as "true" or "false," yielding a range of scores from 0 to 9 on each subscale. Moos (1986) reported alpha coefficients for these scales ranging from .70 to .86. However, in the present study the alpha coefficients were considerably lower, ranging from .43 to .66, because of the highly uneven item distributions (the vast majority of items were rated 1 rather than 0).

*Group impact.* This questionnaire included four open-ended questions: "What difference has being a member of the group made to you?" "Have you changed in any way since you started being a part of this group? If so, how?" "How would things be different for you if there were no group?" "If you were recommending this group to someone else in a similar position, what benefits would you describe to them?" The data from these questions are not presented in the present paper because they largely duplicated the results from the focus group discussions.

*Focus group discussions* were held after participants had completed the questionnaires, so that questionnaire responses would be less influenced by the group, and so that people's thinking would be stimulated by the questionnaire. Focus groups have been recommended for mutual help research as a way of understanding participants' perspectives (e.g., Humphreys & Rappaport, 1994; Morgan, 1988; Rappaport, 1993). The discussions were semistructured and used a number of prompts, for example,

“What difference has attending the group made to you?” “How does the group help you?” “What would things be like if there were no group?” “Has belonging to the group made you any different?” “Has belonging to the group made any difference for your children?” “Is there anything about the group which you would like to be different?”<sup>3</sup> One of the groups did not have a focus group discussion, as it was a group where children were present, making a discussion impossible. The five focus groups comprised 43 participants. All group discussions were audiotaped and transcribed.

Qualitative data from the focus group discussions were analysed using the grounded theory approach to qualitative data analysis (Henwood & Pidgeon, 1992; Pidgeon & Henwood, 1996; Rennie *et al.*, 1988; Strauss & Corbin, 1990). The purpose of grounded theory is to develop frameworks for understanding participants’ symbolic worlds and social realities. It is particularly suited to the study of local interactions and meanings as related to the social context in which they occur. The data analysis began with the method of constant comparison, in which meaning units—participants’ phrases or sentences expressing a single coherent meaning—were compared and assigned to categories. The process of open coding created first-order categories to which all meaning units were assigned, until all categories were saturated and no more needed to be created. These were then clustered into second-order categories, often labelled with participants’ own words. The relationships between these second-order categories were then examined according to the process of axial coding, to create a hierarchical structure in which central categories subsume lower-order categories. This process continued until a single, core category emerged, which was most densely related to the other categories. This is typically an abstract category but it is not vague (Rennie *et al.*, 1988; Strauss & Corbin, 1990). The first author (MS) conducted the analysis, which was then audited by the second author (NP), as recommended by Elliott, Fischer, and Rennie (1999). The results of the analysis were also sent to all participating groups and discussed with Contact a Family, as a form of respondent or “testimonial” validity (Pidgeon, 1996; Stiles, 1993).

## RESULTS

### Helpfulness and Satisfaction

The mean helpfulness rating was 8.1 ( $SD = 1.2$ ), indicating that parents found their groups very helpful. The mean satisfaction rating was 3.6

<sup>3</sup>The focus group discussion and the group impact questionnaire also included questions about any unhelpful aspects of the group. The findings are not reported in the present paper because the data (from both sources) were sparse and because the focus here is on perceived benefits.

**Table II.** Overall Group Environment Scale Scores

	Present study		Toro <i>et al.</i> (1987) <sup>a</sup>	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Cohesion	8.3	1.0	7.6	1.0
Expressiveness	6.6	1.7	5.1	1.0
Task orientation	7.8	1.3	7.5	1.0
Self-discovery	6.2	1.7	6.1	0.7

<sup>a</sup>These data are based on 170 members from 33 groups.

(*SD* = 0.4), indicating that parents were very satisfied with their groups. The helpfulness and satisfaction ratings were strongly correlated ( $r = .76$ ,  $p < .001$ ).

### Group Climate

The overall mean scores on the four GES subscales are given in Table II, together with comparable data from Toro *et al.*'s study (Toro *et al.*, 1987) of mutual support groups in the United States. The ratings from the two studies are very similar. As in Toro *et al.*'s study, groups in the present study were rated relatively higher on cohesion and task orientation, compared to expressiveness and self-discovery.

### Relationships of Group Characteristics With Helpfulness and Satisfaction

The associations between the four GES subscales and reported satisfaction and helpfulness are shown in Table III. Those who perceived their groups to be more cohesive tended to feel more satisfied. Those who reported that their group provided more opportunities for self-discovery also tended to feel more satisfied, and tended to rate their group as more helpful.

In summary, parents were very satisfied with their groups, found them very helpful, and rated them particularly highly on cohesion and task

**Table III.** Correlations of Group Environment Scale Scores With Satisfaction and Helpfulness

	Satisfaction	Helpfulness
Cohesion	.51**	.25
Expressiveness	.23	.21
Task orientation	-.09	-.03
Self-discovery	.36*	.43**

\* $p < .01$ .

\*\* $p < .001$ .

orientation. Groups characterised by cohesion and self-discovery were more likely to be experienced positively.

### Focus Group Discussion Data

In the first stage of open coding 131 distinct categories or “meaning units” were identified in the transcripts of the five focus group discussions. These data were then used to generate second-level categories through the method of constant comparison, where the meanings of all items contained within each category could readily be seen as similar. A total of 12 second-level categories were identified. These were grouped into three higher-order categories through axial coding, from which a single core category emerged.

The results to be presented now are structured around the three higher-order categories: parents’ increased sense of control or agency in the world, parents’ increased sense of belonging and being a part of a community, and parents’ experience of self change. Within each section, the central second-level categories are underlined. Participants’ own words appear in italics or within quotation marks.

#### *Control/Agency in the World*

*When you have a normal child you know what the best is—the best school etc. When you have a child with special needs, you don’t know—the best services, the best care etc. You get that information from the group.*

*Previously, I’d been fighting on my own for a number of things already. But after joining the group, I felt much stronger about the things I was fighting for because a number of people were fighting for the same thing. For the group to take on issues and work through them is encouraging for individuals in the individual battles.*

*If you go into the [educational statementing] process ignorant, you’ll end up with what professionals want to give you, whereas if you go in with the right level of knowledge because you’ve talked to parents who’ve been through it already, then hopefully you’ll come out with what’s best for you and your child. You learn that through other people’s mistakes.*

One consequence of having a disabled child is uncertainty. Parents universally reported that groups provided them with *information* about the primary problem and possible sources of help, which helped to reduce their uncertainty and sense of “not knowing.” Information was considered especially important when parents first joined the groups, as a way of learning more about their child’s disability and about sources of help. “Knowledge is power” was one member’s view, echoed by many others who reported

how their groups had helped them to learn a new language and terminology that was essential when communicating with professionals. Participants reported that groups had a “stock of knowledge,” based on information from individual group members (which was considered trustworthy and reliable), group resources (e.g., lending libraries and newsletters), and visiting professional speakers.

Parents also highly valued the *advice* they received from group members, based on personal experience. “It’s helpful to share ideas, strategies and ways of considering problems from personal experience.”

Parents’ restored sense of predictability and control resulting from the information and advice they received in their groups was especially important for some with regard to *relationships with professionals*, namely taking up issues with professionals in a way that was collective and political rather than simply leaving it up to individuals alone. Parents commonly talked about “fighting battles” with professionals, in which information was “ammunition.” They felt stronger knowing that others were having similar “battles” and some successes, and also because of the local political force of some groups. Some parents described their groups as a “pressure group” with representation on local committees, and as “a political power with a political reputation.” Through group membership, parents’ previously individual “battles” became part of a wider political “campaign.” Groups were felt to have real political power by many parents, for whom “the group is more than a collection of individuals.”

Some parents also mentioned the satisfaction they gained from *helping others*. The typical experience of these parents was one of receiving help initially, and at some point subsequently being able to offer help to others. “Initially you get the help, then once you’re into it you can start to help others, and you start giving back to others.” Involvement in the more political activities of some groups was another way of helping others. This highlighted the dynamic, shifting story over time of parents’ experiences of mutual support.

### *Community/Belonging*

*I’d felt I was alone. It helped so much to know there’s other people in the same situation as me.*

*It’s easy for mothers to feel guilty. Then at groups of people in your area who’ve got the same problem, you realise it’s nothing you’ve done personally, it’s just one of those things.*

*It’s like a grief when you’ve got an autistic child. I think it’s worse than grieving a death, I honestly do. You grieve all that child’s life, as you see that child struggle, but you try telling that to your neighbour. You couldn’t tell that to anyone else because they wouldn’t understand. We know we don’t have to*

*explain that to each other because we all know we're going through exactly the same grief. If you lose a child, everyone understands your grieving, but if you've got a handicapped child you're treated as a second class citizen, the whole family are. But there's nobody you can turn to. You're lucky if someone in your family understands you, but they never understand like these people here.*

Having a disabled child often leads to parents feeling alone, isolated, guilty, and stigmatized. Mutual support groups offered parents an experience of feeling valued through acceptance and *being understood* by others who were able to empathize with the problems which they themselves were facing. "It's knowing that you are comprehended that is one of the most important things."

Some parents said that their group was the only place in which they felt understood, sometimes more so than with their own parents and families: "Other people outside the group wouldn't understand. You can't talk to other people because they avoid you, walk away from you and turn their backs." It was a relief for some parents to be somewhere where there was no need to explain oneself or to make excuses, or to feel "on show."

Parents universally felt that they benefitted from the opportunity that groups provided of *sharing their experience*, by finding out that there were other people who had experienced and were experiencing the similar range of problems and difficulties related to having a child with disabilities. Parents reported feeling "less alone," "less isolated," "not the only one," "not different any more," as a result of group membership. Finding things in common with other members was very helpful in providing relief from the previous experience of loneliness, isolation, and stigma, as well as guilt. There was often a change in parents' attributions once their previously individual experience became part of a shared experience.

Group membership frequently resulted in enhanced social networks and new *friendships* for parents and their children. Parents in some groups talked about the importance of the social life and social activities they enjoyed together. In some groups mothers were friends with each other, and activities and events organised by the group provided new opportunities and a peer group for children and their siblings, as well as for parents. In one group this was contrasted with people's experiences of other mother and toddler groups where disabled children and their families felt stigmatized.

Parents commonly reported that their groups offered them a place to belong and a feeling of *belonging*, which was rare for these parents of disabled children. "It's the only place where I feel I belong"; "You feel like you're part of the human race again." However, even this was tinged with the difficulty of acknowledging a feeling of belonging to the "world of disability." As one parent put it, "it's like being in a club which no-one wanted to join."

Groups also offered parents a place of trust and safety for *sharing emotions*, and provided an important opportunity for “letting off steam.” “I’ve vented my anger here, shown my tears, and if I hadn’t have let them out here I would probably have killed the children.” Parents openly talked about sharing their pain in their groups. In one discussion some people cried as they described their feelings of anger and grief at having a disabled child. However, parents also stressed that their groups were a place to laugh, particularly when sharing embarrassing moments. Some also described sharing their pride with others in the achievements and progress made by their disabled children.

Overall, there was a universal sense of belonging to a community of similar others that offered understanding and acceptance. The groups provided parents with a setting in which they felt relaxed and “normal,” as opposed to feeling isolated from society and stigmatized. Being part of a mutual support group turned parents’ previously individual experience into a shared, social experience, and so changed the nature and meaning of parents’ experience and parents’ identities.

### *Self Change*

Throughout all of the group discussions, parents used words and phrases to describe how they had experienced themselves change personally through belonging to their mutual support group. Although it seems clear that such changes tended to occur as a result of the benefits described in the previous two sections, it was important to create and maintain a separate category of self change to include parents’ reports of *personal, intrapsychic change*, especially with respect to how parents felt about themselves and their relationships with their children when away from their groups.

Parents most commonly said that they felt “far more confident” when dealing with other people than they used to before coming to their group: they were more assertive, “tougher,” and felt less intimidated, inhibited, embarrassed, awkward, and shy. The group helped them to feel “refocused” and “strengthened.” Parents also described changes that were more internal: they felt less depressed, less frustrated, less tense, and more relaxed as a result of belonging to their group. They also felt less of a “burden,” feeling less guilty and not blaming themselves for their child’s disability. Some felt more accepting of themselves.

Many parents also reported changes in their *relationships with their disabled child* or how they viewed their child. They said that they were more accepting of their child’s disability since attending group meetings. One person said that her child’s behaviour was “normal” in the context of the group. A parent from another group admitted that she compared her

child with those of others in the group, and that she felt grateful that her child was not as disabled as some others. “There’s always someone worse off than you.” Some participants said that their “parenting approach” had changed as a result of belonging to the group, that their children were “more stimulated,” and that their children’s behaviour had improved.

### Integration of Themes

These three categories encapsulate the benefits of mutual support group membership in relation to three broad domains: sociopolitical, interpersonal, and intraindividual. Through continuing the process of axial coding, a single, core category or central theme of *identity change* emerged. In relation to the first domain, identity change occurred in terms of empowerment with respect to the external world, along dimensions such as control, agency, and active citizenship. For example, parents changed from feeling ignorant to becoming knowledgeable, from feeling a victim to regaining some control and agency, from being a receiver to being able to give to others, or at least being more able to negotiate with those providing help. In the second domain, identity change occurred in terms of parents’ social identity, comparison, or peer group. For example, parents changed from feeling alone to receiving recognition, from feeling isolated and stigmatized to being part of a valued group. In the third domain, identity change occurred in terms of parents’ sense of self, including self-esteem, as well as parents’ attitudes toward and relationships with their children. For example, parents changed from feeling weak to strong, from feeling depressed to being more assertive and confident.

## DISCUSSION

This study aimed to discover what parents of children with disabilities and special needs find helpful about belonging to mutual support groups. Quantitative data indicated that parents who were members of such groups did, indeed, find them very helpful and were very satisfied with the support they received from their groups. They also described the groups as high in cohesion, expressiveness, task orientation, and self-discovery (although these group climate scales had somewhat low reliability). Qualitative data indicated that the groups were helpful in three broad areas—the sociopolitical, the interpersonal, and the intraindividual—which led to an overarching experience of identity change for parents.

First, parents in the groups experienced changes in relationships with the outside world, gaining a sense of control and agency. These changes derived in part from the “experiential knowledge” (Borkman, 1990) shared

by people who had gone through similar experiences. The groups seemed to provide parents with a range of coping resources identified in the disability literature (e.g., Beresford, 1994): access to information, increased self-efficacy and a more internal locus of control, learning and subsequent cognitive change, hope, and positive thinking. A feeling of empowerment also seemed to be the consequence of a change in role for parents. The birth of a disabled child often puts parents into the position of recipient, receiving diagnoses, assessments, treatments, and a variety of health, education, and social services (Beresford, 1994; Brown & Hepple, 1989). In contrast, members of the groups became active participants instead of just recipients. Collective social and political action was also one important cause, and consequence, of the sense of control and agency for many parents.

Second, parents experienced changes in the interpersonal domain: belonging to a community, being understood and accepted, and having friendships and social networks where they could share emotions and feel more "normal." Parents' accounts echoed the importance of "therapeutic" factors (e.g., catharsis, empathy, acceptance, universality, a psychological sense of community) that have long been recognized in the individual and group psychotherapy literature, as well as in the mutual support literature (e.g., Levine, 1988; Rappaport, 1993; Rogers, 1957; Yalom, 1975). For these parents, most of whom had experienced isolation, stigmatization, or social marginalization as a consequence of having a disabled child (Byrne *et al.*, 1988; Pahl & Quine, 1987), the groups provided a unique experience of recognition, belonging, and feeling valued.

Third, parents experienced changes in the intraindividual domain: feelings of increased self-esteem and confidence, less guilt and self-blame, and greater acceptance of their child's disability. The groups seemed to enable these parents to define themselves more positively and to ascribe more positive meanings to having a disabled child. Furthermore, some parents indicated that their parenting skills had improved; ultimately this may have the effect of reducing children's behavioural difficulties and in turn enhancing parents' sense of competence and self-efficacy (Quine & Pahl, 1989). These changes in parents' relationships with their children point to the potential of "one-step removed" groups to have double benefits, helping both the members themselves (in this case, the parents) as well as the person with the primary "problem" (in this case, the children; Gottlieb, 1982).

The benefits in these three domains all seemed to contribute to an experience of identity change for these parents. One of the mutual support processes identified by Levy (1979) is the emergence of an alternative culture within which members can develop new definitions of their personal identities and new norms upon which they can base their self-esteem. Rappaport (1993) also argues that mutual help organizations can be

understood as

normative narrative communities where identity transformation takes place (p. 239).  
... People who elect to join mutual help organizations are not necessarily deciding to obtain a treatment so much as making a decision that helps them to answer identity questions of the form "Who am I?" (p. 247).

Interestingly, in the present study parents who rated their group as higher on self-discovery were more satisfied and found the groups more helpful, suggesting that the opportunity to explore and develop one's sense of self was a key component of positive group experience.

In Western industrialized society the prevailing discourse of disability often includes notions of victimhood, powerlessness, isolation, and being the recipient of help (often of medically dominated services). Mutual support groups provide individuals with a different discourse out of which identity can be constructed (Shotter & Gergen, 1989). Such groups offer an alternative vision, ideology, and way of thinking about what it means to have a disabled child. For these parents, the groups provided an alternative discourse, which included agency, control, and empowerment, as well as actively sharing in communities rather than passively suffering as isolated individuals.

This study highlights the value of a communal ideology for people who are otherwise simply individual recipients of services. Collective provision "should be based on the principles of group concern, shared care and mutual support" (Dalley, 1992, p. 108). More specifically, the mutual support groups in this study offer an example of a service model based on the concept of social identity rather than integration. Social identity theory predicts that if one is unable to leave a devalued social group, then one consequence is to engage in social action to improve the group's status, and to enhance one's social identity (Tajfel, 1981). This points to the role of mutual support groups in creating change socially as well as individually (Humphreys & Rappaport, 1994), through separateness and reevaluating groups' hitherto negatively perceived characteristics. This is an alternative to the mainstream vision of normalization (e.g., Wolfensberger, 1980, 1983), which incorporates the principle of integration. This study suggests that it is possible for the goals of normalization to be achieved through policies that provide separate opportunities for developing social identities, as offered by mutual support groups.

What are the implications for professionals working in child development settings with children with disabilities and special needs? As advocated by much of the child disability literature (e.g., Cunningham & Davis, 1985; Dale, 1996; Russell, 1997), it is crucial that professionals work in partnership with parents; one aspect of this is for professionals to recognise the benefits of mutual support groups, for both parents and children, and to work cooperatively with such groups. Given the importance of empowerment suggested by this study and others, professionals must take care not to interfere with or

reduce the control and autonomy of group members. Indirect participation in the form of consultation, referral agent, or initiator would seem more appropriate than direct participation in the form of group leader or facilitator (Gottlieb, 1982). A more radical view would see professionals not just as consultants, but as students, learning from parents' groups about alternative models of help, support, and coping, and learning about the deficiencies in services that are highlighted by mutual support groups (Borkman, 1990).

The findings of this study should be considered in the context of some methodological limitations. First, the sample consisted almost entirely of mothers. It is possible that the strongly female character of the groups influenced the way in which the groups functioned and their effects. The stated aims of the two groups that included men appeared to be more task-oriented (e.g., providing information and organizing activities) compared to the all-female groups, which seemed to emphasize informal support. However, statistical analyses showed no differences between all-female groups and mixed gender groups on any of the social climate dimensions or on perceived helpfulness or satisfaction. Clearly, further research comparing single-sex and mixed groups is needed to address the possible influence of gender on group environments, processes, and outcomes. It should be noted, however, that the predominance of mothers in the groups in this study probably represents the typical membership of such groups. Other studies of support groups have also shown a similar pattern (Heller *et al.*, 1997; Taylor, Falke, Shoptaw, & Lichtman, 1986). It remains a difficult challenge for organizations promoting mutual support groups to work toward a more balanced membership.

A second limitation concerns sampling bias: only half the groups initially contacted agreed to take part in the study. Because no information was available on nonparticipating groups, we can only speculate on possible biases in the sample. It is likely that groups that declined to participate were less satisfied or less well-functioning, and therefore may have perceived the study as more threatening. They may also have been less committed to the central national organization, and therefore may have been less motivated to participate in the study. The high ratings of helpfulness, satisfaction, and social climate obtained in the present study also suggest that the sample was probably biased toward better functioning groups, although it was similar, in terms of social climate, to other groups in the published literature. The problem of sampling bias has been widely acknowledged in mutual support group research (e.g., Goldklang, 1991; Levy, 1979); people who are less positive about belonging to such groups are likely to "vote with their feet" and "cancel their membership."

A third, related issue is that of social desirability and the tendency for people receiving help to describe themselves as satisfied. Although participants did express some reservations about the groups (Solomon, 1997),

they may have felt some pressure in the focus group setting to produce positive views. However, there were no noticeable differences between the accounts given in the group discussions and those given on the individual questionnaires. The highly positive evaluations of the groups are consistent with consumer satisfaction ratings of health and mental health services: satisfaction is usually high and varies relatively little between services (Larsen *et al.*, 1979; Lebow, 1984).

Future studies might explore two fundamental issues that were not addressed directly in the present study. First is the issue of heterogeneity: mutual support groups have a diverse membership, embrace a range of aims, and vary in their organizational structure (Jacobs & Goodman, 1989). Even groups belonging to the same national umbrella organization may show this diversity (as was noted in the present study) and may have distinctive "local cultures" (Gubrium, 1989) that frame members' experiences. Future studies, using larger samples, are needed to explore how such variations between groups may affect group process and outcome. The issue of heterogeneity must also be addressed at a broader level: to what extent are the processes and outcomes of support groups for one population (or problem) similar to those for other populations? That is, how much do the findings of this study generalize to the larger world of mutual support groups? Some of the benefits mentioned by parents seem specific to the nature of their situation (e.g., improved relationships with their disabled child), whereas many seem more universal and accord with the existing literature (e.g., the sense of being understood and of belonging). A larger mass of empirical research into mutual support groups is needed before we can begin to understand both the unique and the universal benefits of groups for different populations.

A second area for future research concerns the changing nature of mutual support over time. In the present study, some parents' accounts indicated that their needs for support, and consequently the benefits they derived from the group, had changed over time. For example, gaining information seemed particularly important when first joining the group, whereas helping others was a benefit that was experienced later on. However, because the present study was carried out at one point in time, it was not sensitive to the changing nature of members' experiences. Longitudinal research is needed to elucidate the processes of change (e.g., how changes in identity develop) as well as how groups' "community narratives" (Rappaport, 1993) or "local cultures" (Gubrium, 1989) evolve and mediate the impact on individual members.

This study used a grounded theory approach, alongside more traditional quantitative methods, to describe and specify the helpful aspects of mutual support groups. The study was designed in the spirit of methodological pluralism (Barker, Pistrang, & Elliott, 1994). The quantitative data were useful in setting the groups in context, especially given that not many studies

have been conducted outside North America. The qualitative data provided a rich basis for description and theory-generation (Henwood & Pidgeon, 1992; Rennie *et al.*, 1988). The findings suggest that the benefits of mutual support groups for parents of children with disabilities can be conceptualized in a hierarchical taxonomy according to different aspects of identity, and consequently identity change. Rather than simply providing a list of benefits, the study has attempted to move toward a more sophisticated conceptualization of what people find helpful about mutual support groups. However, in Pidgeon and Henwood's terms (Pidgeon & Henwood, 1996), this is a first "cycle of interpretation," which clearly needs to be followed up by future studies.

## REFERENCES

- Barker, C., Pistrang, N., & Elliott, R. E. (1994). *Research methods in clinical and counselling psychology*. Chichester: Wiley.
- Barrera, M., & Ainlay, S. (1983). The structure of social support—a conceptual and empirical analysis. *Journal of Community Psychology, 11*, 133–143.
- Beresford, B. (1994). Resources and strategies: How parents cope with the care of a disabled child. *Journal of Child Psychology and Psychiatry, 35*, 171–209.
- Borkman, T. J. (1990). Experiential, professional, and lay frames of reference. In T. J. Powell (Ed.), *Working with self-help* (pp. 3–30). Silver Spring, MD: NASW Press.
- Brown, A., & Hepple, S. (1989). *How parents cope: Caring for a child who has a handicap*. London: Barnardos.
- Byrne, E., Cunningham, C., & Sloper, P. (1988). *Families and their children with Down's Syndrome: One feature in common*. London: Routledge.
- Cunningham, C., & Davis, H. (1985). *Working with parents: Frameworks for collaboration*. Milton Keynes: Open University Press.
- Dale, N. (1996). *Working with families of children with special needs: Partnership and practice*. London: Routledge.
- Dalley, G. (1992). Social welfare ideologies and normalisation: Links and conflicts. In H. Brown & H. Smith (Eds.), *Normalisation: A reader for the nineties* (pp. 100–111). London: Routledge.
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38*, 215–229.
- Elliott, R., & Wexler, M. M. (1994). Measuring the impact of sessions in process-experiential therapy of depression: The Session Impacts Scale. *Journal of Counseling Psychology, 41*, 166–174.
- Glendinning, C. (1983). *Unshared care: Parents and their disabled children*. London: Routledge and Kegan Paul.
- Goldklang, D. (1991). Research workshop on methodological issues in evaluating preventive interventions using mutual support. *American Journal of Community Psychology, 19*, 789–795.
- Gottlieb, B. H. (1982). Mutual-help groups: Members' views of their benefits and of roles for professionals. *Prevention in Human Services. Helping People to Help Themselves: Self-Help and Prevention, 1*, 55–67.
- Gubrium, J. F. (1989). Local cultures and service policy. In J. F. Gubrium & D. Silverman (Eds.), *The politics of field research: Sociology beyond enlightenment* (pp. 94–112). Newbury Park, CA: Sage.

- Heller, T., Roccoforte, J. A., Hsieh, K., Cook, J. A., & Pickett, S. A. (1997). Benefits of support groups for families of adults with severe mental illness. *American Journal of Orthopsychiatry*, 67, 187–198.
- Henwood, K., & Pidgeon, N. (1992). Qualitative research and psychological theorising. *British Journal of Psychology*, 83, 97–111.
- Hollins, S. (1985). Families and handicap. In M. Craft, J. Bicknell, & S. Hollins (Eds.), *Mental handicap: A multi-disciplinary approach*. London: Balliere Tindall.
- Humphreys, K., & Rappaport, J. (1994). Researching self-help/mutual aid groups and organizations: Many roads, one journey. *Applied and Preventive Psychology*, 3, 217–231.
- Jacobs, M. K., & Goodman, G. (1989). Psychology and self-help groups: Predictions on a partnership. *American Psychologist*, 44, 536–545.
- Larsen, D. L., Attkisson, C. C., Hargreaves, W. A., & Nguyen, T. D. (1979). Assessment of client/patient satisfaction: Development of a general scale. *Evaluation and Program Planning*, 2, 197–207.
- Lebow, J. (1984). Research assessing consumer satisfaction with mental health treatment: A review of findings. *Evaluation and Program Planning*, 6, 211–236.
- Levine, M. (1988). An analysis of mutual assistance. *American Journal of Community Psychology*, 16, 167–187.
- Levy, L. (1979). Processes and activities in groups. In M. Lieberman & L. Borman (Eds.), *Self-help groups for coping with crisis: Origins, members, processes and impact* (pp. 234–271). San Francisco: Jossey-Bass.
- Lieberman, M. (1979). Analyzing change mechanisms in groups. In M. Lieberman & L. Borman (Eds.), *Self-help groups for coping with crisis: Origins, members, processes and impact* (pp. 194–233). San Francisco: Jossey-Bass.
- Linder, R. (1970). Mothers of disabled children: The value of weekly group meetings. *Developmental Medicine and Child Neurology*, 12, 202–206.
- Maton, K. I. (1988). Social support, organizational characteristics, psychological well-being, and group appraisal in three self-help group populations. *American Journal of Community Psychology*, 16, 53–77.
- Maton, K. I. (1993). Moving beyond the individual level of analysis in mutual help group research: An ecological paradigm. *The Journal of Applied Behavioral Science*, 29, 272–285.
- Moos, R. H. (1986). *Group Environment Scale Manual* (2nd ed.). Palo Alto, CA: Consulting Psychologists Press.
- Moos, R. H. (1996). Understanding environments: The key to improving social processes and program outcomes. *American Journal of Community Psychology*, 24, 193–201.
- Morgan, D. (1988). *Focus groups as qualitative research*. London: Sage.
- Orford, J. (1992). *Community psychology: Theory and practice*. Chichester: Wiley.
- Pahl, J., & Quine, L. (1987). Families with mentally handicapped children. In J. Orford (Ed), *Coping with disorder in the family* (pp. 39–61). London: Croom Helm.
- Parker, G. (1985). *With due care and attention: A review of research on informal care*. London: Family Policy Studies Centre.
- Pidgeon, N. (1996). Grounded theory: Theoretical background. In J. Richardson (Ed.), *Handbook of qualitative research methods for psychology and the social sciences* (pp. 75–85). Leicester: BPS Books (The British Psychological Society).
- Pidgeon, N., & Henwood, K. (1996). Grounded theory: Practical implementation. In J. Richardson (Ed.), *Handbook of qualitative research methods for psychology and the social sciences* (pp. 86–101). Leicester: BPS Books (The British Psychological Society).
- Quine, L., & Pahl, J. (1989). *Stress and coping in families caring for a child with severe mental handicap: A longitudinal survey*. University of Kent at Canterbury: Institute of Social and Applied Psychology and Centre for Health Service Studies.
- Quine, L., & Pahl, J. (1991). Stress and coping in mothers caring for a child with severe learning difficulties: A test of Lazarus' transaction model of coping. *Journal of Community and Applied Social Psychology*, 1, 57–70.
- Rappaport, J. (1993). Narrative studies, personal stories, and identity transformation in the mutual help context. *The Journal of Applied Behavioural Science*, 29, 239–256.

- Rennie, D. L., Phillips, J. R., & Quartaro, G. K. (1988). Grounded theory: A promising approach to conceptualization in psychology? *Canadian Psychology, 29*, 139–150.
- Rogers, C. R. (1957). The necessary and sufficient conditions of therapeutic personality change. *Journal of Consulting Psychology, 21*, 95–103.
- Russell, P. (1997, Spring). Working in partnership with parents of children with disabilities. *Children UK (Quarterly Newsletter of National Children's Bureau)*, 14.
- Shotter, J., & Gergen, K. (1989). *Texts of identity*. London: Sage.
- Singhi, P., Goyal, L., Pershad, D., Singhi, S., & Walia, B. (1990). Psychosocial problems in families of disabled children. *British Journal of Medical Psychology, 63*, 173–182.
- Solomon, M. (1997). *What do parents of children with disabilities and special needs find helpful about mutual support groups?* Unpublished doctoral dissertation, University College London, London, England.
- Stiles, W. B. (1993). Quality control in qualitative research. *Clinical Psychology Review, 13*, 593–618.
- Stiles, W. B., Reynolds, S., Hardy, G. E., Rees, A., Barkham, M., & Shapiro, D. A. (1994). Evaluation and description of psychotherapy sessions by clients using the session evaluation questionnaire and the session impacts scale. *Journal of Counseling Psychology, 41*, 175–185.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.
- Tajfel, H. (1981). *Human groups and social categories: Studies in social psychology*. Cambridge: Cambridge University Press.
- Taylor, S. E., Falke, R. L., Shoptaw, S. J., & Lichtman, R. R. (1986). Social support, support groups, and the cancer patient. *Journal of Consulting and Clinical Psychology, 54*, 608–615.
- Toro, P. A., Rappaport, J., & Seidman, E. (1987). Social climate comparison of mutual help and psychotherapy groups. *Journal of Consulting and Clinical Psychology, 55*, 430, 431.
- Videka-Sherman, L. (1982). The effects of participation in a self-help group for bereaved parents. *Prevention in Human Services. Helping People to Help Themselves: Self-Help and Prevention, 1*, 69–77.
- Videka-Sherman, L., & Lieberman, M. (1985). The effects of self-help and psychotherapy intervention on child loss: The limits of recovery. *American Journal of Orthopsychiatry, 55*, 70–82.
- Wolfensberger, W. (1980). The definition of normalization: update, problems, disagreements and misunderstandings. In R. Flynn & K. Nitsch (Eds.), *Normalization, social integration and community services*. Baltimore: University Park Press.
- Wolfensberger, W. (1983). Social role valorization: A proposed new term for the principal of normalization. *Mental Retardation, 21*, 234–239.
- Woods, G. (1981). Profiles: Parents help themselves. *Child: Care, Health and Development, 7*, 51–56.
- Yalom, I. (1975). *The theory and practice of group psychotherapy*. New York: Basic Books.