What do parents of children with disabilities and special needs

find helpful about mutual support groups?

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ABSTRACT

This study aimed to enhance understanding of mutual support groups run by and for parents of children with disabilities and special needs, by finding out how helpful members found their groups, the characteristics of their groups, and the nature of any relationships between the two, and by discovering in detail what parents of disabled children found helpful about mutual support groups. A sample of six groups affiliated to Contact a Family, a national charity, participated, and each group was visited once. Questionnaires were completed by 56 individuals, and five focus group discussions were conducted. Quantitative and qualitative data were collected and analysed.

Participants found their groups extremely helpful, reporting high levels of satisfaction. All groups were very cohesive, while groups varied more in other characteristics. Apparently different groups had different aims and served different functions. Satisfaction levels were related to the amount of emotional support received from others, as well as levels of cohesion and self-discovery within groups. A range of helpful processes and benefits from mutual support group membership were reported, classified in terms of three domains of identity change, namely empowerment in the socio-political domain, belonging to a community at the inter-personal level, and personal identity change at the intra-individual level. Some unhelpful aspects of the structure of mutual support groups and the content of meetings were also reported. The findings are discussed in the light of general psychological frameworks, and the implications are considered for participants, researchers, clinicians and other professionals.

ACKNOWLEDGEMENTS

1.1 OVERVIEW OF THE TOPIC AND CHAPTER ONE: INTRODUCTION

This study aimed to investigate what parents of children with disabilities and special needs find helpful about mutual support groups. This is an important question to ask for a number of reasons. A growing 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 it is that they find helpful will advance knowledge in the relatively new research area of mutual support, may inform professionals about how they might learn from mutual support processes, and may help mutual support organisations, groups and individual members to discover more about the activity in which they are involved.

Why study mutual support?

The anarchist theorist Kropotkin (1902/1972) described mutual assistance as the oldest form of help known to humanity, predating professional help by several millennia. Recipients of professional help are typically in the non-reciprocating 'one-down' position, such that professional help may resemble charity (Levine, 1988). In contrast, mutual aid develops spontaneously between people as equals, giving and receiving help as required. While a great deal of professional research has focused upon professional help, relatively little has sought to investigate mutual support.

In the late twentieth century, mutual support, or 'self-help', organisations and groups are rapidly growing in number in the Western developed world, especially in the USA

(Borkman, 1990; Humphreys & Rappaport, 1994; Jacobs & Goodman, 1989; Levine & Perkins, 1987), but also in the UK (Orford, 1992). Efforts to understand this phenomenon are important for their own sake, because there are valuable insights to be gained about the nature of 'social support', coping strategies, altruism, identity, group functioning and a number of other psychological constructs.

In addition, it is important to understand mutual support from the professional's perspective, including that of the clinical psychologist. The scarcity of resources in the public sector and the National Health Service in general (e.g. Butler, 1994; Harrison, Hunter & Pollitt, 1990), in mental health services (King's Fund, 1997), and in clinical psychology services in particular (e.g. Lieberman, 1986; Pilgrim & Treacher, 1992), means that there are limits to the extent of support which professionals can give to any one client. Therefore disseminating findings among professionals about the nature of mutual support is important for increasing its acceptance as an important, popular and potentially useful and cost-effective source of help for people. Professionals need to consider how best to provide indirect help to mutual help organisations in certain situations if that is appropriate, and to be aware of the existence of mutual support groups and organisations both nationally and locally so that they can make referrals where appropriate. Knowledge about the processes, benefits, strengths and weakness of mutual support might also inform professional and clinical practice, and even education.

> *It is vital that human service providers know of the existence of self-help organisations of relevance to their work, that they appreciate their philosophies and how they work, and that they know how to make use of the resources self-help provides and how to be of service to self-help organisations if and when required* (Orford, 1992, p. 223).

Why study parents of children with disabilities and special needs?

Parents of children with disabilities, particularly with learning disabilities, are commonly presented with a number of difficulties over time (Cottrell & Summers, 1990; Cunningham & Davis, 1985a, b; Pahl & Quine, 1987; Quine & Pahl, 1985). These include the initial 'news breaking', finding out about their child's condition and prognosis, and then dealing with a number of professional agencies, particularly at times of transition. Help from professionals is available through a variety of agencies, including health, education and social services. But no single profession or agency shares the whole picture (Hollins, 1985). Often the only people who can do this are other parents in similar situations. One common consequence of having a child with disabilities is social isolation, for both child and parent(s). In the context of these experiences, support from other parents has significant potential to be helpful (Brown & Hepple, 1989; Linder, 1970; Pahl & Quine, 1984; Woods, 1981). This makes it important to ask what kind of support do parents find helpful.

Outline of chapter one

This chapter reviews the literature relevant to the question of discovering what parents of disabled children find helpful about mutual support groups. The issue of conceptualising mutual support is discussed, with particular emphasis on the psychological processes and functions of mutual support which have been identified in the literature. The circumstances of parents of disabled children are then discussed, including parents' common difficulties, their ways of coping and the help offered by

professionals. Particular attention is then given to mutual support among parents of disabled children, including the one previous evaluation, as well as studies of other mutual support groups for bereaved parents. The implications of the literature review are discussed in the context of the rationale, methodological and epistemological approaches of the present study, before the chapter concludes with the aims of the present study and the research questions to be addressed.

1.2 CONCEPTUALISING MUTUAL SUPPORT

It is important at the outset to define mutual support, to outline typologies of mutual support organisations and groups, to outline the functions and processes of mutual support as described in the literature, and to link those with relevant psychological theories. However, while doing so it is important to bear in mind that the overwhelming majority of the literature is American, and is largely based on groups for adults with mental health problems.

Defining mutual support

The original definition of mutual support or self-help groups, much cited in the literature, is a broad one which applies to a rich diversity of organisations:

> *Self-help groups are voluntary, small group structures for mutual aid and the accomplishment of a special purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desired social and/or personal change. The initiators and members of*

> *such groups perceive that their needs are not, or cannot be, met by or*
> *through existing social institutions* (Katz & Bender 1976, p. 9).

This definition has been updated recently, to include the more community-oriented

notion of 'mutual help' rather than the more individualistic 'self-help'.

> *Self-help groups are voluntary associations of persons who share some status*
> *that results in difficulties with which the group tries to deal ... The term self-*
> *help group is inaccurate in some respects, because one important feature of*
> *groups is that people help each other. 'Self-help' does not capture the*
> *mutually supportive atmosphere of groups, suggesting instead an ethos of*
> *rugged individualism. The term mutual help group is thus used by many*
> *researchers because it captures the egalitarian and communal aspects of*
> *groups* (Humphreys & Rappaport, 1994, p. 218, original emphasis).

The terms 'mutual help' or 'mutual support' groups will be used throughout this

report.

Mutual help groups are controlled by members and not by professionals. Thus,

professionally led 'support groups' should not be equated with mutual support

groups. For example, one of the empowering features of mutual support groups is

that members experience autonomy, control of the group, and a sense that they are

experts on their problem. When a professional facilitates such groups, members have

less control and may begin to engage in passive 'patient behaviour' (Salem, 1990;

Toro, Reischl, Zimmerman, Rappaport, Seidman, Luke & Roberts, 1988).

Types of mutual support groups

Levine & Perkins (1987) outline five broad types of mutual support groups. One type is comprised of people whom society believes not to be 'normal' in some way, and who are hence subject to 'social isolation, stigmatisation, scorn, pity, or social punishment' (p. 240). Another type is made up of people who have experienced a loss, or whose current life circumstances give them needs which can at least partly be met through a mutual support group. e.g. groups such as Compassionate Friends for bereaved parents (Videka-Sherman, 1982). There are some similarities with groups for parents of children with disabilities.

The third type of mutual support group consists of family members or associates of people with physical, psychological or stigmatising conditions, and who themselves may suffer stigma or social isolation, stress, and uncertainty about how to cope (Borman, 1982; Levine & Perkins, 1987; Orford, 1987). Gottleib (1982) refers to such groups as 'one step removed groups'. Other types include mutual assistance groups organised along ethnic, religious or racial lines, and organisations for the preservation of specific interests, including civic and community groups.

Mutual support groups for parents of children with disabilities and special needs can be categorised as 'one step removed groups', although there are similarities with groups of people who have experienced a loss.

Psychological processes and functions of mutual support

There are a large number of potentially beneficial processes of mutual support cited in

the literature (for reviews see Levine, 1988; Lieberman, 1979; Orford, 1992). These

have been labelled by different commentators as 'process goals', 'reasons for joining

mutual support groups', or 'functions of mutual support groups'. Whatever the label,

however, it is possible to identify a number of processes through which mutual

support groups and organisations are deemed to work. These are: promoting a

psychological sense of community; emotional support; the provision of role models; a

powerful ideology; relevant information; ideas about ways of coping; the opportunity

to help others; social companionship; a sense of mastery and control. While there is

inevitable overlap between categories, it is helpful to make some distinctions between

different processes of mutual support.

Promoting a psychological sense of community

Meeting with people who share the same problem, feelings and experiences

overcomes the tendency to ostracise oneself, and transforms the uniquely personal,

previously defined as deviant and isolating, into the social (Katz & Bender, 1976).

While this can have political consequences, in the personal sphere this can be equated

with Yalom's (1975) notion of universality, namely the process of learning that one's

problems are not unique. From a cognitive perspective, this means that the social

comparison and consensual validation available in mutual support groups leads to a

reduction or elimination of members' uncertainty and sense of isolation or uniqueness regarding their problems and experiences (Levy, 1979).

Providing a psychological sense of community also helps to overcome the stigma attached to any condition which is seen by society as deviant or inferior. Mutual support groups alleviate stigmatised feelings, provide a supportive community for the sharing of a stigmatised attribute, or perceive problems differently to society (Antze, 1976; Borkman, 1984).

Kohut (1971) suggests that the key to therapeutic change may not be insight or understanding, but rather being understood. In the words of Riessman, 'Who better to understand than those who have been there?' (1990, p. 229).

Rappaport (1993) takes this idea further, arguing that mutual support groups provide normative narrative communities in which identity transformation can take place. This may happen in the context of the ideology of the mutual support group, as discussed below.

Emotional support

This has been identified by a number of commentators on mutual support (e.g. Levine, 1988; Maton, 1988; Moos, 1981, 1986; Orford, 1992) as a key feature. Descriptions of the processes involved have borrowed from the group psychotherapy literature, notably Yalom's (1975) highlighting of group cohesiveness and catharsis as curative

factors. Self-disclosure is an essential basis for this, and mutual support groups often provide the first opportunity for people to disclose their difficulties. Levine (1988) labels one of his six 'dynamics of mutual assistance' as 'the opportunity for confession, catharsis and mutual criticism'. It is acknowledged that these processes will often lead to increased cohesiveness in groups, and enhanced self-esteem of members. Observational studies of mutual help groups have included empathy, mutual affirmation and encouragement as behavioural evidence of mutual support (e.g. Paine, Suarez-Balcazar, Fawcett & Borck-Jameson, 1992).

The provision of role models

One feature of mutual support groups which is not well represented in the general literature on social support is the provision of role models. This is the impact of sharing experiences with others who have experienced and may have successfully coped with the same problems, handicaps, disadvantages or social rejection. While social comparison theory (Festinger, 1954) would suggest that people increase their well-being by making comparisons with people less fortunate than themselves to enhance their self-esteem, members of mutual support groups would also make upwards comparisons with effective coping models in the reference group, people who have experienced and overcome the same problems. This is a powerful mechanism for instilling hope and positive thinking (Ablon, 1982; Levine, 1988; Orford, 1992), the first of Yalom's (1975) curative factors of groups.

Role models also provide an important way of learning, and so may promote cognitive change and reappraisal among group members by expanding the range of alternative perceptions of their problems and circumstances and the range of actions they might take to cope with their problems (Borkman, 1976; Levy, 1979; Stewart, 1990a).

A powerful ideology

A group's ideology provides a perspective on the distressing aspects of living with the core problem and its consequences (Antze, 1976; Levine, 1988; Suler, 1984). Ideologies consist of socially shared values that may even contribute to a sense of personal identity by articulating what an individual is to believe. Antze (1976) argues that this is a key, and indeed unique and defining feature of mutual support groups, since they are fixed communities of belief in which members share experience, offer advice and thereby indoctrinate themselves, as well as increasing mutual identification. Levine (1988) goes as far as to suggest that individuals benefit from membership to the extent that they accept and identify with the organisation's ideology. Rappaport (1993) suggests that the way in which a mutual help organisation provides members with an identity is through the narrative it tells about the community of membership, about how members change, and that this narrative serves as a basis for change in one's personal identity story.

Relevant information

Informational support is greatly valued by members of mutual help groups, yet often neglected by service providers. This is one important area where mutual help organisations can fill the gaps left by service providers, according to Lieberman's (1979) 'lack of resource' hypothesis. Imparting relevant, instrumental information and practical advice are well recognised as important factors in mutual support groups (Orford, 1992). They promote cognitive reappraisal among group members by removing members' mystification over their experiences and increasing their expectancy for change and help by providing them with a rationale for their problems or distress and for the group's way of dealing with it (Levy, 1979).

The kind of specialised information of a phenomenon based on first-hand experience which is developed in mutual help groups has been called 'experiential knowledge' (Borkman, 1976). This type of 'wisdom' is concrete, specific, pragmatic, holistic, and oriented to here-and-now action. Mutual help groups develop, disseminate and validate experiential knowledge, which can be distinguished from information relayed by professionals. Learning occurs by mutual exchange of wisdom (Borkman, 1976).

Ideas about ways of coping

Mutual help groups are vehicles for coping with long term difficulties and life cycle transitions. A range of coping models is available. Levy (1979) identifies behaviourally oriented processes (e.g. social reinforcement, modelling) and nine

cognitively oriented processes (including normative and instrumental information, expanding the range of possible coping actions, supporting attitude change).

Members of mutual support groups often transmit concrete behavioural suggestions for dealing with problems. This process of support can be conceptualised in different ways. Yalom (1975) classifies this as imitative behaviour and interpersonal learning. From a cognitive perspective, this form of support can be viewed as enhancing members' awareness and discriminative abilities regarding the stimulus and event contingencies in their lives, i.e. as a functional analysis of their situation (Levy, 1979).

Practical advice on ways of coping can also alter one's perceived self-efficacy, namely one's beliefs and expectations about one's own performance (Bandura, 1977). Teaching effective coping strategies and conveying advice and information about the controllability and predictability of events and tasks increases perceived self-efficacy (Bandura, 1982), and can lead to an enhanced sense of collective efficacy within groups (Bandura, 1986).

Mutual support groups can also offer positive reinforcement for people's efforts to deal with their difficulties. Observers of behaviours in mutual help groups have operationalised this process of support in terms of supportive disclosure and suggestions to solve problems (Paine *et al.*, 1992). Maton (1988) refers to this feature of mutual help groups as 'problem appraisal support'. In addition, at the organisational level, the literature, narrative and ideology of some mutual help organisations includes suggestions and advice about ways of coping.

The opportunity to help others

The roles of helper and recipient of help are interchangeable in mutual support groups, and so members can shift from one role to another. Since Kropotkin (1902/1972), the potential benefits of being in a position to provide as well as receive help were first described in Riessman's (1965) seminal work, the 'Helper Therapy Principle'. These benefits can be: a) the helper feels good because s/he has something to give; b) it is an active role in which the helper feels less dependent; c) the helper obtains a feeling of social usefulness, sometimes accompanied by increased status; d) it is potentially empowering as it gives the helper a sense of control, a feeling of being capable of doing something; e) it encourages the helper to be open to learning so that s/he can help effectively.

Maton (1988) found that 'bi-directional supporters' (i.e. those who both gave and received support) reported more positively about the groups to which they belonged and about their own well-being. Three explanations were proposed. First, helping others produced 'additive benefits' such as increased meaning and purpose through helping others, social reinforcement of helping, increased feelings of self-worth and efficacy, and the cognitive rehearsal of coping strategies involved in advising others. Secondly, 'balance theory' (Maton, 1987), which owes a debt to Kropotkin's (1902/1972) original analysis, predicts that there would be psychological costs, perhaps in terms of feelings of inferiority or indebtedness, of non-reciprocally receiving without giving support to others. Thirdly, the 'need/resource' or selection

hypothesis states that psychological well-being is a precondition for, rather than consequence of, bi-directional supporting. While the third explanation is possible, Maton's (1988) study was the first to provide empirical support for the helper therapy principle.

While Yalom (1975) recognised the value of altruism in psychotherapy groups, mutual support groups have more scope for providing an environment in which providing help to others can occur. Within mutual help groups the helping role can be widely distributed, and giving help can make receiving it easier. The helper and helped have similar problems and the empathy and the inside understanding of the problem can potentially enable the helper to be particularly effective (Levine, 1988; Riessman, 1990).

Equity or social exchange theory states that people have a desire to maintain balance and reciprocity of exchanges in relationships (Blau 1964; Hatfield, Walster & Berscheid, 1978; Homans, 1961). However, while the active promotion of reciprocity and equity in help giving and receiving is a crucial element of mutual support groups, the processes of mutual support can be trivialised by equity theory's premise of cost-benefit analysis.

However, with the exception of the work of Riessman (1965) and Maton (1988) described above, the process of providing help as well as receiving it has been largely overlooked in the mutual support literature. It is rarely mentioned in either theoretical papers or empirical studies, and is not included as a group characteristic in Moos'

Group Environment Scale (1981, 1986), which is designed to measure the

environments of, among others, mutual support groups. The probable explanation is

that most professional commentators think of members of mutual support groups as

research 'subjects' or in terms of clinical 'patients', and so focus upon what those

people get out of being passive recipients of what is being provided. It requires a shift

in thinking to conceptualise the potential benefits from helping others (e.g.

Humphreys & Rappaport, 1994). Doing so would challenge the conventional

boundaries between 'us' (professionals) and 'them' (subjects or patients).

Social companionship

Various studies have shown that members of mutual support groups provide each

other with a network of social relationships. Knight and colleagues (Knight, Wollert,

Levy, Frame & Padgett, 1980) found that when group members were asked how they

had been helped by groups, they most often responded that the group had provided

social involvement or fellowship. Gottleib (1982) found from group members'

reports that mutual help groups bring about fundamental changes in their social

networks. The importance of members becoming integrated with each others' social

networks is highlighted by the finding that a measure of social support and sharing

commonalities - 'meeting others with similar problems/conditions' - was most highly

correlated with the members' overall rating of benefit from the mutual help

experience, and this was also the most highly rated element of support (Gottleib,

1982). Several studies have shown that mutual support members who have a high

degree of contact with members between meetings derive greater benefit from the

group (e.g. Lieberman, 1989; Lieberman & Videka-Sherman, 1986). Maton (1988) found social support and friendship among mutual support group members to be related to well-being.

In a review of the mutual support literature, including these and other studies, Levine (1988) concludes that 'the research we have is uniform in pointing out that from the member's perspective the most important factor is the social support provided in the group' (p. 171).

'Social companionship' can include the mutual provision of concrete, instrumental aid as well as emotional support (Levine, 1988). Friendships can form in an environment in which mutually satisfying experience and intimate self-disclosure can occur with others who are similar in important ways. It is likely that friendship development contributes to the well-being of members (Lieberman & Videka-Sherman, 1985). Significant relationships created through mutual support groups promote positive appraisals among members and hence enhance self-esteem (Lieberman, 1979). Mutual support groups offer social ties which counteract feelings of loneliness and isolation. Furthermore, however, new social networks can provide an alternative or substitute culture, and a social culture within which members can develop new definitions of their personal identities and new norms upon which they can base their self-esteem (Humphreys & Rappaport, 1994; Levy, 1979; Rappaport, 1993). Given that the problems with which many people attend mutual support groups can lead to social isolation, the availability of social networks and relationships is potentially extremely valuable.

A sense of mastery and control

Feelings of powerlessness are common among new members of mutual help groups. Groups can provide support for changes in attitudes towards oneself, one's own behaviour, the behaviour of others, and towards society (Levy, 1979). Mutual help groups can also help members to change their attributional style through situational rather than personal attribution regarding difficulties (Stewart, 1990a). One of the most general properties of mutual help is the fostering of empowerment through an increased sense of mastery and control over the problems that have brought a member to a group (Katz & Hermalin, 1987). Mutual help can be a form of collective action for reducing powerlessness (Orford, 1992). Help obtained from joining with others with similar problems creates a sense of control rather than dependency, and movement towards advocacy (Rappaport, Seidman, Toro, McFadden, Reischl, Roberts, Salem, Stein & Zimmerman, 1985).

1.3 PARENTS OF CHILDREN WITH DISABILITIES AND SPECIAL NEEDS

Issues of definition and terminology are discussed first, followed by a review of the difficulties commonly experienced by parents of disabled children, according to the research literature. The ways in which parents cope are then discussed, followed by a review of the help traditionally offered by professionals.

Definitions

The issues of definitions and labels in the area of disability are too complex for discussion here (see, for example, Sinason, 1992 for a review). The description of 'children with disabilities and special needs' covers a wide range of people, conditions and views about how children with a variety of impairments, handicaps and special educational needs should be referred to. This phrase is used throughout despite its apparent cumbersome nature, mainly because it is the preferred label used by families and professionals working with them.

While recognising the potentially huge impact of a disabled child upon siblings, this project looks specifically at parents who attend mutual support groups. In most cases this means mothers, as the burden of caring in western industrial society falls mainly on women generally (e.g. Graham, 1984; Pascall, 1986) and especially for mothers of severely disabled children (Pahl & Quine, 1987).

Common difficulties

Having a child with a disability does not necessarily lead to problems or 'disorder'. The extent of possible consequences of having a disabled child depends on many variables, including the degree of impairment, the characteristics of child, parent and family, and their attitudes and beliefs (Crnic, Friedrich & Greenberg, 1983).

However, while problems are not inevitable, there is an important body of literature which shows that having a disabled child is likely to lead to a number of difficulties.

In one study, Singhi and colleagues (Singhi, Goyal, Pershad, Singhi & Walia, 1990) found that families with disabled children perceived greater financial stress, frequent disruption of family routine and leisure, poor social interaction, and ill effects on their physical and mental health compared to families of non-disabled children.

In another study which interviewed 200 families, Pahl & Quine (1987) found that common problems reported were financial worries, the burden of caring for a child (which fell disproportionately upon mothers), social isolation (for both children and parents), strain upon siblings and on parents' relationships, and significant levels of stress. Mothers who reported feeling lonely and socially isolated were more likely to report feeling stressed.

A large body of literature has claimed that mothers of handicapped children are vulnerable to stress (e.g. Glendinning, 1983; Parker, 1985). Pahl & Quine (1987) found that stress did not vary by diagnostic category, but was significantly related to multiple impairments, a greater burden of extra work because of their handicapped child, and to the degree of behaviour problems, as well as socio-economic adversity. They found that stress in mothers of severely mentally handicapped children was most strongly related to two types of variables: first, those related to the children, namely behaviour problems, night-time disturbance, multiplicity of impairments and the child

having an unusual appearance; secondly, those related to the social and economic

circumstances of the family, namely social isolation, adversity and financial worries.

How parents cope

While traditionally the literature has focussed upon the stressors associated with

caring for a disabled child, and the consequences on parental well-being, a small but

growing body of research literature is turning attention to exploring the ways in which

such families cope (e.g. Beresford, 1994; Brown & Hepple, 1989; Gallimore,

Weisner, Bernheimer, Guthrie & Nihira, 1993; Quine & Wade, 1991). This work has

significant implications for understanding and improving the ways in which these

families can be helped, and for informing any analysis of the ways in which they help

themselves and each other. A brief review of coping resources and strategies, based

on the process model of coping (Lazarus & Folkman, 1984), can be applied very

usefully and informatively in these respects.

Beresford (1994) states that both personal and socio-ecological coping resources

affect the way in which parents appraise the challenge of having a disabled child. This

appraisal, together with the presence or absence of coping resources, then determine

which of a range of problem-focussed and emotion-focussed coping strategies are

used to try to alleviate the levels of stress experienced.

There is a range of potential personal coping resources which have been found to be

helpful, or their absence found to increase vulnerability, for parents of disabled

children. These include: physical health; beliefs and ideologies, including spiritual or

religious beliefs, and the degree of flexibility which enables parents to alter previous

life philosophies; personality variables, most significantly optimism (Beresford &

Lawton, 1993), humour (Brown & Hepple, 1989), and beliefs about locus of control,

since internal locus of control beliefs appear to be more adaptive than external beliefs;

previous coping experiences; and parenting skills (Quine & Wade, 1991).

Furthermore, the sustainability of the whole household's routine has been found to be

an important factor in how parents cope (Gallimore *et al.*, 1993).

There is also a range of coping resources found in an individual's environment or

social context. Both personal reports and research findings suggest that spouse

support is the most important form of support to these parents (e.g. Byrne,

Cunningham & Sloper, 1988). Practical support is as important as emotional support.

More widely, 'social support' generally can be usefully conceptualised as a coping

resource as well as a strategy, in that it affects confidence and perceived stress levels.

Social support has a number of functions, including emotional support, information,

practical help or encouraging feelings of normality (Barrera & Ainlay, 1983).

Perceptions of social support are a distinct coping resource, as they may differ from

the objective availability of support. Factors which mediate the efficacy of social

support include personality variables such as social skills and other coping resources.

Other coping resources in a person's environment include: support from extended

family and friends, especially practical support; support from formal agencies, as

discussed below; respite care; changing needs for support resources; maternal employment; family environment, particularly cohesion, integration and adaptability, which can either be a resource for coping or an additional source of stress; marital status; socio-economic circumstances, namely money and education (Quine & Pahl, 1991). Financial difficulties mean that money is a diminished coping resource. Parental education is associated with parental well-being, at least partly mediated through access to information and problem-solving skills (Quine & Pahl, 1991).

Coping strategies can be conceptualised as either emotion-focused, directed at the somatic or emotional level, or problem-focused, which can be either external or internal, such as cognitive restructuring and challenging irrational beliefs (Beresford, 1994). The research literature is not clear about what may constitute an 'effective' coping strategy. Outcomes depend on the nature of the stressor, as well as a number of other individual variables. Also, it is rare that only one strategy would be used at any one time. Research findings are largely conflicting, although some results are consistent. One consistent finding is that active coping strategies are adaptive. This includes planning, direct problem-solving and information seeking (e.g. Miller, Gordon, Daniele & Diller, 1992; Sloper, Knussen, Turner & Cunningham, 1991; Thompson, Zeman, Fanurik & Sirotkin-Roses, 1992). Certain cognitive coping strategies also appear to be adaptive. These include positive restructuring and self-praise (e.g. Brown & Hepple, 1989; Thompson *et al.*, 1992).

How professionals help

A traditional model of expert help provided by professionals has been the context for a number of professionally-run groups for parents of children with special needs. Cunningham & Davis (1985a) make the distinction between 'therapeutic' groups, aimed principally at providing emotional support and aiding adjustment, and 'educational-behavioural workshops', offering practical support and skills. However, they state that this distinction is primarily professional or academic, since parents find most value in the common, non-specific factors, such as reduced social isolation and wider social networks, and tend to report that they receive both emotional and practical support from both types of groups.

Cunningham & Davis (1985a) outline some areas of evaluation for parents' groups. However, they quote very few studies to support their arguments. They assert that parents' groups have been evaluated positively in terms of: providing support, both emotional and practical, to parents; increasing parents' confidence in interacting with their child; increasing parents' knowledge and skills, especially in observing and understanding their child's behaviour; producing positive changes in children's behaviour (e.g. Hornby & Singh, 1983); having long-term effects of maintaining social contacts, and sometimes leading to the formation of mutual support groups. They conclude by stating that groups tend to be more successful if they meet parents' needs, fit in with parents' resources, convey the impression of value, are well organised and planned, and have good quality staff.

A number of parents' groups have used the model of stress and coping to inform their interventions (e.g. Zeitlin, Rosenblatt & Williamson, 1986; Gammon & Rose, 1991). Strengths and weaknesses in parents' coping strategies are identified, and training programmes undertaken for certain coping strategies. In a two-year follow-up, Kirkham (1993) reported that enhanced coping skills had been maintained, with associated benefits in terms of satisfaction with social relationships, including that with the child.

Dale (1996) argues that professionals can provide a useful role in helping parents locate support groups or set up such groups (Linder, 1970; Evans, Forder, Ward & Clarke, 1986). Professionals can work in partnership with parents in running parent befriender schemes of parent-to-parent support schemes, where the professional acts as trainer and consultant, as in the Home Start programme described by Van der Eyken (1982). This is a way for professionals to act to empower families, according to a model of 'resource exchange'.

In addition to parents' groups and workshops, there are other instances of professionals working together with parents of children with special needs. These include the Portage home teaching scheme (Pugh, 1981) and training in behaviour modification (Gath, 1978). These and others are based on the recognition that 'collaboration with parents must in the future be seen as one of the hallmarks of the well trained professional' (Mittler, 1979, p. 12). This topic has now in its own right been the subject of an extensive book (Dale, 1996).

However, some commentators have expressed caution about the effect of professional efforts to help, arguing that formal support itself can be a potential source of stress and vulnerability. Waisbren (1980) believes that public services do not play a significant role in relieving the strain of caring for a disabled child. Furthermore, interactions with professionals may themselves be stressful (e.g. Lloyd-Bostock, 1976; Turnbull & Turnbull, 1978), and problems of accessibility or dissatisfaction may cause additional stress. In one survey problems in contact with services were often reported to be of greater importance than problems arising directly out of the child's disability (Lloyd-Bostock, 1976). Given these concerns, professionals should consider thoughtfully the nature of their work with parents of disabled children.

1.4 MUTUAL SUPPORT AMONG PARENTS OF DISABLED CHILDREN

The context of mutual support among parents of disabled children is presented before their development is described. The limitations of mutual support for parents are outlined. The work of a national organisation, Contact a Family, is introduced, before a review is presented of the only previous evaluation of mutual support groups for parents of disabled children, conducted with Contact a Family groups.

Context and descriptions

Mutual help groups for parents and families with caring responsibilities have proliferated in Britain over recent years in the context of moves towards 'care in the

community' (Russell, 1997). Glendinning (1986) among others has shown the limited nature of support for families from statutory services, which focus specifically on medical treatment and special education provision for the disabled children themselves. 'Caring for the carers remains a largely unfulfilled ideal' (Hatch & Hinton, 1986, p. 4). Although such comments were written in the mid-1980s, the shortcomings of statutory services have not changed significantly, and the implications for mutual help are still valid (Russell, 1997).

Mutual help groups for parents and families of handicapped children have been set up in many parts of Britain since the 1970s (Russell, 1983; Shearer, 1986). Some have grown out of voluntary organisations working for better services for mentally handicapped people, while others, such as Contact a Family, are specifically aimed at enabling parents with handicapped children to meet each other. The central theme of these groups is that 'a problem shared is a problem halved', and they work from the assumption that parents are able to give each other help and support in a way that professionals cannot: the essence is mutuality.

Despite their growth, there is very little literature specifically concerned with mutual support groups for parents of children with disabilities. Even in texts specifically concerned with families of disabled children (e.g. Cunningham & Davis, 1985a; Dale, 1996), mutual support groups are only mentioned briefly. A thorough literature search discovered only two articles which gave very brief descriptions of such groups (Linder, 1970; Woods, 1981), and one evaluation study (Hatch & Hinton, 1986) which is discussed in detail below.

Russell (1983) argues that mutual help groups for parents of children with special

needs reduce parents' stress and provide the peer group which so many parents

desperately lack when their child is handicapped. Mutual help groups for such parents

offer increased comfort, solidarity, practical advice and general support, and lead to

reduced social isolation. Groups can also help parents to identify their own needs and

literally begin to plan. They can also influence local service developments in a

positive and informed way.

Limitations

Mutual support groups do not suit everyone, and not everyone has the same resources

to be able to participate. Indeed, mutual support has been described as a 'deceit'

(Finch, 1984), since working class people are allegedly not capable of organising and

thus benefiting from groups. Such an argument seems to be an unjustified and

condescending extrapolation of the consistent finding of socio-economic gradients in

participation in mutual support groups. Hatch & Hinton (1986) found that

participation in mutual support groups for parents of handicapped children was higher

among families with younger children, with more severely disabled children, with

more information, and with less disadvantage (as measured by socio-economic status,

ethnicity, education and housing status).

However, it is important to note that there are also socio-economic differences in the

rates of take-up of other forms of support for parents of disabled children. For

example, in a review of training courses and groups run for parents by professionals,

Cunningham & Davis (1985a) found that 'several studies have indicated that

regardless of the approach used, parents from higher socio-economic groups tend to

be more likely to enrol and complete courses' (p. 122). The implication is that

courses tend to be biased towards those parents who find value in the activity.

McConkey & McEvoy (1984) conducted a rare study looking at parents who do not

enrol on courses. Those parents, or rather mothers, of mentally handicapped pre-

school children did not enrol because they felt that they were already doing as good a

job as possible as parents, they did not share the values of the course, and/or they

were less actively involved in play with their child. These factors may be just as

relevant in explaining why some parents do not participate in mutual support groups.

Dale (1996) states that groups for parents of children with special needs can be a

source of valuable support, although parents vary in when and whether they find them

helpful. The dynamic, changing nature of the needs of parents is emphasised

throughout the literature, and this is equally relevant for mutual support groups and

groups run by professionals. The acceptability of the 'differentness' and the

'disability' connotations of these groups will vary across time and across parents,

some of whom will prefer a more integrated setting or will not feel ready to enter 'the

world of disability'.

Pahl & Quine (1987) argue that mutual support may not be appropriate for very

stressed families who may be coping, for example, with multiply impaired or

behaviourally disordered children, often with inadequate financial resources. While

this is a reasonable point to make, and is generally one which is supported empirically, they then go on to argue that 'to suggest that these families should tackle their problems through mutual support resembles setting a physically disabled man to pull himself up by his own bootstraps' (p. 57).

This last statement indicates a partial and significantly incorrect view of mutual help. First, it assumes that mutual support and professional help are mutually exclusive, an assumption which is not supported philosophically or empirically, based on studies of both members of mutual help groups and professionals (e.g. Gottleib, 1982; Lieberman, 1979; Todres, 1982). Secondly, it frames mutual support quite negatively, emphasising only the costs of involvement, without acknowledging the benefits. Thirdly, it presents only a static picture in time, without acknowledging the dynamic, shifting nature of a caring relationship, so that while involvement in a mutual help group may well not be appropriate at one point in time, situations, circumstances and resources do change over time.

Contact a Family

Contact a Family was created as a response to the isolation and lack of support experienced by families with handicapped children. It began as a local project in Wandsworth in 1974, and became a national charity in 1979. Its basic ideology is that 'a problem shared is a problem halved'. Its aim is to encourage families who have a child with physical or intellectual handicaps to form their own neighbourhood groups, to give mutual support, to organise activities with the help of volunteers, and to press

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for the services they need. According to Shearer (1986) there are four things that mark Contact a Family out from many other mutual help organisations in the field of disability. Its approach is firmly rooted in the ideals and techniques of community work rather than social work with individuals. It emphasises the involvement of the whole family. It does not cater for a specific handicap because it finds that families with a child who is handicapped have so much in common. And it is neighbourhood-based, because what it has found parents want most is a network of local support.

A previous evaluation

There has been one evaluation of the work of Contact a Family (Hatch & Hinton, 1986), which is worth reporting in some detail. The research was conducted in the period 1984-85, before significant changes in the way Contact a Family worked, and aimed to analyse how Contact a Family functioned and to evaluate the benefits of participation in groups using both 'subjective' measures (e.g. what participants reported as the benefits from their involvement) and 'objective' evidence (e.g. the General Health Questionnaire (Goldberg, 1972) as a measure of 'morale').

Respondents reported that they joined mutual support groups to improve social lives for themselves and their children, to share problems, and to receive support and understanding. People reported a number of differences which participating in mutual support groups had made. They felt that they were able to share problems and experiences with others in a similar situation, which led to the growth of relationships outside group meetings from which individuals could gain practical and emotional

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support. People also felt more confident and able to cope with other people's reactions. Thirdly, people were able to give and receive advice and information through informal channels.

However, some of these findings were contradicted by 'objective' evidence collected. The researchers found that group membership did lead to increased knowledge of, exchange of information about, and use of services. They also found support for the 'subjective' reports of increased informal support between parents. However, they found that group membership did not lead to increased knowledge of and skills in coping with a child's disability, and that such skills and competencies were transmitted by professionals, not group members. They also found that group membership did not affect 'morale', as measured by the General Health Questionnaire, although they acknowledged that 'stress measures ... could well be measuring inputs more than impact' (Hatch & Hinton, 1986, p. 81), highlighting the difficulty in distinguishing measures of process and outcome.

Hatch & Hinton concluded by stating that 'the problems of isolation and identity do seem to require a group solution for many families' (1986, p. 87). They argued that Contact a Family groups are empowering in three ways. They reduce isolation, enabling members to become part of a supportive network. They enable members to become more effective consumers, able to exercise their rights to benefits and services. And they enable members to act collectively as a group, able to take their own initiatives and pursue their own interests.

However, Hatch & Hinton's study does have limitations. While their analysis is strong on the political aspects of empowerment in a mutual help context, it does little to examine or unpack the psychological processes which interact with political processes. It also treats all Contact a Family groups, and by implication all mutual help groups, as homogenous, with no account or even acknowledgement of variations between groups. This would seem to be key in any analysis of the perceived benefits and helpfulness of mutual help groups. Groups do differ, and only by examining those differences and then asking people what they find especially helpful or unhelpful about their particular group is it possible to begin to unpack the benefits of mutual support. Hatch & Hinton were unable to do this partly because of their research design, which focussed exclusively on the individual level of analysis, rather than focussing on both individual and group levels as is common in the general research literature on mutual support.

A final criticism concerns the faith which the researchers placed in their 'objective' measures. While they acknowledged that it was unclear whether such measures were of process or outcome, they were presented as contradictions to respondents' own reports, in a way that they could be framed as 'disproving' such self-reports. While all self-report data should be treated with caution due to possible biases, particularly so in self-selected groups as will be discussed below, the framing of so-called 'objective' evidence to discount respondents' own reports does seem to devalue people's own perceptions and experiences. Contact a Family itself questioned this one aspect of the study, and it is worth quoting their comments, which appeared in the preface to the report, in full.

> *The mothers' comments recorded by the researchers do indicate the emotional benefits of the support they gained from other mothers. We feel that this is an important result of our facilitating role. Yet it often comes about so informally (for example parents simply ringing each other up) that its significance is difficult to grasp. The measures of outcomes discussed suggest that membership of Contact a Family did not have a very strong effect on informal support networks. Hence we wonder whether the measures used were sufficiently sensitive (1986, p. v).*

Devaluing the experiences of mutual support group members in the light of 'objective', professionally-oriented measures seems to run counter to the whole ideological basis of mutual support. Such an approach seems to be particularly inappropriate given the lack of information about the details of people's experiences of the phenomenon which is supposed to be being evaluated. Description must precede evaluation in any research field, and it seems that more detail is needed about people's own experiences of being part of mutual help groups for parents of handicapped children, and their own perceptions about what is helpful and unhelpful. This is discussed further in the section below on the rationale for this study.

Evaluations of mutual support groups for bereaved parents

There has been more extensive research into other parents' groups, notably 'Compassionate Friends' for bereaved parents in the USA. Lieberman (1979) found that parents reported helpful aspects of participation which related to three factors, namely universality, altruism and existential factors. For parents in these groups affective, expressive experiences were more important than cognitive mechanisms of change. One interesting question is whether this would also be the case for parents of

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children with special needs, for whom daily practical problems and difficulties still abound.

Videka-Sherman (1982) found that the level of involvement in Compassionate Friends was associated with 'personal growth' but not with levels of depression as measured by a symptom checklist. Those parents who were most involved in the group were more likely to maintain a sense of positive personal change over the one year span of the study. Two possible reasons were proposed. One explanation was cognitive change stemming from the group's ideology and belief system. Another explanation is the role of altruism, as participating in the group may, in existential terms, provide the parent with an ongoing source of meaningfulness and purpose in life, a source of interpersonal closeness to others with whom the parent can identify, a mechanism of mastery of an experience over which the parent had no ultimate control, and an opportunity to confront the meaning of life and death. Some of these factors might also be pertinent to groups for parents of children with disabilities.

In a follow-up study, Videka-Sherman and Lieberman (1985) found that neither involvement in Compassionate Friends nor psychotherapy resulted in improvement in mental health or social functioning for bereaved parents. Given the existential changes reported previously, including changes in value and belief systems, one possible conclusion was that 'perhaps participation in a self-help group like Compassionate Friends influences the meaning that parents attribute to their experiences rather than their psychosocial functioning' (p. 80).

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There are two implications of these findings for the present study. One is to ask whether mutual help groups for parents of children with disabilities have the same benefits as those for bereaved parents. What is the relative importance of emotional support and cognitive mechanisms of change? The other implication relates to measurement of 'outcome'. How relevant is it to use professionally-based measures of psychosocial functioning to assess the impact of processes which are not 'treatment' aimed at 'curing' something? What are the most important and appropriate 'outcomes' for ways of helping with particular difficulties and experiences?

1.5 IMPLICATIONS OF THE LITERATURE FOR THE PRESENT STUDY

The rationale for the study is presented, with particular attention given to epistemological and methodological issues which have emerged in the mutual support research literature. Such issues and concerns have led to certain recommendations being made for further studies of mutual support groups, which are outlined at the end of this section.

Rationale of the present study

The primary aim of this study is to discover and describe what parents of children with disabilities and special needs find helpful about mutual support groups. This is a useful question to ask in the light of the extent of knowledge and understanding in this

area. It is widely acknowledged that the research literature concerning mutual support generally is still in its early stages of development, and so there is still an important role in describing the phenomenon of mutual support. Furthermore, there is a very limited body of knowledge concerning mutual support for parents of disabled children. As reported above, there has only been one attempt at an evaluation (Hatch & Hinton, 1986), which highlights issues regarding measurement and the differences between subjective accounts and professionally-driven constructs and measures. These problems would seem to reinforce the importance of describing phenomena in a way that is satisfactory to all parties, particularly participants themselves, as an essential precursor to examining effectiveness or any other outcomes.

These issues have been discussed in the mutual support literature. In a review of a research workshop on methodological issues in evaluating mutual support, Goldklang (1991) states that 'one problem in doing research with naturally occurring self-help groups is that if the requirements of research design are imposed on these groups, there is the potential that their very nature may change' (p. 791). The fact that mutual support groups exist in the community without professional involvement means that concerns about professionally-driven research issues such as sampling bias and conventional outcome measurement must be held in mind but not used to alter the nature of the phenomenon being studied. These two issues are discussed in detail below.

Issues inherent in investigating mutual support

Methodological problems 'are essentially intrinsic to the study of self-help groups' (Levy, 1979, p. 234). In particular, the issues of sampling bias and objective 'outcome' measurement have received attention in the research literature.

Sampling bias

'Sampling bias is virtually inherent in the study of self-help groups .. and seems unavoidable, given the nature of these groups' (Knight *et al.*, 1980, p. 55).

Humphreys & Rappaport (1994) outline arguments that mutual support group research presents a 'unique combination' of special difficulties that coalesce. As it is easy to drop out, at any moment in time those who are attending a mutual support group will be more likely than any comparison group to be those who benefit from the group. Mutual support requires a certain level of social competence, and despite other difficulties this may make members more likely than non-members to be those who benefit from social interaction and from friendship networks. As it is voluntary, mutual support group members must make a commitment to take an active role in changing. All of these factors (any of which may be the case for other 'treatments') come together in mutual support group research. Taken together, they provide an 'intrinsic advantage' with respect to outcome. Theoretically, this can be overcome by use of a randomised treatment design. However, random assignment would 'result in a fundamental distortion' (Humphreys & Rappaport, 1994, p. 220) of the groups

because their composition would be changed. Mutual support groups 'do not exist as interventions apart from their members who are both the instrumentality and the objects of the intervention; change the characters and their membership and the intervention is changed as well' (p. 220).

Measuring 'outcome'

> *The common 'pre-post' measurement of outcomes in treatment groups, in comparison with control groups, is an awkward model to apply to self-help groups* (Lieberman & Borman, 1976, p. 459).

Moreover, there is also doubt about the equivalence of the comparison groups. The study of Compassionate Friends (Videka-Sherman & Lieberman, 1985) was a quasi-experiment, leaving many unanswered questions about what 'treatment' the experimental group was exposed to and about whether the experimental group and the non-equivalent comparison group were similar enough in the beginning to justify comparing outcomes.

Jacobs & Goodman (1989) state that 'unlike psychotherapy, the very nature of self-help groups generally precludes research that is as tightly controlled by the investigator' (p. 540). Such a stance has led a number of commentators to argue that research with mutual support groups should adopt 'an alternative paradigm for inquiry and action' (Chesler, 1991, p. 757). Approaches include 'participatory action research' (Chesler, 1991, p. 760), 'collaborative, culturally compatible models of self-help research' (Powell, 1993, p. 159), integrating 'quantitative and qualitative knowing in mutual support research' (Tebes & Kraemer, 1991, p. 739), and the

inclusion of 'consumer review and approval' as an integral part of mutual support and other clinical research (Kaufmann, 1993, p. 257).

'Outcome' measurement should include a consideration of the goal of the mutual support organisation and the goals of individual members. As Levy (1979) hypothesised, mutual help groups seek to create supportive, safe, benign environments for their members. These 'outcomes' differ from conventional 'outcomes' of professional 'treatment', and so conventional professionally-driven measures may not be intended for, or successful in, measuring such constructs. This means that in studying this area, the onus must be on the investigator to consider whose criteria for 'outcome' are used. The challenge is to be sensitive to the criteria of both participants and researchers, as highlighted in the preface to the previous study of Contact a Family groups (Hatch & Hinton, 1986), quoted above.

> *Evaluations of naturally occurring self-help groups have produced discrepancies between what members report they have derived from the groups and data based on measures of symptomatology, adjustment or improvement. These discrepancies pose a potentially serious problem because the popularity and the growth of the groups derive largely from their members' views of their value to them, while their legitimacy as interventions rests largely on the assessments of their effectiveness on researchers' criteria* (Goldklang, 1991, p. 792).

Some commentators have gone further. In discussing the fact that mutual help groups are not the same as services provided by non-professionals, or peers, who are trained, supervised, or in programmes administered by professionals, Humphreys and Rappaport (1994) argue that controlled outcome studies of mutual support groups

may be neither possible nor desirable. Their alternative suggestions are discussed below.

Recommendations for further studies of mutual support

Goldklang (1991) stresses the need for more descriptive, formative and process-focused research. In particular, one question that needs to be addressed is to discover the active components in mutual support interventions. She also clearly states that outcomes should go beyond simple mental health measures.

Humphreys & Rappaport (1994) go further, urging for 'worldly evaluation research' (p. 223). Rather than trying to control who goes to a mutual support group, researchers should study affiliation as it occurs naturally. They argue that mutual support groups should be seen as 'normative socially supportive groupings rather than as treatments for problems' (p. 225). Mutual help should be seen not as a treatment but as a social network like any other. 'The effects of mutual support groups that are typically studied from this framework are changes in friendship networks, identity, world view, personal stories, and increases in social support' (p. 225). By viewing mutual help as social support rather than as a 'treatment', the whole nature of 'outcomes' and of the aim of mutual support is altered. 'Particularly after the distress caused by the presenting problem is ameliorated, self-help for many people becomes a life-style and a basis for friendship and social activity' (p. 226).

In a previous article Rappaport outlines a methodological approach which operationalises these ideas that the stance of listening to stories is an antidote to professional centrism. In particular he advocates observation of meetings and focus group discussions, as research questions are starting to be asked in a post-modern environment.

> *It is now widely believed that personal reality is constructed and that there is an iterative process between the internal and external. The way that we have begun to study this is to conduct research in which we spend time trying to explicate the details of the community narrative. This can be accomplished in a variety of ways, including extended observation of meetings, conducting focus groups, and detailed reading of available texts* (1993, p. 252).

Such concerns and recommendations informed the aims and design of the present study.

1.6 AIMS OF THE PRESENT STUDY

This section outlines the aims and research questions of this study. The aims are presented in the context of a discovery-oriented epistemological approach to research. The preliminary research questions are presented, followed by the main research question, along with a brief outline of the methods of data gathering and data analysis used.

The aim of discovery

The primary aim of this study is to provide a description of what parents of children with disabilities and special needs find helpful about mutual support groups. This is one area in which theory generation is appropriate since 'existing theory is incomplete, inappropriate, or entirely absent' (Henwood & Pidgeon, 1992, p. 102). Hence the emphasis of this study is on discovery and description. This approach and research design is consistent with the naturalistic research paradigm in the social sciences, based on the search for *Verstehen* (meaning or understanding) (Dilthey, 1894/1977), with an emphasis upon description and the representation of reality 'through the eyes of participants' (Henwood, 1996, p. 27). This approach views science as generating working hypotheses rather than immutable empirical facts, and theorising as generating concepts from data (Henwood & Pidgeon, 1992).

Prior to this, however, the study aimed to address three important preliminary questions in order to provide a context for the main research question.

Preliminary research questions

The three preliminary questions were: 'How helpful are mutual support groups?' 'What are the characteristics of mutual support groups?' 'What are the relationships (if any) between group characteristics and helpfulness of mutual support groups?'

In order to address these questions, quantitative methods were used alongside a qualitative approach, so that data could be compared across individuals, groups and studies, and so that relationships between variables could be investigated.

Main research question

The main research question of this study was: 'What do parents of children with disabilities and special needs find helpful about mutual support groups?'

This question was addressed mainly using a qualitative approach to generate a description based upon participants' own reports of their experiences.

Outline of the approach of this study

In order to address these questions, the study was conducted with participating individuals and groups, as recommended by reviewers of the mutual support group research literature (Goldklang, 1991; Rappaport, 1993). Groups affiliated to a national charity, Contact a Family, in and around the London area were visited, and members were asked to complete a questionnaire containing closed and open-ended questions, before participating in focus group discussions about their experiences. Background information was also collected about each group. This approach values the self-reports of participants' experiences which, while having obvious limitations with respect to bias, are the most appropriate source of information for discovering what it is that participants find helpful about mutual support groups.

At this point it is worth outlining briefly the rationales for using focus group discussions and grounded theory analysis to address the main research question. Both methods are recommended by Humphreys & Rappaport (1994) for use in studies of mutual support groups.

Focus group discussions

As a form of qualitative research, focus groups are basically group interviews. The emphasis is on interaction within the group based on topics that are supplied by the researcher, rather than simply on an alternation between the researcher's questions and the participants' responses. The researcher typically takes the role of moderator, with the level of involvement usually dependent upon the research questions to be asked. A balance needs to be struck between the researcher's agenda of covering specific topics and allowing participants to discuss their experiences and interests in more depth.

Focus groups had their origins in sociology. However, their utility and appropriateness is rapidly becoming recognised both in psychological and social science research generally (e.g. Coyne & Calarco, 1995; Harrison & Barlow, 1995; Kitzinger, 1995; Morgan, 1988), and in mutual help research in particular (e.g. Humphreys & Rappaport, 1994; Rappaport, 1993). The purpose of focus groups is to provide insight and to aid understanding of participants' perspectives. As an accompaniment to quantitative methods, its use allows the questions of 'how' and

'why' to be addressed as well as 'what', 'how much' and 'how many' (Hague, 1993). When used in combination, a triangulation of methods of data collection ensures that both types of questions may be answered simultaneously.

Focus groups are particularly appropriate for use in an area about which relatively little is known, as is the case in this particular study, since they facilitate an in-depth discovery and investigation of a group's experience. Focus groups are interactive, allowing ideas to flow around the group and to develop to a greater degree than is often possible in individual interviews. This active participation empowers people and makes them feel that their views and experiences are valued. In contrast to individual interviewing, participants' interaction among themselves in group interviewing replaces their interaction with the interviewer, leading to a greater emphasis on participants' points of view. The data obtained are rich and unique, and can be used to clarify meanings and to aid interpretation of findings (Morgan, 1988). This is particularly useful when the technique is employed alongside quantitative methods.

Focus groups are a useful adjunct to questionnaire surveys, and not just at a preliminary stage. Focus groups can usefully serve as a follow-up data collection, pursuing exploratory aspects of the analysis. As Morgan (1988) argues, 'focus groups have a considerable potential for contributing to survey research' (p. 36). More specifically, while questionnaires are more appropriate for measuring how many people hold a certain (pre-defined) opinion, 'focus groups are better for exploring how those opinions are constructed' (Kitzinger, 1995, p. 302).

Grounded theory

The data obtained in this study from focus group discussions and from individuals'
responses were analysed according to the grounded theory approach (Glaser &
Strauss 1967; Pidgeon, 1996; Pidgeon & Henwood, 1996; Strauss & Corbin, 1990).
The term is used to refer to theory which is generated in the course of the close
inspection and analysis of qualitative data (Glaser and Strauss, 1967). On inspecting
vast amounts of unstructured data, researchers begin by allowing an array of concepts
and categories to emerge from systematic inspection of a data corpus. What emerges
is an open-ended indexing system, or data description language, with a hierarchy of
categories which move from participants' own language to a taxonomy which reflects
a balance between the researcher's own intellect and the requirement of fitting the
data well. 'A grounded theory is typically a blend of descriptive and constructed
categories with the former often subsumable under the latter' (Rennie, Phillips &
Quartaro, 1988, p. 143). This approach is particularly appropriate for studying
mutual support groups, as it places emphasis on the value of the experiences of group
members (Humphreys & Rappaport, 1994).

Combining quantitative and qualitative approaches

The choice of research method depends on its usefulness. 'The distinction between
qualitative and quantitative research is really a technical matter whereby the choice
between them is to do with their suitability in answering particular research questions'
(Bryman, 1988, pp. 108-109). It is common in psychological research to use both

qualitative and quantitative methods. While many researchers ground the latter by prior use of the former, a second possibility is to use both research methods in parallel, as advocated by Silverman (1985) among others.

This study used both quantitative and qualitative measures. By combining the two approaches this study aimed to elicit original descriptive and analytical information. By obtaining data at the level of the group, the associations between individuals' experiences and the nature of the groups to which they belonged could be examined, as could differences between groups. Much of the mutual support literature treats mutual support groups as homogeneous, rather than examining differences between groups. While this may be more appropriate in the USA, where mutual help organisations typically provide a written and readily reproducible literature and ideology for a multitude of groups to follow (Humphreys & Rappaport, 1994), in the UK organisations are not as developed and so greater differences between groups might be expected. Maton (1993) argues that group characteristics have the potential to influence individual well-being, and therefore attention should be paid to measuring variables at the group level of analysis.

Summary

This study adopted a discovery-oriented approach to research. It was undertaken within a theory-generating research paradigm, mainly using the approach of grounded theory. Quantitative and qualitative methods were combined to obtain data which could provide both a rich description of participants' experience as well as a means of

measuring and comparing their reports. In this way, this study sought to address the following research questions:

Preliminary questions

1. How helpful are mutual support groups for their members?

2. What are the characteristics of mutual support groups?

3. What are the relationships (if any) between group characteristics and helpfulness of mutual support groups?

Main question

4. What do parents of children with disabilities and special needs find helpful about attending and belonging to mutually supportive groups?

OVERVIEW OF CHAPTER TWO: METHOD

This chapter has four main sections. Section 2.1 describes the recruitment of the

sample. Section 2.2 describes the data collection procedure and the measures used,

outlining the use of the questionnaire, focus group discussions and the collection of

data about each group. Section 2.3 describes the sample, giving details of each

participating group as well as the characteristics of the sample of individual

participants. Section 2.4 describes the data analysis procedures, with particular focus

upon the grounded theory approach and method of qualitative data analysis.

2.1 RECRUITING THE SAMPLE

Participants were parents attending meetings of mutual support groups run by and for

parents of children with disabilities and special needs. Recruitment was done on a

group rather than individual basis, through Contact a Family, a national charity whose

aim is to encourage mutual support between families containing children with

disabilities and special needs. The target population was all members of groups

affiliated to Contact a Family in 1996.

Contact a Family identified 12 affiliated groups in and around London, and sent out a

short letter to those groups notifying them of a forthcoming research project and

asking groups to reply at that stage if they did not want to receive any further

information about participating in the project. One group replied at that stage that they had decided not to participate.

Ethical approval for the study was granted by the UCL/UCLH research ethics committee in May 1996 (see Appendix 1). Co-ordinators of the 11 remaining groups were then sent a pack of three letters (see Appendix 2). One letter was from Contact a Family, introducing the project, the researcher and outlining the potential value and usefulness of the project. The second letter was from the researcher, describing the project, outlining what would be required of participants and describing the envisaged benefits of the project. The third letter was from UCL, briefly describing me as a *bona fide* researcher. A reply slip and stamped addressed envelope were included for groups to indicate whether or not they wanted to take part in the project. By the deadline, seven groups had replied that they did agree to take part, while no replies were received from the other four groups.

The researcher then telephoned the named co-ordinator for each of the seven groups to check that the proposal for taking part in the project had been discussed in the group, to obtain some background information about each group and to arrange a convenient time to visit. At this stage one group, which had returned the most positive reply slip with very enthusiastic comments, began to voice doubts about taking part, and after much deliberation decided not to participate.

After the deadline for replies had passed, the researcher wrote a short reminder letter to the co-ordinators of the four groups whose replies had not been received. One

group now agreed to take part. Three groups still did not reply, and this was taken as

a decision not to participate. One group then cancelled the arranged meeting and

found it 'impossible' to re-arrange a time for the researcher to visit. This left six

groups participating in the project.

2.2 DATA COLLECTION

This section outlines the data collection procedure and the measures used, describing

the contents of the questionnaire and the prompts for the focus group discussions.

Procedure

The researcher visited one meeting of each of the six participating groups. The

project was introduced to each group. People were told what would be expected of

them, and also what they would receive in return. The information sheet and consent

forms (see Appendix 3) were given out and people were invited to ask any questions

before they decided to participate. Participants were reassured that both the

questionnaire and the discussion were anonymous, and were clearly told when the

tape recorder was being switched on and off. At the end of each discussion, before

my departure, I reiterated that each group would, in due course, be receiving a

summary report of the findings of the study.

Measures

The study used a combination of both quantitative and qualitative measures. First, participants were given a written questionnaire to complete on their own. This took approximately 20 minutes to complete. Secondly, a focus group discussion was held with five of the six groups, lasting approximately another 20 minutes.

Questionnaire

The questionnaire was constructed to incorporate both open-ended qualitative questions asking about the nature of people's experiences and perceptions, and closed, quantitative questions taken from previous research studies in the area of mutual support. Some open-ended questions were adapted from previous studies in the area of psychotherapy service evaluation. See Appendix 4 for a copy of the questionnaire.

The Group Environment Scale (GES)

Questions 1-36 were from the Group Environment Scale (GES) (Moos, 1981; 1986). The GES is a measure of 'the social-environmental characteristics of task-oriented, social, and psychotherapy and mutual support groups' (Moos 1986, p. 1). It consists of a total of 90 items with 'true' or 'false' response categories.

The 36 questions comprised four of the original ten GES sub-scales, selected because they were the most applicable to mutual support groups specifically. The four sub-scales were: cohesion - the degree of members' involvement in and commitment to the group, and the concern and friendship they show for one another; expressiveness - the extent to which freedom of action and expression of feelings are encouraged; task orientation - the degree of emphasis on practical, concrete, and 'down-to-earth' tasks and on decision-making and training; self-discovery - the extent to which the group encourages members' revelations and discussions of personal information. (Definitions are taken from Moos, 1986, p. 2.).

Reliability. Moos (1986) reports the reliability of the GES based on data obtained from 148 groups. Test-retest reliabilities of individual scores were calculated for 63 members of seven groups who took the GES twice with a one-month interval between testings. Reliabilities of the ten sub-scales were 'acceptable'. Values for the four sub-scales used in this study were .83 (Self-Discovery), .79 (Cohesion), .78 (Task Orientation) and .67 (Expressiveness). Internal consistencies for the four sub-scales, using Cronbach's Alpha, were .86 (Cohesion), .83 (Self-Discovery), .72 (Task Orientation) and .70 (Expressiveness). These values all indicate that these GES sub-scales have good reliability.

Validity. The constructs of cohesion, expressiveness, task-orientation and self-discovery all correspond to conceptual accounts of group characteristics. Yalom's (1975) 'curative factors' of psychotherapy groups include group cohesiveness, catharsis, imparting information and interpersonal learning. Leszcz, Yalom & Norden

(1985) list ten factors typically reported by group psychotherapy researchers, including cohesion, expression of feelings, advice, both interpersonal and vicarious learning, and gaining self-understanding. It seems, therefore, that these four GES sub-scales have good content validity. By inspection they also have good face validity. Moos (1986) reports differences on sub-scales between three types of groups as evidence of construct validity. He cites psychotherapy and mutual support groups as highest on Expressiveness and Self-Discovery, and lowest on Task Orientation. Task-oriented groups are highest on Task-Orientation and lowest on Self-Discovery.

The four particular GES sub-scales were selected to provide a picture of the environments in different groups, and particularly to detect variations between groups in closeness, trust, intimacy, and ostensible purpose, with the aim of examining associations with helpfulness.

Social support and organisational characteristics

Questions 37-40 were taken from Maton's (1988) study of social support, organisational characteristics, psychological well-being and group appraisal in three self-help populations. They asked about the extent of different mutual support group processes, namely role differentiation, friendship, and 'bi-directional supporters', i.e. those who both provide and receive emotional support. These were selected because Maton found that respondents' appraisals of their groups were positively associated with receiving social support, being both a provider and receiver of social support (a

'bi-directional supporter'), having friendships with other group members, and, at the group level, with higher levels of role differentiation.

Question 41 was an original question, asking for more quantitative detail about the extent of friendships with other group members.

Helpful aspects of mutual support

Question 42 was an original open-ended question, asking for people's thoughts about the ways in which their group had been helpful, before being asked about specific elements based on an agenda stemming from previous research. The subsequent questions (43-51) were taken from Gottleib's (1982) study of members' views of the benefits of mutual help groups. They sought to measure the extent of perceived benefits from nine elements of mutual helping.

Satisfaction

Questions 52-55 were four out of the eight items of the Client Satisfaction Questionnaire, or CSQ-8 (Larsen, Attkisson, Hargreaves & Nguyen, 1979). While the CSQ-8 was intended for clients of health services, it is easily and only slightly adapted in order to provide a measure of the extent to which group members are satisfied with the 'service' they receive from their mutual support group. The four items selected were then aggregated into a scale (alpha = .76).

Overall helpfulness

Questions 56 and 57 were adapted from the Helpful Aspects of Therapy

Questionnaire (Llewelyn, 1984). While intended for psychotherapy clients, it is easily

adapted to provide a useful way of eliciting more detail about what group members

find helpful, and also gives a specific opportunity for people to report what they find

unhelpful. This explicit invitation was important in the context of obtaining self-

report data from such a self-selecting population.

Question 58 was adapted from Elliot & Wexler's (1994) Session Impacts Scale. As

discussed by Stiles and colleagues (Stiles, Reynolds, Hardy, Rees, Barkham &

Shapiro, 1994), this single item global measure of helpfulness of psychotherapy

sessions has been found to overlap with other, more complex, indices, despite its

obvious limitations and crudeness. This measure of perceived helpfulness is better

conceived as an outcome rather than process variable, according to Mallinkrodt's

(1994) classification of counselling process research.

Focus group discussions

Focus group discussions were held after individual respondents had completed the

questionnaire. This order was chosen so that questionnaire responses would be less

influenced by the group, and so that people's thinking would be stimulated by the

questionnaire and that they would 'hit the ground running' in the focus group

discussion. A number of prompts were prepared and asked in each group discussion.

These were:

'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?'

However, within that general framework each discussion led its own course, with different degrees of intervention by the researcher, depending on the nature of the discussion.

One of the groups did not have a focus group discussion, as it was a group where parents and children were present, making a discussion impossible.

Group characteristics

For each group a number of characteristics were recorded. This was done primarily at the stage of telephone contact. Group characteristics included: the size of the group; the age of the group; whether the group contained the original founders; the frequency of group meetings; whether the group had a newsletter; whether the group was led by parents or professionals; whether professionals were involved in the group at all, and if so then to what extent.

2.3 THE SAMPLE

The sample consisted of six groups and 56 individuals.

Participating groups

Group A

This was an inner London group for parents of children with a variety of special needs. Facilitated by 'Contact a Family' itself and a project worker, the group's age was about 21 years. The membership was about 80, although there was a core group of about 20. The group met once a fortnight. Participating in the study took up the first part of a regular fortnightly meeting, held in a local community hall. There were 11 participants, all of whom were women.

Group B

This was an outer London group for parents of children with dyspraxia. The group had existed for about 18 months, and consisted of 20 members, including the founder, with an average attendance of 8-12. The group met once every two months, not in school holidays. Participating in the study took up the last part of a regular group meeting, held in the organiser's home. There were seven participants, comprising six women and one man.

Group C

This was a home counties group for parents of children with a variety of special needs. It was set up about 10 years ago, and some founders were still involved although less actively. There were about 170 members in total, comprising both parents and professionals. The group was run by a committee of 13 parents which met once every 4-6 weeks. The group had a newsletter and a 'chat line'. The group was a registered charity. Participating in the study took up the first part of a committee meeting, held in one member's home. There were seven participants, comprising four women and three men.

Group D

This was a home counties group for children with special needs, their siblings and their parents. It was set up two years ago as a toddler group which met once a week. There were also occasional meetings at other times. The founders were actively involved in the committee organising the group, which had 70 families on the mailing list. On average 20 children attended each week. The group had a newsletter. Parents who were interested in participating in the study completed a questionnaire during the morning they were at the group, held at a local community hall. There were 13 participants, all of whom were women.

Group E

This was an outer London group for parents of children with autism and disorders on the autistic spectrum. The group's age was about 4-5 years, and included the founders among a membership of about 40. There were meetings once every two weeks, alternating informal 'chat' evenings with open meetings to which outside speakers were invited. The group was parent-led, and well supported by professionals who attended open meetings. The group had a newsletter. Participating in the study took up about a half of a monthly evening open meeting, held at a local community hall. There were 11 participants, all of whom were women.

Group F

This was a home counties group for parents of children with autism. The group was set up 4-5 years ago and was still co-ordinated by its founder. The membership was about 10 parents. The group met once a month during term-time. Participating in the study took up about a half of a regular monthly meeting, held at the organiser's home. There were seven participants, all of whom were women.

Questionnaires were administered to participants in all six groups, and focus group discussions were held with five out of the six groups. The sixth (Group D) was the only group where children were present, and so a discussion was not possible.

Participating individuals

There were 56 participants from the six groups, consisting of 52 women and four

men. Ages ranged from 27 to 58 years, with a mean of 39 years. Forty three

participants (77 per cent) described their ethnicity as 'English', 'British' or 'white',

three (five per cent) as 'African', three (five per cent) as 'Caribbean' or 'Afro-

Caribbean', two (four per cent) as 'Irish' and one person (two per cent) as

'American', with information for the remaining four (seven per cent) missing. Forty

three people (77 per cent) described their religion as Christian, eight (14 per cent) as

having no religion, and one person (two per cent) as Buddhist, with information for

the remaining four (seven per cent) missing. Sixteen participants (29 per cent)

described their occupation as 'housewife', 'carer' or 'mother', 15 (27 per cent) were

in professional occupations or had partners who were, nine participants (16 per cent)

or their partners were in skilled occupations, five participants (nine per cent) or their

partners were self-employed, three (five per cent) were students, and three

participants (five per cent) or their partners were in unskilled occupations, with

information for the remaining five (nine per cent) missing.

The length of time in which participants had been members of their groups ranged

from 0 to 21 years. The mean length of membership was 3.9 years (s.d. = 4.4 years).

Participants had between one and eight children, with a mean of 2.5 children. The

most common was two children.

The age of children with special needs ranged from one year to 26 years. The mean

age was nine years (s.d. = 5.5 years). Participants described the nature and extent of

their children's special needs in a variety of ways. A crude categorisation of

responses showed that 16 participants (29 per cent) had children with specific learning

difficulty, dyspraxia, attention deficit disorder or speech delay, 15 (27 per cent) had

children with severe or profound mental and/or physical disability, 14 (25 per cent)

had children with autism or disorders on the autistic continuum, and six (11 per cent)

had children with moderate learning disabilities, with information for the remaining

five (nine per cent) missing.

2.4 DATA ANALYSIS

This section describes how quantitative and qualitative data were analysed, with

particular emphasis on describing the grounded theory approach to data analysis.

Analysis of quantitative data

Quantitative questionnaire responses were analysed using the 'SPSS for Windows'

statistical package.

Analysis of qualitative data

Qualitative data were obtained from the responses to the open-ended questions in the questionnaire, and from the focus group discussions.

Data were collected from questions 42, 56-57, 68-72 in the questionnaire. These questions asked about the ways in which the group had helped (Q.42), what had been most helpful (Q.56) and unhelpful (Q.57) in group meetings, what difference being a member had made (Q.68), whether respondents had changed since joining the group, and if so how (Q.69), how things would be different without the group (Q.70), how respondents would recommend the group to another (Q.71), and an opportunity for people to say anything else about their experiences in the group (Q.72).

Obviously these questions were asking about different aspects of people's experiences, and asked about both processes and outcomes. Nevertheless, replies to all of these questions were analysed together to draw out the key features of people's experiences. Previous researchers have also recommended that the distinction traditionally made in treatment evaluation between process and outcome is not appropriate for mutual support group research (e.g. Humphreys & Rappaport, 1994; Levy, 1979; Lieberman & Borman, 1976).

Each focus group discussion was tape recorded, and field notes of each discussion were taken as soon afterwards as possible, as recommended in the literature (e.g. Morgan, 1988). Each discussion was transcribed by hand.

Data from the questionnaires and focus group discussions were each analysed

separately but in the same way, using the grounded theory approach to qualitative

data analysis and the constant comparison method (Glaser & Strauss, 1967; Henwood

& Pidgeon, 1992; Pidgeon, 1996; Pidgeon & Henwood, 1996; Strauss & Corbin,

1990).

Grounded theory approach and method

The key analytical method in the grounded theory approach is constant comparative

analysis. Here the researcher is urged to be constantly alert to the similarities and

differences which exist between instances, cases and concepts, to ensure that the full

diversity and complexity of the data is explored (Henwood & Pidgeon, 1992; Pidgeon

& Henwood, 1996; Strauss & Corbin, 1990). The process of open coding (Strauss &

Corbin, 1990) is one in which, as categories emerge, units of analysis are compared to

each category. Each unit is assigned to as many categories as possible. If no

categories fit a given unit, a new category is developed to represent it. After the

categories have been saturated (i.e. no new categories emerge from further data), the

analytic focus shifts to the relationships among the categories. The process of axial

coding (Strauss & Corbin, 1990) compares open categories and it becomes apparent

that the network of linked categories forms a hierarchical structure in which central

categories subsume lower-order categories. This process may continue until a single,

core category emerges, which is most densely related to the other categories. It is

typically an abstract category but it is not vague (Pidgeon, 1996; Rennie, Phillips &

Quartaro, 1988; Strauss & Corbin, 1990).

In this study both sets of qualitative data were inspected and broken down into

meaning units. These units were then assigned to categories according to the process

of open coding (Strauss & Corbin, 1990). Categories were created to fit the

emerging data until saturation point was reached, namely the point when the data

were assigned to existing categories without the need for further categories to be

created. In each case this stage produced a large number (running into hundreds) of

first order categories which closely fitted the data. These were then clustered into a

number of second-order categories, often labelled with participants' own words. The

frequencies with which each of these second-order categories were mentioned in the

questionnaire responses were recorded and are reported in Chapter Three. This adds

valuable detail to the analysis by giving an indication of the relative importance

attached to each category by the participants. Silverman advocates an approach which

includes basic quantitative analysis with qualitative studies by arguing that 'simple

counting techniques can offer a means to survey the whole corpus of data ordinarily

lost in intensive qualitative research' (1985, p. 140).

The relationships between these second-order categories were then examined

according to the process of axial coding (Strauss & Corbin, 1990), to create a

hierarchy of categories. In each case it was possible for a single core category to

emerge, which was densely related to the lower-order categories.

The focus group data were analysed after the qualitative questionnaire data. It was appropriate to analyse these data from a different source separately, because they were spoken rather than written, because people were responding to different questions, and because they emerged from group discussion rather than purely individual responses. This analysis was undertaken after the analysis of the questionnaire responses, and so is open to the possible criticism that it was influenced by the previous analysis. The lower-order categories which emerged in the analysis of the focus group data were different to those in the analysis of the questionnaire data. However, in each case the same three higher-order categories and single core category emerged consistently.

Another way of addressing the issue of reliability is replication. In this study, the axial coding process (Strauss & Corbin, 1990), in which the first-order categories were grouped into higher-order categories, was replicated by another researcher experienced in the grounded theory approach and method. Labels and definitions of the first-order categories were provided to this second researcher, who then undertook the axial coding process. There were some differences in the assignment of a small number of individual first-order categories. However, the same three higher-order categories emerged from this replication. This supported the most central findings of the analysis in terms of the higher-order categories, while providing a reminder that in some cases the boundaries between those categories were slightly blurred or overlapping.

After the data were analysed, a summary report was sent to Contact a Family and to all participating groups. Discussions with Contact a Family constituted a form of respondent validation, in which the research findings were recognised by staff and advisors in the mutual support organisation as corresponding broadly with their experience.

OVERVIEW OF CHAPTER THREE: RESULTS

This study aimed to address four main research questions. The preliminary questions

were: 'How helpful are mutual support groups?', 'What are the characteristics of

mutual support groups?', and 'What are the relationships (if any) between group

characteristics and helpfulness of mutual support groups?'. The main research

question was: 'What do parents of disabled children find helpful about mutual support

groups?'

This chapter begins by describing the results obtained from the quantitative

questionnaire data which pertain to the three preliminary research questions. Results

indicating the extent of the helpfulness of the groups are presented first, followed by

descriptions of the characteristics of the groups, in terms of group environments,

social support and organisational characteristics, bi-directional social support, length

of attendance and amount of informal contact between group meetings. The

relationships between these characteristics and reported helpfulness and satisfaction

are also described.

Answers to the question 'What do parents find helpful about mutual support groups?'

are then presented. Quantitative questionnaire data are presented to provide a

starting point, followed by the qualitative data provided by participants in this study.

A grounded theory analysis of the written responses in participants' questionnaires is

presented first, followed by a similar analysis of the data provided by focus group

discussions. Finally, these two sources of qualitative data are used to provide an account of what can be unhelpful about mutual support groups.

3.1 HOW HELPFUL ARE MUTUAL SUPPORT GROUPS?

There were two global measures of 'outcome', namely an overall helpfulness score and a satisfaction rating.

Overall helpfulness

There was one question of global helpfulness, with responses on a scale from one (extremely unhelpful) to nine (extremely helpful). The mean score was 8.1 (s.d. = 1.2). There were significant differences between groups ($F(5,50) = 2.89$, $p < .05$), with mean group scores ranging from 7.4 to 8.7.

Satisfaction

A global measure of satisfaction was obtained by calculating a mean score from the four questions adapted from the Client Satisfaction Questionnaire (Larsen *et al.*, 1979). The scores had a possible range from one to four. The actual distribution of scores is shown below in Table 1.

Table 1. Distribution of satisfaction scores

Range of Satisfaction Scores	Frequency
1.00-2.00	0
2.25-2.50	1 (2%)
2.75-3.00	9 (17%)
3.25-3.50	12 (22%)
3.75-4.00	32 (59%)

The mean score was 3.6 (s.d. = 0.4). These scores show an extremely high level of satisfaction with groups. Perhaps this is not surprising, since people who were less satisfied might have been expected to have voted with their feet previously and left groups. However, as reported later, some people were able to voice their concerns while remaining members of their groups.

Despite the consistently high levels of satisfaction and the small degree of variation in scores, there were significant differences between groups ($F(5,48) = 2.82$, $p < .05$). The lowest mean group score was 3.3, for the group in which there was subsequent discussion of people's concerns about the group. The maximum group score was 3.9.

Not surprisingly, overall helpfulness and satisfaction scores were significantly inter-correlated ($r = .76$, $p < .001$).

3.2 CHARACTERISTICS OF MUTUAL SUPPORT GROUPS

This section describes the mutual support groups in terms of group environments,

social support and organisational characteristics, pattern of length of attendance,

distribution of giving and receiving emotional support and informal contact between

meetings. In each case the relationships with reported helpfulness and satisfaction are

investigated and reported.

Group environments

The mean scores for the four Group Environment Scale sub-scales are shown below

in Table 2.

Table 2. Mean scores for the four GES sub-scales.

	The present study		Moos (1986)	
GES sub-scale	M	SD	M	SD
Cohesion	8.3	1.0	5.5	2.0
Expressiveness	6.6	1.7	6.0	1.8
Task Orientation	7.8	1.3	4.6	1.8
Self-Discovery	6.2	1.7	6.5	1.8

Note. Possible sub-scale scores ranged from 0 to 9.

These scale scores show an extremely high level of cohesion within the groups, far higher than that reported in the 'psychotherapy and mutual support groups' investigated by Moos (1986). Unfortunately, the lack of information about sample sizes from Moos' (1986) study means that precise statistical comparisons are not possible.

However, it is still possible to provide an approximate comparison by estimating Moos' sample size. A conservative estimate would be 50 participants, and an alternative would be 200. The results using each estimate are reported.

Unlike the other three scales, there were no significant differences in this study between the mean cohesion scores for each of the six groups ($F(5,50) = 1.48$, n.s.), which when viewed in the light of the ceiling effect and hence very small standard deviation among the scores, shows that participants in all groups consistently reported extremely high levels of cohesion. The groups in this study were highly significantly more cohesive than the groups in Moos' study ($t(104) = 8.95$, $p < .001$ or $t(254) = 14.39$, $p < .001$).

Task orientation scores were also very high, with only a slightly larger variation than for cohesion, probably also due to the ceiling effect. They were significantly higher than those obtained by Moos ($t(104) = 10.38$, $p < .001$ or $t(254) = 14.86$, $p < .001$), although those also included psychotherapy as well as mutual support groups. Some of the mutual support groups in this study were involved in organising activities as well as, or sometimes rather than, talking emotionally, which would explain this

finding. There were significant differences between the mean task orientation scores

for the six groups $(F(5,50) = 3.84, p < .01)$, with group means ranging from 6.4 to

8.6, indicating that the groups varied significantly in the extent to which they

concerned themselves with tasks and activities.

Scores for the expressiveness and self-discovery scales were lower and varied more.

Group means for expressiveness ranged between 5.5 and 8.3 $(F(5,50) = 5.79, \quad p <$

.001). Overall groups in this study were significantly more expressive than those in

Moos' study $(t(104) = 1.76, p < .05 \text{ or } t(254) = 2.30, p < .05)$. Group means for self-

discovery in this study ranged between 4.7 and 7.6 $(F(5,50) = 5.75; p < .001)$.

Overall there was no significant difference in self-discovery ratings compared with

Moos' study $(t(104) = 0.88, \text{ n.s. or } t(254) = 1.15, \text{ n.s.})$.

As a preliminary exploration of the role of gender in these mutual support groups, the

characteristics of the four all-women groups were compared with those of the two

mixed groups. The all-women groups had significantly higher levels of reported self-

discovery $(F(1,54) = 10.46, p < .01)$.

In summary, participants in this study rated their groups consistently as extremely

cohesive. They were also very task-oriented, although the extent varied significantly

between groups. Groups differed enormously in the extent to which self-expression

and self-discovery were facilitated. For some groups this was their *raison d'être*,

while for others it was incidental. Reported expressiveness, and particularly cohesion

and task orientation, were significantly higher than Moos' (1986) previous study of

mutual help and psychotherapy groups. Members of all-women groups reported

greater self-discovery than members of mixed groups.

Relationships of GES sub-scales with helpfulness and satisfaction

The associations between the four GES sub-scales and reported satisfaction and

helpfulness are shown in Table 3.

Table 3. Correlations of GES sub-scales with satisfaction and helpfulness

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

** p < .01   *** p < .001

The degree to which people reported their groups as cohesive was highly correlated

with satisfaction scores, as those who perceived their groups to be more cohesive felt

more satisfied. Those who reported that their group provided more opportunities for

self-discovery also felt more satisfied, but in addition were more likely to rate their

group as more helpful.

Social support and organisational characteristics

The mean scores for the four support variables used by Maton (1988) are shown

below in Table 4.

Table 4. Mean scores for four social support variables

Support variable	M	SD
Role differentiation	5.9	1.6
Close friendship	5.8	1.3
Provide emotional support to others	5.5	1.4
Receive emotional support from others	5.6	1.2

Note. Response categories ranged from 1 (disagree strongly) to 7 (agree strongly).

All four support variables were rated highly. Unfortunately Maton (1988) does not

report the results obtained from these questions, so no direct comparison is possible.

Participants reported that roles were highly differentiated in their groups. However,

there were significant differences between groups ($F_{(5,47)} = 3.50$, $p < .01$), with

mean group scores between 4.2 and 6.9, as some groups relied almost exclusively on

a single co-ordinator while others were run by a committee. Participants reported

close friendships with other group members, although there were significant

differences between groups ($F_{(5,49)} = 3.34$, $p < .05$), with mean group scores ranging

from 4.2 to 6.5.

The mean scores for providing and receiving emotional support were both high and were similar to each other. There were significant differences between groups, with group means for providing support between 4.4 and 6.5 ($F(5,49) = 3.33$, $p < .05$), and for receiving support between 4.8 and 6.4 ($F(5,48) = 2.54$, $p < .05$). Those groups with higher mean scores for providing emotional support tended to have higher mean scores for receiving such support. At the individual level, these two variables were highly correlated ($r = .47$, $p < .001$).

Relationships of social support variables with helpfulness and satisfaction

These four social support variables were correlated with satisfaction and overall helpfulness to replicate Maton's (1988) results from a sample of bereaved parents from the organisation 'Compassionate Friends'.

Table 5. Correlations of social support variables with satisfaction and helpfulness

	Contact a Family - this study		Compassionate Friends - 1988	
	'Satisfaction'	'Helpfulness'	'Satisfaction'	'Benefits'
Role differentiation	-.13	-.04	n.k.	n.k.
Friendship	-.04	.08	.01	.53**
Support provided	.04	.13	-.05	.30*
Support received	.42**	.50**	.47**	.26

* $p < .05$ ** $p < .01$ (n.k.: not known)

Table 5 shows that the degree to which parents felt that they received emotional support from other members was significantly related to their reports of satisfaction with their groups. This finding confirms that of Maton (1988). Support received was also significantly related to global ratings of overall helpfulness. Perhaps this is not surprising given that satisfaction and helpfulness were themselves highly correlated, although it is a finding that was not obtained by Maton when using a slightly different but comparable measure of 'benefit'. Conversely, Maton found that the other support variables measuring the extent of friendships with other group members and of providing emotional support to others were significantly related to his measure of benefit, whereas there were no significant relationships between those variables and either satisfaction or helpfulness in this study.

Length of attendance

Unsurprisingly, length of attendance at mutual support groups was significantly correlated with providing support to others ($r = .34$, $p < .05$). Nevertheless, it would appear that it is just as important for more experienced members to feel that they receive adequate support from others as it is for newer members, if they are to feel satisfied with their group. Length of attendance was not significantly related to either helpfulness or satisfaction.

Bi-directional support

According to Maton (1988), the two variables of providing and receiving emotional

support can be used to create categories of 'bi-directional support', by dividing each

variable at its median. Eighteen individuals (33 per cent) who scored above the

median for both providing and receiving emotional support were labelled 'bi-

directional supporters'. Ten people (18 per cent) were above the median for receiving

but below the median for providing support and were labelled 'receivers'. Eight

people (15 per cent) were above the median for providing but below the median for

receiving support and were labelled 'providers'. Eighteen people (33 per cent) scored

below the median for each and were labelled 'lower supporters'.

Relationships of bi-directional support with helpfulness and satisfaction

Maton (1988) used these same categories in his study to examine the relationship

between bi-directional support and satisfaction of mutual support group members.

Table 6 shows a comparison of the mean rating scores for satisfaction and helpfulness

across the four categories of bi-directional supporters, unidirectional supporters

(providers and receivers) and lower supporters.

Table 6. Mean satisfaction and helpfulness scores for four categories of mutual

supporters

	Satisfaction [a]	Helpfulness [b]
Bi-directional supporters	3.7	8.6
Receivers	3.9	8.6
Providers	3.3	7.8
Lower supporters	3.4	7.8

[a] Possible satisfaction ratings ranged between 1 and 4.
[b] Response categories for helpfulness ranged from 1 (extremely unhelpful) to 9
(extremely helpful).

Analyses of variance of satisfaction scores ($F(3,49) = 4.29$, $p < .01$), and of

helpfulness scores ($F(3,50) = 2.85$, $p < .05$) were each significant. This might be seen

to support Maton's bi-directional support hypothesis. However, by inspection of

Table 6 it would appear that it is the extent of emotional support received,

irrespective of whether people also provide it to others, which is related to appraisals

of satisfaction with and helpfulness of groups. This is contrary to Maton's finding

that bi-directional supporters reported more positive appraisals than all other

categories including so-called receivers.

To investigate this further, analyses of variance of satisfaction and helpfulness ratings

were conducted with the median-split 'receiving' and 'providing' variables as

independent, explanatory factors. The analysis of variance of satisfaction scores

showed that the main effect of receiving emotional support from others was highly

significantly related to satisfaction ($F(1,52) = 12.65$, $p < .001$). Neither the main

effect of providing emotional support to others (F(1,52) = 1.22, n.s.) nor the interaction effect between receiving and providing (F(1,52) = 0.06, n.s.) was significant. Similar results were obtained regarding helpfulness ratings. Receiving support was significantly associated with helpfulness (F(1,53) = 7.62, p < .01), while neither the main effect of providing support (F(1,53) = 0.01, n.s.) nor the interaction effect (F(1,53) = 0.01, n.s.) were significant.

These findings indicate that parents rate their satisfaction with their groups solely according to the amount of emotional support which they receive, and not according to the extent to which they can also become involved in helping others. Contrary to Maton's (1988) findings, it is those who reported receiving adequate emotional support from others who were most satisfied with their mutual support groups, regardless of the amount of help which they provided to others.

Informal contact between meetings

Table 7 below shows the extent of informal contact with other members between meetings for the entire sample.

Almost half of the sample reported having contact with other members between meetings at least once a week. This emphasises the ongoing impact which mutual support groups have for their members outside the times when they have formal meetings.

Table 7. Pattern of informal contact between mutual support group members

Amount of contact between meetings	Number of responses
Never	3 (6%)
Once a month	12 (26%)
Once a fortnight	12 (22%)
Once a week	15 (27%)
More than once a week	11 (20%)

The ongoing availability of support which members offer each other was important for the vast majority of parents, as only 6 per cent reported that they had no contact with others between meetings. The amount of contact between meetings was not significantly related to either satisfaction or helpfulness.

Summary of relationships of group characteristics with helpfulness and satisfaction

These findings provide some evidence for identifying which group characteristics are related to the extent to which members report their mutual support groups as helpful and satisfactory. A consistent finding is that the amount of emotional support which members receive is strongly related to how helpful and satisfying they find their group. Contrary to Maton's finding (1988), this relationship is unaltered by the extent to which people also provide emotional support to others. Helpfulness and satisfaction are associated only with receiving support.

In addition, there are certain aspect of the group environment which are positively

associated with reported helpfulness and satisfaction. Cohesion, namely the degree of

members' involvement in and commitment to the group, and their concern and

friendship they show for one another, is strongly associated with reported satisfaction.

Self-Discovery, namely the extent to which the group encourages members'

revelations and discussions of personal information, is strongly associated with both

reported helpfulness and satisfaction.

3.3 WHAT IS HELPFUL ABOUT MUTUAL SUPPORT GROUPS?

This was the main research question of this study. Quantitative results are presented

first, followed by the qualitative results obtained from individual participants'

questionnaires. Finally the qualitative results obtained from focus group discussions

are presented.

Quantitative results

Table 8 shows the mean scores for the nine elements of support first reported by

Gottleib (1982), alongside Gottleib's own findings for his sub-sample of 'one-step

removed' mutual support groups, in which members are close relatives of someone

with an identified 'problem'.

Table 8. Mean scores for nine elements of mutual support

Element of support	M	SD	Gottleib (1982)
Helping others	5.7	1.3	5.8
Help from others	6.2	1.1	6.0
Coping strategies	6.1	1.2	6.3
Sense of community	6.1	1.1	6.1
Coping with public attitudes	6.2	1.2	5.7
Factual information	6.5	1.0	6.3
Spirit of hope	6.3	1.0	5.6
Self-confidence	6.1	1.1	6.3
Meeting others with similar problems	6.5	0.8	6.2

Note. Response categories ranged from 1 (very unhelpful) to 7 (very helpful).

Parents in this study reported that they had found all nine elements of support helpful. The most helpful were the opportunities to meet others with similar problems and to share factual information. The only element with a mean score of lower than six out of seven was helping others. The finding that this is of slightly less help supports the previously reported findings that providing help to others is not quite so beneficial to parents in this sample, although it was still consistently rated as helpful.

Most of the results are very similar to Gottleib's and so provide a good replication. The lack of any statistics other than means from Gottleib's study means that formal

statistical comparison is not possible. Nevertheless it is still reasonable to state the

similarities between the two studies, as well as noting two differences in relation to

coping with public attitudes and spirit of hope. The former may be more important to

this sample because their children's 'problems' - either their disability or behaviour -

are very visible and tend to provoke strong reactions from others. The latter may be

more important because of the significance of parental hopes for their children's

future.

A series of analyses of variance showed significant differences between groups in the

mean scores for two of the elements of support, namely helping others ($F(5,47) =$

3.75, $p < .01$), where mean group scores ranged from 4.6 to 6.5 and increased self-

confidence ($F(5,50) = 2.54$, $p < .05$), with mean group scores between 5.4 and 6.8.

Qualitative results - Questionnaire data

In the first stage of open coding 164 categories of response or 'meaning units' were

identified from the questionnaires. The next stage of the grounded theory approach

was to use these responses to generate second-level categories, where the meanings

of all items contained within each category could readily be seen as similar. A total of

27 second-level categories were identified. For each of these second-level categories,

the number of respondents who gave responses falling in each category was recorded.

The second-level categories are presented below, each consisting of a label, frequency

and definition. Unlike the results of the focus group discussions presented later, there

was no scope to elaborate on the definitions provided by participants' written

responses, since written questionnaire responses rarely provide the richness of material required to make elaborations meaningful or interesting. Hence each category is simply defined. Participants' own words are reported in quotation marks.

1. Hard information (86%)

Information relating to the primary problem of disability, and to the availability of help, local services and benefits and entitlements.

2. Fellowship (66%)

Meeting others in a similar situation; feeling understood by others because of their similar situation; a sense of mutual recognition among 'people in the same boat' in a way that is accepting and not stigmatising. 'Fellowship' was the word used by one participant to describe this bond of recognition, understanding and acceptance among group members.

3. Feeling not alone (59%)

No longer experiencing physical, social and psychological isolation; feeling 'not the only one having to face these problems'.

4. Practical advice/strategies (55%)

Hearing how others coped with similar difficulties or situations, and what others found useful in dealing with both the primary problem (disability) and its consequences for the child (e.g. difficult behaviour), professionals (e.g. strategies for

dealing with education authorities) and the general public (e.g. strategies for dealing with people's reactions to one's child).

5. Sharing worries and other emotions (52%)

Expressing anxieties and painful feelings which may be difficult to express in other contexts.

6. Increased self-confidence (45%)

Feeling more confident as a result of being a part of the group.

7. Friendship (34%)

Friendships which develop over time with other group members which are not restricted to group meetings.

8. Normal(ised) social activities (self; family; unspecified) (32%)

Social life for parents, providing a peer group, regular friendships. Normal activities for parents and children together 'as a whole family'.

9. Valuing one's child (32%)

Having a greater understanding of one's child and her/his disability, as well as valuing one's child in her/his own right, for what s/he is able to do as well.

10. Feeling happier, more relaxed (30%)

Feeling less tense, more relaxed and happy as a consequence of being a part of the group. 'Feeling less bitter and not asking "why me?" so much'.

11. Normal(ised) social activities (children; siblings) (29%)

Activities organised by groups provide opportunities for disabled children and their siblings in terms of the activities themselves and peer groups.

12. Understanding others' problems, disability issues generally (23%)

Being more understanding and tolerant of others' difficulties and disability generally.

13. Non-judgmental acceptance/openness/welcome (18%)

'A warm welcome' which was felt to be caring, friendly, accepting and non-judgmental, in contrast to other settings. This was reported particularly in relation to the early stages of group membership and attendance.

14. Positive group attitude/strength (18%)

With the exception of two references to 'positive group spirit' and 'positive group attitudes' in reply to the specific questions, a number of people commented on the 'strength' of the group and their feelings of 'pride' when asked if there was anything else that they would like to say at the very end of the questionnaire.

15. Helping others (16%)

Advising others, being able to provide help, or to exchange help. Feeling positive knowing that one is helping and able to help others.

16. Access to professionals and outside speakers (14%)

Visiting speakers have first hand information and can answer questions directly. Speakers come to talk to the group on members' terms, in contrast to individuals going to talk to professionals on their terms.

17. Hope (13%)

A sense from other group members that things can be different.

18. Availability of support (13%)

Informal support from other group members is available whenever it is needed. People only 'just have to pick up the telephone'. It is not restricted to group meetings, and does not need to be arranged through appointments like professional help.

19. No personal change (13%)

People have not changed as a result of belonging to the group.

20. Humour (11%)

The group offers an opportunity to laugh, in a context where the need for humour is understood and people can laugh without feeling guilty, awkward, or needing to explain themselves.

21. Opportunity for organising (11%)

Involvement in organising a group offers 'a role in life', 'an outside interest', a reclaiming of 'a life of my own', as well as an opportunity to develop organisational skills.

22. Belonging (9%)

Being a part of something which is active and worthwhile, and which is 'important in the community'.

23. Long-term support over time (9%)

Support which is continuous and long-term, and which changes over time according to one's changing needs as one's child gets older.

24. Increased self-awareness (7%)

Increased 'self-reflection', 'self-evaluation' and 'personal growth' as a consequence of being part of the group.

25. Feeling more prepared for the future (5%)

Group membership helps to prepare for the future, by 'being more aware of my

child's future needs'.

26. Force for political change (5%)

The group is a 'force' for changes in the way in which local services are provided.

Pride and satisfaction in being part of something which is 'visible' and noticed in the

local community.

27. Newsletter important (4%)

The group's newsletter is an important, and in some cases the only, means of

communicating to members.

The next stage in the grounded theory approach was axial coding, in which these

second-level categories are structured into a smaller number of higher level clusters.

The 10 third-level categories which emerged are:

1. *Knowledge* - hard information; access to professionals; newsletter.

2. *Community* - fellowship; not alone; friendship; acceptance; belonging;

understanding disability.

3. *Normalisation* - normalised social activities for parents and children.

4. *Sharing emotions* - sharing worries; humour.

5. *Sharing strategies* - practical strategies.

6. *Agency* - organising; political change; helping others.

7. *Ideology* - positive group attitude and strength.

8. *Time dimension* - long-term; availability; preparing for the future.

9. *Personal change* - self-confidence; happy/relaxed; self-awareness; hope; none.

10. *Valuing one's child.*

In turn, these generate three fourth-level categories.

1. *Empowerment* - knowledge; strategies; agency; ideology.

2. *Togetherness/participation* - sharing emotions; community; normalisation; over time.

3. *Self change* - personal change; valuing one's child.

These three categories also emerged from a replicated grounded theory analysis undertaken by a second researcher experienced in the grounded theory approach and methods.

Finally, a single fifth-level category was generated, namely *identity*. In this way a model emerges which proposes that the experience of being a member of a mutual support group for parents of children with disabilities is one of *identity change*. The experience of identity change is both process and outcome. Identity change can be viewed in terms of empowerment, participation and self change. Empowerment incorporates changes from ignorant to knowing, from passive to active, encompassing identity change in relation to citizenship and political agency as well as one's values, attitudes and beliefs. Participation incorporates social changes from isolation to belonging, individual to community, and stigmatised to normalised, encompassing

identity change in relation to one's social identity in particular. Self change

incorporates intra-individual changes in psychological well-being, mental health and

mood states. These domains together describe a process of identity change at the

socio-political, inter-personal and intra-individual levels.

Qualitative results - Focus group 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. The next stage of the

grounded theory approach was to use these data to generate second-level categories,

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 are defined

and elaborated below, based on the spoken words of participants in the focus group

discussions. Verbatim reports are recorded in quotation marks or in separate

italicised paragraphs. No frequencies of occurrence were recorded as it was not

appropriate given the different courses of the focus group discussions.

1. Information

Definition. Knowledge and awareness provided by the group's resources, other

individual group members and visiting professional speakers, about the primary

problem, namely the disability, and also about possible sources of help including

statutory services, benefits and entitlements.

Elaboration. Information is vital for enabling newer group members to become more

aware of the problem. Members of groups which had outside speakers thought them

interesting and a valuable source of first hand information, and were able to ask

questions. Information from other group members was important because it was

trustworthy and reliable, coming from the same perspective rather than that of a

professional. People appreciated learning about what questions to ask of

professionals. Some groups had built up their own resources, including lending

libraries and regular newsletters. Through these informal and formal means there was

felt to be a 'stock of knowledge' in groups. Many people talked about the

empowering consequences of possessing information. The information available

reduced people's uncertainty and sense of 'not knowing'. '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.' 'Knowledge is power' was one person's view, echoed

by many others who reported how their groups had helped them to learn a new

language and terminology which was essential when communicating with

professionals.

> *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.*

2. Advice

Definition. Sharing ideas and strategies for coping with difficulties based on the personal experience of group members.

Elaboration. Many people reported the value of using the experiences of others to help them solve problems or replicate strategies for coping with their children and with the reactions of others, both the general public and professionals.

3. Relationships with professionals

Definition. The role of the group in taking up issues in a way that is collective and political rather than simply leaving it up to individuals alone.

Elaboration. Many people talked about 'fights' and 'battles' with professionals. Some talked about 'having to teach professionals because as parents we often are more expert than professionals'. Groups provided a source of 'ammunition', both factual and emotional, for the 'fight'. People felt stronger knowing that others were having similar 'battles' and some successes, and also because of the local political force of some groups. Some people described their groups as 'a pressure group' with representation on local committees, as 'a political power' with 'a political reputation'. Groups took on the role of 'fighting ignorance and judgements' at the political level, providing individual members with encouragement and strength. Members of one group endorsed the view that their group was 'more than a collection of individuals'.

> *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.*

Taking on issues as a group also meant that people were fighting for and advocating on behalf of other children and not just their own, and so what they were doing was 'not selfish'. Members of one group described good links and relationships with local professionals who were 'caring and supportive', as shown by their attendance at the group meeting. One consequence was the high level of awareness of the group among professionals who referred parents of newly diagnosed children to the group.

4. Helping others

Definition. The opportunity to provide support to others, usually after having been recipients themselves.

Elaboration. People mentioned the opportunity to pass on help, often over time. The typical experience 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. The importance of the informal nature of helping others was also mentioned, by virtue of it being instantly available and not just restricted to group meetings or to appointments like professional support. 'We can get help and support at the time when we need it ... Support is always available. There's no waiting for an appointment.'

5. Awareness of others and of disability issues more generally

Definition. A change in attitude towards others with problems and disabled people generally.

Elaboration. Some people reported that they were more aware and tolerant of others' problems as a result of group membership. They felt and expressed less 'sentimental pity', 'horror' and 'embarrassment' towards other disabled children. 'It helps because you become more aware of other people's difficulties, and more tolerant.'

6. Sharing the experience

Definition. Finding out that there are other people who have experienced and are experiencing the similar range of problems and difficulties related to having a child with disabilities.

Elaboration. Many people reported that they felt 'less alone', 'less isolated', 'not the only one', 'not different any more', as a result of attending their group. 'I felt I was alone. It helped so much to know there's other people in the same situation as me.' 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. '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.' People were able to feel that they were 'not the only one' with both the primary problem of a disabled child, and also the secondary problems of dealing with the reactions of others.

7. Sharing emotions

Definition. Expressing a range of emotions with other people who empathise and are not judgmental.

Elaboration. Groups provided an important opportunity for 'letting off steam' for many people. Many people talked about sharing their pain in their group. In one discussion some people cried as they described their feelings of anger and grief at having a disabled child. '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.' People 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.

8. Friendships

Definition. Groups provide opportunities for making friends, providing peer groups for parents, children and siblings.

Elaboration. Members of some groups talked about the importance of the social life and social activities they enjoyed together. In some groups parents (mothers) were friends with each other, and activities and events organised by some groups provided new opportunities and a peer group for children and their siblings, as well as parents. In one group this was contrasted with people's experiences of other mother and toddler groups where disabled children and their families felt stigmatised.

9. Belonging

Definition. The feeling of belonging, being part of a group.

Elaboration. This was felt to be important by many people. 'It's the only place where I feel I belong.' One person said that 'you feel like you're part of the human race again'. However, it was something that was not easy to articulate. The honesty of someone from another group hints at a possible reason for the difficulty in acknowledging a sense of belonging to the "world of disability". 'It's like being in a club which no-one wanted to join'.

10. Being understood

Definition. Being with others who are able to understand and empathise with the problems facing members.

Elaboration. Many people described 'being understood' as the most helpful part of attending their group. 'It's knowing that you are comprehended that is one of the most important things.' Being with people in the same situation, who take an interest and who understand is very important for group members. 'You get more support from other parents who have some kind of problem with their child.' Some people 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 people to be somewhere where there was no need to explain oneself or to make excuses, or to feel 'on show'. People in one all-women group said that it was the understanding of other mothers that was important, as '99 per cent of fathers do not feel the same'. The importance of feeling understood by other group members was encapsulated movingly by one participant:

> *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 you 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 all 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.*

11. Personal change

Definition. People reported various ways in which they felt they had changed as a

result of being a member of their group.

Elaboration. Many people 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 even 'bolshy', and felt less intimidated, inhibited,

embarrassed, awkward and shy. People said that their group helped them to feel

'refocused' and 'strengthened'. People also described changes that were more

internal. People 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.

12. Relationship with child(ren)

Definition. Some people reported that their relationship with their disabled child had

changed, or that they viewed their child differently.

Elaboration. Some people 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. Someone from a different group was

honest in admitting that she was able to compare her child with those of others in her

group, and that she felt grateful as a result that her child was not as disabled as some

others. 'There's always someone worse off than you'. Some people said that their

'parenting approach' had changed as a result of belonging to the group, that their

children were 'more stimulated' and that some children's behaviour had improved.

The next stage of grounded theory analysis was axial coding, where these 12 lower-

order categories were merged into three higher-order categories, thus:

1. *Control/agency in the world* - information; advice; relationships with professionals;

helping others.

2. *Community/belonging* - awareness of others and disability; sharing the experience;

sharing emotions; friendships; belonging; being understood.

3. *Self change* - personal change; relationship with child(ren).

The final stage of any grounded theory analysis is for a single category to emerge

from the data, if such a step is appropriate and meaningful. It would appear that the

theme of *identity change* is superordinate to these three categories of relating to

others in the external world, belonging to a community of people who share and

understand, and changes in one's self and functioning.

Summary

The results obtained from the grounded theory analysis of the data from the focus

group discussions confirm those obtained from the analysis of individuals' written

questionnaire responses. While the lower-order categories which emerge in the two

grounded theory analyses do differ, the higher-order categories are similar, and each source of data leads to the same core category of identity change. Three higher order categories consistently emerge from both sources of data, broadly encapsulating three ways in which individuals are helped to change in relation to socio-political, interpersonal and intra-individual spheres, as a result of attending and belonging to mutual support groups.

The first domain of change for people which is facilitated by mutual support groups is developing a sense of control and agency in relation to the outside world in general and professionals in particular. Members are helped to feel empowered through gaining knowledge and obtaining information, giving and receiving advice, as well as the less tangible influence of the ideology of mutual support. Identity change occurs in terms of empowerment with respect to the external world, along dimensions such as control, agency and active citizenship. For example, people change from feeling ignorant to becoming knowledgeable, from feeling a victim to regaining some control and agency, or from being a receiver to being able to give to others, or at least being more able to negotiate with those providing help.

The second area in which people benefit from mutual support groups is having a sense of participation in a community of others in a similar situation. People are enabled not only to realise that they are not the only one in their situation, but to meet and be with others 'in the same boat' over time, in a context where there is mutual understanding and acceptance. Members can express their emotions with each other and are readily available in and out of meetings. Groups provide individual members with a setting

where they can feel part of a community, where they can feel valued and 'normal', as opposed to feeling isolated from society and stigmatised, and where they can feel that their experience is truly understood. Identity change occurs in terms of one's social identity, comparison or peer group. For example, people change from feeling alone to receiving recognition, from feeling isolated to feeling a part of something, from feeling stigmatised to being part of a valued group.

The third way in which mutual support groups benefit their members is through helping to enable individuals to change internally. People feel less depressed, less anxious and more confident. Parents of children with special needs also improve their relationships with their children as a result. Identity change occurs within individuals in terms of one's self-identity, including one's self-esteem. For example, people change from feeling weak to feeling strong, from feeling depressed to being more assertive and confident.

3.4 WHAT IS UNHELPFUL ABOUT MUTUAL SUPPORT GROUPS?

Participants were given the opportunity to say what, if any, were the unhelpful aspects of their mutual support groups. Results from the questionnaire responses and group discussions are presented below.

Questionnaire data

One questionnaire item asked participants to say what had been most unhelpful aspects of group meetings. A grounded theory approach was used to analyse the responses, together with a frequency count for each category. Twelve categories emerged.

1. Nothing unhelpful in group meetings (32%)

2. Discussions hijacked/monopolised/dominated (11%)

3. Lack of time to talk (7%)

4. Irritation with other members (5%)

5. Hopes dashed by confrontation with reality (5%)

6. Irrelevant discussion (5%)

7. Meetings too structured (4%)

8. Frustrations with professionals (4%)

9. Feeling let down by the group (4%)

10. Lack of minority ethnic membership (4%)

11. Too political (2%)

12. Too time-consuming (2%)

The most common response was that there was nothing unhelpful about group meetings. A number of questionnaires also had no response at all to this question, suggesting that for others too there was nothing unhelpful to report. While few

responses cited unhelpful aspects of groups, it was possible for two broad categories

to emerge, namely structure and content.

1. *Structure* - lack of time; too structured; lack of minority ethnic membership; too

political; too time-consuming.

2. *Content* - discussions hijacked; irritation with others; hopes dashed by reality;

irrelevant discussions; feeling let down by the group; frustrations with professionals.

Focus group data

Concerns about the groups were raised in focus group discussions with two groups,

briefly at one and at greater length at another. These were around 'structural' issues

rather than 'content', possibly because the latter incorporated a number of concerns

which might be personal with regard to other group members.

In one focus group discussion the subject of the limitations of the group was raised,

and people spent some time discussing their frustrations and concerns about the

group. One person said that 'I give more than I get'. This prompted a discussion

about the developmental history of the group, and it was agreed that while the group

was extremely helpful for those with younger children, the few members with older

children felt that there was less on offer for them. The discussion then broadened out

to consider a variety of people who, by their absence, possibly highlighted some of the

limitations of whom the group could support, including those with older children,

black parents, men, and those with children who were much more disabled.

It was reflected back to this group that it was an indication of the strength within it that such concerns could be raised and discussed so openly.

In another group people thought that it was certain types of people who attended groups. Such 'groupies' had to be sufficiently confident initially to go to a group in the first place. Thus groups might not be able to help those parents substantially lacking in confidence.

Summary

There were relatively few reports of unhelpful aspects of groups. Nevertheless people were able to report their concerns, both on paper and, in two instances, in group discussions. Through the 'private' medium of written responses, people reported concerns with both structural issues about the organisation of their groups and also more interpersonal difficulties in the content of the group meetings themselves. In the more 'public' forum of focus group discussions two groups were open enough to discuss some structural concerns and limitations of what they were able to achieve.

OVERVIEW OF CHAPTER FOUR: DISCUSSION

This chapter begins with a brief summary of the research questions, methods and main findings of this study. It then interprets the findings in the context of the research questions, the existing literature concerning mutual support processes and families with disabled children cited in Chapter One, as well as other areas of psychological literature which enhance an understanding of the findings. Limitations of the study are described, and some suggestions for further research are made. Finally, the scientific, practical, professional and clinical implications of this study are outlined.

4.1 SUMMARY OF THE AIMS, METHODS AND FINDINGS

This study aimed to enhance understanding of mutual support groups run by and for parents of children with disabilities and special needs, by finding out how helpful members found their groups, the characteristics of their groups, and the nature of any relationships between the two, and by discovering in detail what parents of disabled children found helpful about mutual support groups. A sample of six groups affiliated to Contact a Family, a national charity, participated, and each group was visited once. Questionnaires were completed by 56 individuals, and five focus group discussions were conducted. Quantitative and qualitative data were collected and analysed.

Participants found their groups extremely helpful, reporting high levels of satisfaction. All groups were very cohesive, while groups varied more in other characteristics.

Apparently different groups had different aims and served different functions.

Satisfaction levels were related to the amount of emotional support received from

others, as well as levels of cohesion and self-discovery within groups. A range of

helpful processes and benefits from mutual support group membership were reported,

classified in terms of three domains of identity change, namely empowerment in the

socio-political domain, belonging to a community at the inter-personal level, and

personal identity change at the intra-individual level. Some unhelpful aspects of the

structure of mutual support groups and the content of meetings were also reported.

4.2 INTERPRETING THE FINDINGS

This section is divided into two parts. First, the results of measuring the helpfulness

and characteristics of mutual support groups are discussed in relation to the three

preliminary research questions. Secondly, the findings obtained from the investigation

of the study's main research question are interpreted.

Helpfulness and characteristics of mutual support groups

How helpful are mutual support groups?

It is not surprising that mutual support groups were found to be so helpful by their

members. One might assume that anyone who felt less positive about belonging to

such a group would 'vote with their feet' and 'cancel their membership'. It is highly

likely that this does happen, and the problem of sampling bias is explicitly

acknowledged in the literature (e.g. Goldklang, 1991; Levy, 1979) and was outlined

in Chapter Two.

However, this study shows that members were able to express concerns and

dissatisfaction with their groups while 'retaining' their membership. This indicates

that some members of mutual support groups would prefer to remain part of a valued

group which enhanced their social identity, even if they had grievances. This would

be predicted by social identity theory (Tajfel, 1981), and by Hirschman's (1970)

account of the options of 'Exit, Voice and Loyalty' available to people in social

groups. Briefly, people may choose to remain 'loyal' to a valued group rather than

leaving ('exit'), and may seek to improve their social identity by improving the status

of the group through social and political action ('voice'). These accounts are

elaborated upon below in more detail.

What are the characteristics of mutual support groups?

Participants in all groups reported consistently high levels of cohesion. If the creation

of a safe, supportive, benign and cohesive environment for their members is, as some

argue (e.g. Humphreys & Rappaport, 1994; Levy, 1979), a desirable 'outcome' of

mutual support groups, then all groups participating in this study had been extremely

successful. There was, however, more variation between groups in other

characteristics, reflecting the different aims and functions of different groups. Broadly

speaking, groups in this study had one of two primary functions, either focussing

mainly on emotional support, expressiveness and self-discovery, or concentrating on organising activities for members and being more political in the local community. This variation in turn reflects sensitivity to a number of factors including local needs, the provision of local services, and the skills and interests of the people involved.

Much of the mutual support group literature assumes that groups are basically the same, due to at least three possible reasons. First, most of the literature in this area comes from the USA where mutual support organisations provide groups (or 'branches') with explicit ideologies, literature and written programmes. Secondly, most of the research literature concerns groups of adults with mental health problems, notably addiction, and so once again written programmes predominate. Thirdly, the literature ignores variations in other aspects of identity such as race and gender.

In contrast, however, this small study of only six groups highlights the heterogeneity of British mutual support groups in this area. Future studies in this area should take account of, and explore further, the variations between mutual support groups, rather than falsely assuming homogeneity among groups. This is particularly the case for studies undertaken in the UK, where there is a paucity of knowledge, and in areas other than adult mental health, particularly among so-called 'one-step removed' groups, where there is a potentially wide range of ways in which mutual support groups can help their members, as well as exploring further the impact of gender in mutual support group processes.

What are the relationships between group characteristics and helpfulness?

One caution about the firmness of conclusions drawn about any relationships between group characteristics and helpfulness is the ceiling effects of reported helpfulness and satisfaction. Nevertheless, a number of statistically significant findings were obtained. Certain group characteristics were positively associated with reported helpfulness and satisfaction. Cohesion, namely the degree of members' involvement in and commitment to the group, and their concern and friendship they showed for one another, was strongly associated with reported satisfaction. Perhaps this is not surprising. In addition, however, Self-Discovery, namely the extent to which groups encouraged members' revelations and discussions of personal information, was strongly associated with both reported helpfulness and satisfaction. This finding may be slightly more surprising, given the variety of aims and functions among different mutual support groups, and may have implications for groups of all types. Even those groups which focus more upon organising activities and politicised action would appear to be most helpful to their members if they also provided an opportunity for disclosure and discussion of personal information. There might also be implications for 'single sex' and 'mixed sex' groups, since Self-Discovery was significantly higher in all-women groups than in mixed groups.

The amount of emotional support which participants received from other group members was strongly and consistently related to how helpful and satisfying they found their groups. This association was unaltered by the extent to which people also provided emotional support to others.

One explanation for this finding is simply that people are not helped by becoming

helpers themselves, casting doubt on the 'bi-directional support' hypothesis (Maton,

1988), the 'helper therapy principle' (Riessman, 1965), and the importance of altruism

as a curative factor in therapeutic groups (Yalom, 1975).

Another possible explanation is that, while helping others does offer benefits to those

able to do so, relatively few people are able to take on this role. Only some people

may ever be able to provide help to others. In particular, such is the situation of

parents with disabled children that many may remain perpetually needy and unable to

offer help to others. However, such a conclusion would run counter to other

evidence obtained in this study, in which participants described their groups as places

where they could receive various kinds of help and support from other members.

A third explanation is that only some people are willing to take on a more active

helping role. Other members of mutual support groups may leave after they have

received help from the group, before they have reached a stage at which they are able

to give help to others, leaving fewer people to take on a helper role. The lack of an

association between providing help to others and satisfaction may have been due to a

relative lack of 'helpers' in the sample. However, although providing help to others

was not related to the outcome measure 'satisfaction', nevertheless it was cited as a

valuable helpful process by a significant minority (16 per cent of the sample). Helping

others was particularly important for group organisers, and it is highly likely that the

importance of helping others increases over time. (As one participant said, 'Initially

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you get the help, then once you're into it you can start to help others, and you start

giving back to others.')

This final explanation highlights a limitation of a 'snap-shot' study such as this,

because the balance of mutual support processes is dynamic and changes over time. It

also highlights a similar criticism of the literature in this area, which tends to describe

mutual support group processes as static, with little or no account of the changing

nature of what may be helpful for mutual support group members. This limitation is

discussed below.

What do parents find helpful about mutual support?

While the original goal of grounded theory was to build comprehensive theoretical

systems from samples of data, it has come to be more commonly used to reach more

achievable goals including basic taxonomy development, focussed conceptual

development, and cycles of interpretation (Pidgeon & Henwood, 1996). Analyses of

data from participants in this study have produced a detailed classification of helpful

mutual support processes, which form a hierarchical taxonomy based on different

components of identity and sense of self. Much of the mutual support literature

simply provides lists of what is helpful, as summarised in Chapter One. The

development of a hierarchy of classification according to different aspects of identity,

and consequently identity change, which incorporates the social and inter-personal as

well as the individual, is a positive development (possibly a first 'cycle of

interpretation' in Pidgeon and Henwood's terminology) towards a more sophisticated conceptualisation of what people find helpful about mutual support groups.

The emergence in the analyses of different domains of identity transformation - social, inter-personal and intra-individual - focuses interpretation in terms of the specific contributions which different areas of general psychological literature can make towards the further development of conceptual understanding of mutual support processes. Consequently mutual support groups can be seen less as something totally unique requiring their own, separate theory, but rather as offering their members unique opportunities to enjoy the benefits of general psychological and social psychological processes.

Participants experienced changes in the ways in which they defined themselves in relation to the outside world both individually and as part of the community of group members, with consequences for their sense of self and psychological well-being. These processes can be analysed using different psychological frameworks, in particular those based on cognitive, social psychological, social constructionist and psychoanalytic models of identity formation and identity change. Cognitive approaches are usefully employed when discussing changes in the ways in which people see themselves in relation to the outside world, in their interactions in the social and political domain, and the consequences for one's self-esteem and personal identity. Social psychological, social constructionist and psychoanalytic approaches provide a valuable framework for analysing changes in people's relations to and interactions with their immediate mutual support group community, and the

consequences for one's social identity and sense of self. This distinction is meant to aid understanding rather than as a definitive dichotomy, and is not intended to rule out other conceptual frameworks.

Changes in identity in relation to the public domain

Participants reported that information and advice - i.e. knowledge - and a sense of agency and control were important. These all contributed to a sense of empowerment, in terms of an increased sense of control and reduced dependency. As discussed below, people felt empowered through learning and increased self-efficacy, changes in attributions, and social comparison processes.

Advice and ideas about ways of coping from people who have had similar experiences is a form of vicarious learning, which affects 'self-efficacy' (Bandura, 1977), namely one's beliefs, expectations, abilities and confidence to persist at and overcome aversive situations and problems. Access to information also increases self-efficacy by increasing one's sense of perceived control over a situation. Parents reported increased self-efficacy through access to information, advice and ideas from others, as a direct consequence of their membership of mutual support groups. For many this led to increased self-esteem. For some parents, their increased self-efficacy contributed to, and in turn resulted from, their confidence in 'taking on' issues that were not simply personal but also social and political, by organising groups and becoming political. The comparison with Gottleib's (1982) 'one-step removed' groups indicated that parents in this sample were particularly helped by a spirit of

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hope and learning how to cope with public attitudes. These can be viewed as two aspects of self-efficacy when relating to the outside world.

Parents also experienced a sense of empowerment and increased control through changes in attributions as a result from their group membership. Parents reported that simply by attending groups, they were able to establish that they were meeting others in a similar situation, or in Kelley's term they were able to exchange 'high consensus information' (Kelley, 1967). Parents reportedly shifted their attribution of the 'cause' of their child's disability from an internal, self-blaming attribution to one that was more external and situational, often resulting in less guilt and improved self-esteem. This accords with the findings of studies linking attributional styles and depression (e.g. Abramson, Seligman & Teasdale, 1978). Parents also tended to shift their attributions of the 'effects' of their child's disability, from viewing consequences as uncontrollable to seeing them as more controllable, thus altering their self-perception from one of victimhood towards one of agency and control over what happened to them and their children. This also had consequences for parents' self-esteem.

Support for the empowering effects of improved self-efficacy and more adaptive attributions comes from a third source, social comparison theory (Festinger, 1954), which states that people have a drive to compare themselves with others.

> *Social comparison theory suggests that people with a 'problem' they are uncertain or fearful about should ... seek out similar others, sharing their problems with selected friends or perhaps joining self-help groups composed of people in similar situations. Receiving information that others share their problems should increase their self-esteem and reduce self-stigmatisation* (Brewin, 1988, p. 162).

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This has clear echoes of Yalom's conclusion that 'universality' - sharing one's experiences with similar others - is one of the most potent factors for change in therapeutic groups (Yalom, 1975). The empowering effects of increased self-efficacy, altered attributions, social comparisons and universality were clearly evident in most parents' reports of increased self-esteem and confidence.

Parents made it clear that the quality of the information available from each other played a significant part in increasing their self-efficacy and sense of control in particular ('Knowledge is power'). Some reports vividly illustrated Borkman's distinction between 'experiential knowledge' and 'expert knowledge' (Borkman, 1976). In the embattled atmosphere of relating to the outside world, especially professionals, information from other parents was felt to be far more trustworthy and reliable than information from 'experts', a message that has implications for professionals which are discussed below.

A feeling of empowerment also results from a change in role for parents. In most cases, the birth of a disabled child puts parents into the position of recipient. Parents receive diagnoses, assessments, treatments and a variety of health, education and social services. In contrast, this study supports the previous conclusion of Hatch and Hinton that mutual support groups such as those affiliated to Contact a Family empower individual members by 'turning the mothers into participants instead of just recipients' (1986, p. 87). The implications for professionals are discussed below.

Collective social and political action was one important cause and consequence of empowerment for many individuals and groups. People found other members and the groups as collectives to be a source of strength, and often a source of 'ammunition' for 'fights' with local professionals and authorities. Groups were often 'more than a collection of individuals'. It was important for many people to feel empowered through identifying with a potent 'political force'.

Mutual support groups provide parents with a range of coping resources identified in the disability literature (e.g. Beresford, 1994), by offering practical advice and strategies shared by people who have gone through the same experiences. These include access to information, increased self-efficacy and a more internal locus of control, learning and subsequent cognitive change, hope and positive thinking. Parenting skills, a vital coping resource, are also augmented. This has the effect of reducing children's behavioural difficulties and in turn enhancing parents' sense of competence and self-efficacy (Quine & Pahl, 1989). This latter effect has been found to be associated with reduced parental stress irrespective of the extent of improvements in the child's behaviour (Pisterman, Firestone, McGrath, Goodman, Webster, Mallory & Goffin, 1992).

The results obtained from this study make it possible to compare the support valued by parents with a disabled child with the types of support valued by those parents who have experienced the death of a child. Parents belonging to Compassionate Friends, the US mutual support group for bereaved parents, found emotional support far more important than cognitive and behavioural mechanisms of change (Lieberman, 1979).

In contrast, parents in groups affiliated to Contact a Family found cognitive and practical support at least as important as emotional support. This is likely to be due to the ongoing daily challenges which parents with a disabled child have to manage, in addition to the emotional processing of their situation.

Changes in social identity in the inter-personal domain

Participants reported that belonging to a community, being understood and accepted, having friendships and social networks where they could feel 'normalised' and could share emotions, were all important. These all contributed to significant shifts in social identity, and sense of self generally, for the majority of participants. Such changes occurred through the effects of the culture, ideology and norms of the mutual support groups and their social networks, which were highly valued by participants and which differed from those outside the mutual support community.

These findings are enriched by the arguments of community-oriented mutual support group commentators. 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.

More recently, Rappaport has argued that mutual help organisations can be understood as 'normative narrative communities where identity transformation takes

place' (1993, p. 239). Consequently he argues that narrative analysis is a preferable

alternative to the 'treatment and services' paradigm for studying mutual support.

> *Mutual help organisations are simply a special case of a more general phenomenon: The experience of identity formation and change takes place within a social context that contains community narratives that can be read, observed, communicated or otherwise understood. These organisations might be better understood as voluntary communities rather than as social service agencies. When membership leads to significant change in a person's identity and behaviour it could be understood as a change in community of membership and lifestyle rather than as a 'treatment outcome' ... In this view, people who elect to join mutual help organisations 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?'* (1993, pp. 246-247).

People are inevitably affected by the prevailing culture and ideology in organisations

to which they belong. Members of mutual support groups are no different. Personal

identity is constructed partly from the community identity, which is in turn affected by

the identities of the people within it. According to social constructionists, identities

are continually being constructed in context (e.g. Burr, 1995; Shotter & Gergen,

1989). Our identities are said to be constructed out of the discourses which are

culturally available to us. A discourse may be broadly defined as a way of talking

about or representing something (Burr, 1995). People join mutual support groups

because of initial problems or difficulties that tend to be talked about within

discourses which are stigmatising, non-understanding, critical, and generally negative

in various ways. Such cultural discourses provide a context in which individual

'sufferers' construct their identities.

By offering people an alternative discourse in which to talk and think about their

particular situations, mutual support groups are simply a special case of communities

which provide members with a different perspective on what is possible and not possible to do and think, what is right and not right to do and think, what is appropriate and inappropriate to do and think (Burr, 1995). In short, mutual support groups offer members a different sense of identity, of who they are.

Parents' ideologies and beliefs are an important coping resource when caring for a disabled child (Beresford, 1994). Ideologies available to parents by organisations and social networks offered by mutual support groups can provide parents with a communal narrative of change which forms a basis for personal change. In the case of Contact a Family, the explicit ideology or community narrative is that 'a problem shared is a problem halved'. However, the impact of participating in the normative communities and social networks available through mutual support groups is far more wide-reaching than modestly claimed by Contact a Family.

In Western industrialised society the prevailing discourse of disability might include notions of victimhood, powerlessness, isolated individuals, passivity, status of recipient of help, receiving medically-dominated services, assessments and treatments. Mutual support groups like those affiliated to Contact a Family provide individuals with a different discourse out of which identity can be constructed. Such groups offer an alternative vision, ideology and way of thinking about what it means to have a disabled child. Such an alternative discourse includes agency, control and empowerment, as well as actively sharing in communities rather than passively suffering as isolated individuals ('a problem shared is a problem halved').

The importance of the new social networks and friendships within and surrounding mutual support groups is also central to their helpfulness. At the individual level, mutual support groups offer compensatory social ties through counteracting feelings of loneliness and isolation (Gottleib, 1985). The significant relationships created through mutual support groups promote positive reflected appraisals and hence enhance self-esteem (Lieberman, 1979). At the inter-personal level, social comparison and consensual validation leads to reduced feelings of uniqueness, uncertainty and stigma in the new community. The previously personal becomes transformed into the social.

In the alternative culture offered by mutual support groups, people become part of a community with new norms. Feelings of normality are encouraged (Barrera & Ainlay, 1983), and people start to construct new identities within the alternative discourse provided.

In addition to the recent social constructionist accounts of identity formation and identity change, more traditional psychological models can also be usefully employed, particularly Mead's (1934) symbolic interactionism and Tajfel's (1981) social identity theory, as well as Hirschman's (1970) originally economic analysis of 'exit' and 'voice'.

According to Mead (1934) human action depends upon the meanings that people ascribe to their situations. These meanings derive from shared interactions. As thinking, acting, creative individuals, human beings respond to the actions of others

after interpreting these others' intent and action. This symbolic interactionist perspective is clearly very useful in conceptualising what people find helpful about mutual support groups. In the wider society, parents of children with disabilities and special needs tend to interpret the intent and actions of others as sentimental, pitying, avoidant, critical, stigmatising or outright hostile. Parents reported that the mutual support groups investigated in this study provided them with a very different context in which the intent and actions of others were interpreted as accepting, understanding, normalising and friendly. The perceived consequence for most parents was that they ascribed a different meaning to having a disabled child.

The basis of social identity theory is that individuals are members of numerous social groups which contribute, positively or negatively, to one's self-image. One's social identity is defined as 'that *part* of an individual's self-concept which derives from his knowledge of his membership of a social group (or groups) together with the value and emotional significance attached to that membership' (Tajfel, 1981, p. 255, original emphasis). The theory assumes that an individual can make an effort to improve his or her self-image either by trying to enhance personal identity or by trying to enhance social identity.

A complementary framework is provided by Hirschman in his analysis of 'Exit, Voice and Loyalty' (1970). Although primarily concerned with economic consumption, it makes a valuable contribution to understanding people's actions in other social contexts (Brown, 1986). If one is dissatisfied with being a member of some social groups, then one can 'exit' by leaving. However, there are some groups from which

it is impossible to leave. Having a disabled child is one such social group from which 'exit' is impossible. An alternative way of promoting one's social identity is, therefore, 'voice', namely taking positive social action to raise the value of the group identity, in order to achieve and maintain self-esteem.

Social identity theory, together with Hirschman's analytical framework, offers a valuable perspective on the experience of parents of disabled children who become members of mutual support groups. It is particularly valuable because it provides a framework through which identity change over time can be conceptualised. In the first place, parents whose children have disabilities and special needs become part of a social category which is currently devalued in our society. This is a transition which may be denied or resisted, but the entry into the 'world of disability' at some point is inevitable. Tajfel (1981) states that if one is unable to leave a devalued social category (or, in Hirschman's terms, one is unable to 'exit') then one consequence is to engage in social action to change the situation and improve the group's status. (In the words of one participant, 'It's like a club that no-one wanted to join'.) According to Tajfel, individuals will join new groups and remain in them if they have some contribution to make to the positive aspects of one's social identity. Simply by joining a mutual support group, one is engaging in 'social action', while some groups go further, engaging in collective politicised action to improve the status of the group, its members, and also the wider group of disabled children and their families generally. There are clear implications for the role of mutual support groups in creating social change, an aspect rarely acknowledged in the literature which focuses so much on personal change (one exception being Humphreys & Rappaport, 1994).

One important component of social support which participants found very helpful was emotional support. Self-disclosure and catharsis have long been recognised as important therapeutic factors in individual and group psychotherapy (e.g. Yalom, 1975). The importance of being understood is also discussed by Rogers (1957), Kohut (1971) and Malan (1979), among others. For Rogers, empathy is one of the key factors in therapeutic change. For Kohut too, being understood is the key to therapeutic change. As adults we all need supportive or 'mirroring' relationships, which help to foster self-confidence. Mutual support groups are one context in which such affirming relationships are found. For Malan, real understanding and unconditional acceptance provide an experience of 'symbolic love'. Mutual support groups provide members with a rare opportunity to share emotions, to share understanding, and perhaps to share 'community care' in its literal sense.

Intra-individual changes

As mentioned throughout, changes in parents' self-perception in relation to the public sphere and the social, inter-personal community, have fundamental consequences for their sense of self. While some parents reported that they had not changed, the majority reported that membership of mutual support groups had made a significant impact on their inner psychological states, in terms of increased self-esteem and confidence, reduced depression and less anxiety.

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In addition, however, parents also reported changes in relationships with their children. Such a consequence is largely ignored in the mutual support literature, mainly because of the focus on adults with mental health problems rather than 'one-step removed' groups. This impact is very important for all such 'one-step removed groups', as it indicates the benefits for the 'person with the problem' as well as their carers, and particularly for the population of parents with children with special needs. The changes in parents' relationships with their children occurs directly through behavioural advice obtained in the groups, and indirectly through parents' increased self-efficacy, through the ideology of more positive social identity and valuing disability, and also through a more generalised improvement in parents' psychological state.

Overall conclusion

Many psychological theories state that self-identity develops in the context of social interactions. These are more helpful than over-simplified lists of benefits for understanding helpful processes of mutual support. Mutual support groups provide their members with an alternative social context in which a different sense of self can develop and identity change can take place. Parents of children with disabilities and special needs experience a sense of empowerment in relation to the outside world, and develop a more positive identity as individuals, members of a community and as parents. In these ways mutual support groups provide parents of disabled children with an alternative culture which fosters feelings of empowerment and community in

which parents can create new and different meanings of their situation and develop an alternative sense of who they are.

4.3 LIMITATIONS OF THE STUDY

The study's limitations can be discussed in terms of generalisability, the research design, the measures used and the method of data analysis.

Generalisability of the findings

The limits to the external validity of the findings of this study are determined by the restricted sample of participants. The most important limitation of this study is that the sample of six groups were self-selecting. While they constituted one half of the number of groups who were approached initially, the other half did not participate in the study. It is uncertain whether the non-participating groups were similar or different to those which did take part. It is possible that those groups which did take part were better organised, better functioning, more open and more confident about being 'researched'. If that were the case, then members of non-participating groups would be expected to make less positive statements about their experiences. It is unlikely that the generalisability of the overall conceptualisation of what parents find helpful about mutual support groups in general would be significantly affected. However, it is far more likely that the external validity of the findings of the extent to which parents are helped by those processes in their specific groups would be limited.

The sample of individuals consisted almost entirely of women. However, this appears to be a representative sample of members of parents' mutual support groups. Groups in inner London had more members from black and ethnic minorities, which again would be representative of the population of mutual support group members.

There were only six groups and 56 individual participants, and they were all from London and the South East of England. A larger number of groups from a wider geographical area would improve the external validity of the findings. In particular, there might be regional differences in findings, as different areas might have different contexts of existing services, so leaving different gaps for mutual support groups to fill (according to Lieberman's (1979) 'lack of resource' hypothesis), as well as different degrees of professional involvement in and support for the groups themselves.

While the problem of sampling bias, resulting from dissatisfied members 'dropping out', has been discussed above, it was not relevant to the research questions addressed in this study, with the exception of what might be unhelpful. It might have been interesting to have found out more about answers to that question from a sample of people who stopped attending mutual support groups.

Research Design

The extent to which the design of the study was sensitive to all potentially helpful

mutual support processes remains questionable, particularly with respect to when and

where mutual support happens. Some participants highlighted the dynamic, changing

nature of mutual support over time, which is largely ignored in the literature (with the

exception of Lieberman & Bond, 1979), and to which this study was not sufficiently

sensitive. Ideally a longitudinal design would be better to explore changes over time

in what people find helpful.

As well as just being 'one-shot', this study focussed largely upon group meetings.

However, this is only one context in which mutual support takes place. This focus

was largely due to a preconception of meetings as some form of 'treatment', rather

than a conceptualisation of mutual support groups as social networks. The design of

the study made it difficult to assess directly the impact of group activities outside

meetings, such as informal contacts and also newsletters.

The research design also had limitations for the internal validity of the study's

findings. As a descriptive study, there was a limit to what could be concluded about

the causal nature of relationships between variables. While as a piece of field research

this study had a relatively high degree of external validity, the cost was that it was not

possible to move beyond associations between variables to make inferences about

causality.

Measures

On reflection, it is questionable how sensitive some measures were for eliciting the helpful aspects of mutual support groups, or even how appropriate some measures, and particularly the distinction between measures of 'process' and 'outcome', were for this field of enquiry.

Group 'process' was measured largely by questionnaires, mainly taken from previous research studies. Group environments were measured by the Group Environment Scale, which gave direct access to participants' own perceptions, was straightforward to administer, and provided data which allowed quantitative comparisons to be made between individual participants and between different groups. However, there was little room for discussion, and participants could not qualify or explain their answers, and in some cases omitted them altogether. Participants may have felt constrained by the closed question format, and so it was important to add open-ended invitations for people to describe their experiences of being in groups.

Focus groups too have their limitations. Compared to participant observation, focus groups are unnatural settings. While they offer the opportunity to observe a large amount of interaction on a topic in a limited period of time, the fact that the observer is in control of the discussion makes it an unnatural setting. Rather than collecting data on a larger range of behaviours, a greater variety of interactions, and a more open discussion of the research topic, as possible in participant observation, by contrast focus groups are limited to verbal behaviour, consist only of interaction in

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discussion groups, and must be created and managed by the researcher. Compared with individual interviewing, there is less opportunity to follow up new leads or skip unwanted material, as it is often important to retain some form of structure to prevent the discussion from becoming too chaotic.

Some researchers have used observational data for analysing the processes of mutual support (Roberts *et al.*, 1991; Paine *et al.*, 1992). However, the resources required for such an approach meant that it was not feasible for this study. Nevertheless, despite potential biases in self-report data, self-report questionnaires and group interviews were still a valuable source of information, particularly concerning people's subjective experiences of the meaning and significance of mutual support for themselves.

If it had been possible to spend more time with each group, then more in-depth focus groups might have yielded more detailed data about people's experiences. One area of further exploration would have been the communal narrative or ideology of Contact a Family as a mutual support process, and investigating its impact upon individuals' own personal narratives.

Measures of 'outcome' were also problematic. The global ratings of 'helpfulness' and 'satisfaction' appear to be crude and unsophisticated measures of 'outcome'. According to some mutual support commentators (e.g. Humphreys & Rappaport, 1994; Levy, 1979; Rappaport, 1993), variables which are traditionally viewed as 'process' measures may be more appropriate measures of 'outcome'. The successful

creation and maintenance of supportive social networks is an important outcome, and inter-personal environmental factors such as cohesion, belonging and expressiveness, can be measured by, among others, the Group Environment Scale.

An alternative way of selecting appropriate measures would have been to collaborate with mutual support group members themselves in order to agree on mutually satisfactory outcome measures, as recommended by those researchers advocating alternative paradigms of research (e.g. Chesler, 1991; Goldklang, 1991; Powell, 1993).

Method of analysis

Qualitative data were analysed using the approach of grounded theory. This is not without its limitations, and neither was the application of the approach in this particular study. Since grounded theory was not the only approach used in this study, there were compromises in terms of sampling and both collecting and analysing two sources of data.

While the grounded theory method of 'constant comparison' was used explicitly in analysing the data, the other recommended method of 'theoretical sampling' was not used. Given time and organisational constraints, a sample had to be recruited prior to data collection and analysis, and there was no scope for further recruitment subsequently. Given more time and more resources for travel, then more groups could have been recruited on the basis of 'theoretical sampling'. In particular, it

might have been extremely interesting to visit groups which were explicitly focussed upon either providing 'therapeutic' emotional support, or 'normalised' social activities, or social and political action, in order to explore the helpful aspects of each activity in greater detail.

Secondly, the fact that this study used questionnaires as well as focus group discussions meant that two sources of data had to be collected and analysed. For participants, this meant that the focus group discussions were held after questionnaires were completed, and so the data obtained from the discussions were not wholly independent from the questionnaire. This was the cost of having two sources of data, of obtaining independent questionnaire data, and of prompting participants to think about their experiences before the discussion in order to 'hit the ground running' in a focus group discussion of limited time.

Inevitably, the analysis of the focus group discussion data could not have been totally uninfluenced by the prior analysis of the questionnaire data. The benefits of having two modes of expression for participants bore a cost of not having two completely independent analyses, despite the efforts to make the analyses as transparent as possible. Independent analyses could have been achieved by using two different 'coders', but this was not feasible in this study.

Thirdly, the data analysis was inevitably influenced by the preceding literature review. However, this is not necessarily a weakness. Glaser (1978) stresses that if researchers do 'borrow' concepts from the literature, then they should ensure that these concepts

merit a place in their analysis. Hopefully in this case the 'borrowing' (or duplication)

of any concepts from the literature (such as the importance of relevant information for

parents of children with special needs) has been clearly merited on the basis of the

data from participants as reported explicitly in Chapter Three.

Pidgeon and Henwood (1996) outline four assessment criteria for grounded theory

studies. Two of these criteria are the quality of the documentation of the analysis and

the justifiability of the ways in which concepts are linked together. By reporting in

detail in the previous chapter the lower order 'meaning units' which emerged from

participants' responses, and explicitly describing how concepts were linked together

(thus leaving an 'audit trail' in the terminology of Lincoln & Guba, 1985), the

intention was to make the analysis as transparent as possible, minimising the

potentially 'blinkering' effect of familiarity with the existing literature.

While no researcher is a *tabula rasa*, steps can be taken to make the analysis as

credible as possible (Rennie *et al.*, 1988). The outcome of the analysis must be

persuasive and the method adopted must be described in detail. The detailed

presentation of a representative example from each category is another way of

demystifying the process. The method, analysis and their reporting in this study were,

it is hoped, sufficiently persuasive and transparent to make the findings credible.

A third assessment criterion is whether respondent validation was attempted. This is

defined as the recognition of the researcher's interpretations when presented to the

participants in the study or to others within a similar social and interactional context

(Pidgeon, 1996, p. 84). Lack of time prevented this happening with the respondents themselves, which is an obvious limitation of this study. However, the views of Contact a Family itself were sought and the findings discussed with them. Their response was that the interpretations of the researcher agreed with their intuitive sense of what parents find helpful, based on their experience. This could be seen as an indirect form of respondent validation, before all participating groups were sent a summary report of the findings of the study.

The fourth criterion is whether the problem of reflexivity (the role played by personal, ideological and cultural assumptions in knowledge) is addressed. The most fundamental assumption underlying this study was that mutual support groups are helpful in some way. This was one personal assumption or belief which prompted the wish to explore this further. Other contextual factors were described in Chapter One, namely the recent growth in mutual support groups and organisations, the lack of knowledge about how they help their members, particularly in a British context and particularly for this 'one-step removed' parent population. The context of limited NHS and clinical psychology resources and the implications of mutual support and increased understanding of it for health and mental health professionals were also outlined in Chapter One, and are elaborated upon below.

4.4 SUGGESTIONS FOR FURTHER RESEARCH

These suggestions broadly correspond to the areas of limitations described above.

Generalisability

It would be highly desirable to replicate this study with a higher proportion of groups

approached actually participating in the study. Ideally one might approach again

those six groups who did not participate in this case. Alternatively, another study

might allow for more time and resources to be spent on achieving a higher 'response

rate' among groups invited to participate. It would also be desirable to replicate this

study with more participating groups over a wider geographical area. One aim would

be to construct a typology or classification of groups affiliated to Contact a Family, to

explore further the different functions served by different groups.

Another aim would be to test the generalisability of the findings, to see whether they

also hold for: other mutual support groups of parents with disabled children; other

mutual support groups for parents (e.g. bereaved parents, parents of children with

chronic illnesses); other 'one-step removed' mutual support groups (e.g. mutual

support groups for those caring for someone with dementia); other types of mutual

support groups (e.g. mental health and addiction groups); other types of 'therapeutic'

groups (e.g. psychotherapy groups); other types of groups providing social networks,

either for parents (e.g. parent and toddler groups) or others (e.g. community, social or

political organisations).

Mutual support groups could also be compared with professionally facilitated groups.

If there were no difference in the benefits of each, then there would be significant

implications for cost-efficient service delivery and for considering the most

appropriate roles for professionals, as discussed in more detail below.

Research designs

A longitudinal study, or series of follow-up studies, would go a long way to

discovering any changes over time in what people find helpful about mutual support

groups, and for studying the lifetime development of groups. This accords with the

recommendation of Humphreys & Rappaport for more 'programmatic research'

(1994, p. 227).

Further research would also be productive if designed to investigate the social

networks of mutual support group members, their nature and impact, as a highly

significant, if not the most significant, way in which mutual support groups help

people (Humphreys & Rappaport, 1994).

What to measure?

One area of 'outcome' hitherto largely ignored in the literature is the social and

political impact of mutual support groups. A significant minority of mutual support

group members in this study were motivated and helped by the prospect and reality of

political influence. Political power can be defined as 'a matter of influencing the way

people think about an issue' (Birch, 1993, p. 154). Mutual support groups can have

an impact not only on their members directly, but also on local and even national

discourses, political planning and decision-making. In this way mutual support can be

considered as a social movement rather than individual psychological treatment.

Further research could examine this in greater depth, focussing upon collective

efficacy as well as individual self-efficacy. The collective political efficacy reported by

many mutual support group members in this study contrasts significantly with the

prevailing lack of perceived self-efficacy among individuals who use and may be

dissatisfied with statutory health services (Solomon, 1994).

This is one example of alternative outcome measures that might be used in future.

Arguably the most sensitive way to develop appropriate measures of outcome of

mutual support groups is by partnerships between researchers and participants.

Although this study was the product of successful collaboration between researcher

and mutual support organisation, future research should aim to be more collaborative,

preferably in terms of long-term, ongoing partnerships between researchers and

mutual support groups themselves, in order to build up a picture using designs and

measures that are developed together.

Developing a grounded theory

Further research should refine measures of mutual support group 'processes' and

'outcomes' to develop our conceptual understanding. This study can be viewed as a

first step in the 'theoretical sampling' of grounded theory towards the ultimate aim of

a general theory of mutual support group processes. 'Grounded theory analyses can

provide future researchers with sources of explanatory and predictive comparison'

(Charmaz, 1990, p. 1171). Further research could develop our understanding of changes in members' overall sense of self, changes in relation to the outside world and to other group members, and changes in personal ideologies and beliefs. Researchers could also address in greater depth the influence of certain theoretical ideas, such as symbolic interactionism (Mead, 1934), and the role of ideology (Antze, 1976) or 'community narrative' (Rappaport, 1993).

4.5 IMPLICATIONS OF THE STUDY

The implications of this study for theory, research and practice are outlined. There is then a discussion of the implications for professional service providers in the light of the social, political, economic and ideological contexts of service delivery. Finally the implications for the roles and ultimately education of clinical psychologists and other professionals are discussed.

Academic and research implications

Mutual support groups are heterogeneous rather than uniform, at least in the UK in this particular field. They also differ in terms of the characteristics of their members. For instance, all-female groups may well differ from mixed groups. Members of a wide range of 'one-step removed' mutual support groups would tend to be women due to the carer burden falling disproportionately on women generally (e.g. Graham, 1984; Pascall, 1986), and even more so upon mothers of disabled children (Pahl &

Quine, 1987). This is not mentioned in the mutual support literature, but the impact on group environments, processes and outcomes is potentially significant and should be acknowledged and explored further.

Helpful mutual support processes can change over time. Therefore conceptual frameworks for understanding these processes need to be dynamic rather than static. Theories of social identity and social movements appear to be particularly valuable in this respect, and their application to understanding mutual support should be explored further and incorporated into the specific mutual support literature.

Some processes are more helpful than others. Among parents of disabled children, the provision of relevant information, the opportunity to feel a sense of belonging to a community, and social companionship, were universally helpful. On the other hand, helping others and having a sense of mastery and control were helpful to fewer people, or else are only felt to be helpful at a later stage. This again would highlight the need for dynamic accounts of helpful processes over time.

Mutual support groups may be more usefully regarded as social networks rather than psychological treatments. As discussed above, this has enormous implications for research design, measures and fundamental goals of research, as well as for professionals.

Implications for parents' mutual support groups in practice

Although there are variations between groups in their primary functions and characteristics, there are a number of universally reported factors which parents find helpful. By having the importance of empowerment and community brought to the attention of the participating groups and to the wider mutual support organisation, people who run groups themselves or support those who do so will be in a better position to base their practice on the evidence of universally helpful processes.

Groups provide parents with an opportunity to have some control and sense of agency, possibly for the first time since the birth of their disabled child. Groups do this by providing and sharing information and knowledge, by sharing practical advice and experience of services, and sometimes by access to professionals which differs to that which can be achieved by individuals. Even if professionals are involved in a group, it is extremely important that parents feel that they have control of the group. Groups also provide parents with a 'community' to which they feel they can belong, through making parents feel welcomed and accepted, understood and 'not alone'. The welcome given to first-time attenders is especially important in this respect. Fundamentally, group organisers or co-ordinators can best help parents by providing them with an experience which is different, where parents can feel better informed and can feel a part of a normative community in which both difficulties and achievements can be shared. By being in a context in which they feel valued rather than stigmatised, parents can begin to feel differently about themselves and their disabled children.

Clinical and professional implications

There are a number of implications of this study for service delivery generally,

professionals and clinical psychologists in particular. There are implications for both

the cost-effectiveness of service delivery in the current NHS context of scarce

resources, as well as for the ideology on which service delivery generally is based.

More specifically, there are implications for all services based upon normalisation

principles. The relevance of this study for clinical psychologists in particular as well

as for professionals working in 'human services' generally can be discussed in terms

of the implications of understanding mutual support groups for professional roles and

particularly professional education.

Professional implications in the current NHS context

According to Lieberman's (1979) 'lack of resource' hypothesis, mutual support

groups are created at least partly because of gaps in existing professional services.

Therefore groups for parents of children with special needs indicate areas of need into

which scarce resources might be usefully directed, particularly as participation in

mutual support groups tends to lower demand for professional services (Humphreys

& Rappaport, 1994). Consequently there may well be justification in terms of cost-

effectiveness for funding mutual support groups.

Furthermore, professionals and service providers can build constructive partnerships

with mutual support groups to make suggestions for improving existing services and

targetting resources. This would increase members' self-efficacy and collective

efficacy yet further.

Implications for a collectivist ideology of service delivery

This study highlights wide professional implications for service delivery in general.

Along with other mutual support literature, this study highlights the value of a

collectivist or communal ideology for people who are otherwise simply recipients of

services delivered on the basis of the prevailing individualistic ideology in western

industrialised society. The alternative ideology of collectivism includes the principles

of equity and egalitarianism, based upon 'fellowship' (Meacher, 1982), which

incorporates sharing, altruism and co-operation. This study of mutual support groups

highlights a special case of a more general move towards acknowledging the value of

a collective ideology in 'human services' generally, as an alternative to individual-

based service delivery (Dalley, 1992), even to the point of participants using the same

highly valued description 'fellowship' as politicians. Collective provision 'should be

based on the principles of group concern, shared care and mutual support' (Dalley,

1992, p. 108).

Implications for all services based on normalisation principles

More specifically, the mutual support groups participating in this study offer

alternative models to those services presently based upon normalisation principles as

interpreted by Wolfensberger and colleagues (e.g. Wolfensberger, 1980; 1983).

Mutual support groups constitute a specific instance of a challenge to Wolfensberger's version of normalisation which incorporates the principle of integration. Mutual support groups are one example of an alternative model to integration. As discussed above, they build a positive social identity through being separate and different to the rest of society (Tajfel, 1981). They create a separate group identity for the group and enables a re-evaluation of its hitherto negatively perceived characteristics. This has implications for other groups of people with disabilities and for the professionals who work with them (see, for example, Szivos, 1992; Szivos & Griffiths, 1992). This study clearly demonstrates that 'normalisation', in terms of providing a socially normative environment, can be achieved through segregation and developing more positive social and personal identities, as well as through integration which had been experienced by parents as stigmatising.

Understanding mutual support groups and its implications for professional roles and education

Increased awareness, knowledge and understanding of how mutual support groups help people can lead to improvements in professional and clinical practice. In particular this study has revealed the importance for parents of disabled children of receiving accurate, trustworthy information from the time of diagnosis onwards, as well as indicating the extent of problematic relationships with professionals. This should provide professionals with an incentive to reflect upon how they can be more helpful to parents of disabled children, and consequently improve their practice.

This study also found that the behaviour of disabled children, and the quality of their family relationships, were perceived to have improved as a result of parental membership of mutual support groups. This has implications for all professionals working in child development settings with children with disabilities and special needs. These are also important findings for any context in which carers meet together in groups which can influence the quality of their relationships with identified 'patients'.

The existence of mutual support groups does not mean that professional support is or should be absent. Previous research suggests that 'mutual assistance organisations seem to thrive best with a professional in the background' (Levine, 1988, p. 180). The main issue is the nature of the most appropriate role(s) for professionals to take.

In his survey of mutual support group members, Gottleib (1982) found that the idea of professional involvement was well accepted, but those roles that received the highest ratings were those suggesting more indirect participation in the form of consultant, referral agent, or initiator. The more direct, group leader, role for professionals was thought to be less appropriate, especially by members of 'one-step removed' groups. The findings of this study confirm those of others that autonomy and control are important features of mutual support groups (Katz & Hermalin, 1987), and professionals must take care not to damage the autonomy and resulting empowerment felt by mutual support group members. As Stewart maintains:

> *Ultimately their* [mutual help groups'] *empowering effect stems from the sense of confidence and competence they instil, and from the dignity restored to people when they experience change at their own hands rather than at the hands of professionals* (1990b, p. 1155).

Therefore professionals should offer support to mutual support groups of parents with disabled children in whatever way(s) the group feels may be appropriate. This confirms the recommendation of Orford (1992) quoted at the beginning of Chapter One. This keeps the control with parents and their groups, not with professionals. One important role may well be a pro-active one in terms of acting as referral agent. Professionals need to make themselves aware of the existence of mutual support groups in their area, in order to put families in contact with each other, and actively seek consent to do so. Professionals can also act as initiators if appropriate, by actively helping parents to set up groups in their area if none exist. Indirect professional support may also include initial offers of help with providing room space, administrative support, postage etc.

These roles would all constitute one aspect of professionals working in partnership with parents, as advocated by much of the literature in this field (e.g. Cunningham & Davis, 1985a; Dale, 1996; Russell, 1997). Furthermore, such roles would also be sensitive to the specific benefits of mutual support, by which parents are helped by being a part of a community where facts and feelings are shared with others in the same situation, largely without the presence of professionals.

The importance of autonomy and control is reinforced by the findings of this study that information from others in the same situation is perceived as far more reliable than information from professionals: personal experience is trustworthy while professional expertise is suspicious. This has clear implications for the attitudes, ideologies and ultimately education of professionals.

Increased understanding of mutual support groups and how they help their members

has implications for the education of a variety of professionals, including clinical

psychologists, who need to be educated about 'member-owned self-determining

voluntary associations ... the educational programme about self help groups would

include teaching professionals respect for self help groups and how to relate to them

without co-optation or control' (Borkman, 1990, p. 330). Increased awareness

means that professionals not only need to appreciate and respect that the ideology of a

mutual support organisation may be very different to that of her or his own service

organisation or professional group, but also need to be prepared to change one's

customary professional role in response to the needs of a mutual support group. For

clinical psychologists, this may well mean acting indirectly as a consultant or

administrator rather than directly as a therapist or facilitator.

However, a more radical view would see professionals not just as consultants, but

ultimately as students, learning from mutual support groups about alternative models

of help, support and coping, and learning about the deficiencies in services which are

highlighted by mutual support groups. These groups can become a source for

changing the professional, formal health care and other human service systems

(Borkman, 1990).

This would require a radical shift in the ideology of the clinical psychology profession.

Involvement with mutual support groups is an important part of helping populations

of patients or clients. Conventional 'expert' models of clinical psychology

intervention do not fit well with people's experiences of mutual support, and so a

change in professional attitude is required if people are to feel better helped.

Ultimately this requires clinical psychologists and other professionals to learn from

mutual support group members themselves, whose experience is not readily

investigated by traditional research methods. This presents a challenge to the

profession.

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APPENDICES

UNIVERSITY COLLEGE LONDON MEDICAL SCHOOL

Administration
Gower Street
London
WC1E 6BT

Telephone 0171 387 7050
Direct Line *0171 209 6306*
Fax 0171 383 2462

DT/cw

7 May, 1996

PLEASE ADDRESS ALL INTERNAL CORRESPONDENCE TO:
Miss Carol Walcott
UCL Medical School
Administration
6th Floor, St Martin's House
140 Tottenham Court Road

Dr Nancy Pistrang
Sub-Department of Clinical Psychology
UCL

Dear Dr Pistrang

The Joint UCL/UCLH Committees on the Ethics of Human Research

COMMITTEE A

Number: 96/61   *(PLEASE QUOTE THIS NUMBER IN **ALL** FUTURE CORRESPONDENCE)*

Title: What do parents find helpful about mutual support groups?

Thank you for your application to the above Committee. I have now had the opportunity to go through the papers and am happy to take Chairman's Action, you may now go ahead with this study.

Yours sincerely

Dr F D Thompson
Chairman

Helping families who care for children with any disability or special need

Dear

Re Research Project: What parents find helpful about mutual support groups

Following my earlier letter I am writing to introduce your group members to Mike Solomon who is planning to undertake the research project which will explore what parents find useful about belonging to mutual support groups run by and for parents of children with special needs. As we have not heard from you I assume that you are willing at this stage to learn more about the project with a view to participating in it.

I enclose a letter from Mike and supporting information from University College London. This has been agreed with our Director Harry Marsh and Dr. Zarrina Kurtz (on behalf of our Board of Directors) both of whom will take an interest in the progress of the project.

I would be grateful if you could discuss this with your group members at the earliest possible date and return the reply slip below by **June 14 or earlier if possible.**

With many thanks for your interest,

Yours sincerely,

Pauline Shelley
Senior Development Officer

Could you please complete the reply slip on the next page and return in the envelope provided.
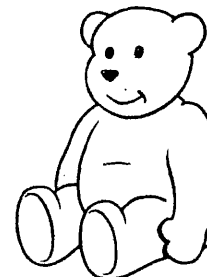
REPLY SLIP

Name of group...

We are willing to take part   Yes   No

If yes, times and location of meetings...

....

....

Name of contact and telephone number...

Return to Mike Solomon in the enclosed envelope.

UNIVERSITY COLLEGE LONDON

GOWER STREET LONDON WC1E 6BT

Direct Lines: 0171-380 7897 / 7896
UCL: 0171-387 7050
Code from overseas: +44 171
Fax: 0171-916 1989

Research Project: What do parents find helpful about mutual support groups?

Aims of the project

It is widely accepted that groups of people with similar concerns who meet together in order to help each other are "a good thing". However, relatively little is known about what it is that people find helpful about attending and belonging to such groups. The aim of this project is to find out what it is that parents of children with disabilities and special needs find helpful about meeting with other parents in a similar position.

What will be expected if you agree to take part?

If your group agrees to take part, I would come to one group meeting, or at least a part of one meeting. You would be asked to complete a questionnaire which asks about: your perceptions of the group; what you find helpful about the group in general; what you found helpful about that group meeting in particular; how long you have belonged to the group. This would take approximately 30 minutes to complete. The questionnaire will be anonymous - you will not be asked for your name. There will then be a short discussion (approx. 15-20 minutes) about the benefits that you feel have resulted from being part of the group. This discussion will be tape recorded. All conversations will be anonymous. All information given will be treated confidentially.

How will you benefit from taking part?

Each group taking part will receive a copy of the summary report of the project. This will contain findings obtained from a number of groups, so you will have a chance to consider your own group in relation to others. Hopefully the report will be useful for you to think about the future of your group, and the ways in which the group meets the needs of its members.

I would be very happy to discuss this project further. If anyone would like to know more, please leave a message for me at the above address or phone number, and I will contact you.

Thank you for considering your participation in this project.

Mike Solomon
Clinical Psychologist in Training
University College London
April 1996

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GOWER STREET LONDON WC1E 6BT

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4th March 1996

To whom it may concern:

MIKE SOLOMON

Mike Solomon is a clinical psychologist in training. He is currently in the second year of a three-year doctorate in clinical psychology at University College London. As part of his training, he is required to carry out a research project. This project is conducted under supervision, and the methods to be used have been approved by this department. I expect the project to be granted ethical approval by the University Ethics Committee in April 1996.

Yours faithfully,

Nancy Pistrang

Dr Nancy Pistrang
Senior Lecturer and Research Project Supervisor

Research Project: What do parents find helpful about mutual support groups?

Mike Solomon, BA M.Sc.
Nancy Pistrang, Ph.D.
Sub-Department of Clinical Health Psychology
University College London
Gower Street
London WC1E 6BT
(0171) 380 7896/7

Information Sheet for Participants

This project aims to find out what it is that parents of children with disabilities and special needs find helpful about meeting in groups with other parents in a similar position.

You are invited to take part in this study which will involve replying to questions which ask about your experiences in your mutual support group. If you agree to take part, you will be asked to complete a questionnaire which asks about: your perceptions of the group; what you find helpful about the group in general; what you found helpful about this group meeting in particular; how long you have belonged to the group. This will take approximately 30 minutes to complete. The questionnaire will be anonymous - you will not be asked for your name. There will then be a short discussion (approx. 15-20 minutes) about the benefits that you feel have resulted from being part of the group. This discussion will be tape recorded. All conversations will be anonymous. All information given will be treated confidentially.

Each group of people taking part will receive a copy of the summary report of the project. This will contain findings from a number of groups, so you will have a chance to consider your own group in relation to others. Hopefully the report will be useful for you to think about the future of your group, and the ways in which the group meets the needs of its members.

All proposals for research with people are reviewed by an ethics committee before they can proceed. This proposal was reviewed by the joint UCL/UCLH Ethics Committee.

You do not have to take part in this study if you do not want to. If you decide to take part you may withdraw at any time without having to give a reason.

If you would like to contact the researchers for any reason, they can be reached at the address and phone number above.

Research Project: What do parents find helpful about mutual support groups?

Mike Solomon, BA M.Sc.
Nancy Pistrang, Ph.D.
Sub-Department of Clinical Health Psychology
University College London
Gower Street
London WC1E 6BT
(0171) 380 7896/7

Consent Form for Participants

Confidential

	Delete as necessary
Have you read the information sheet about his study?	YES/NO
Have you had an opportunity to ask questions and discuss this study?	YES/NO
Have you received satisfactory answers to all your questions?	YES/NO
Have you received enough information about this study?	YES/NO
Which researcher have you spoken to about this study?	....

Do you understand that you are free to withdraw from this study

* at any time
* without giving a reason for withdrawing   YES/NO

Do you agree to take part in this study?   YES/NO

Signed ....: .... Date ....

Name in Block Letters ....

Researcher ....

Research project: What do parents find helpful about mutual support groups?

Section 1: The nature of your group

The following statements are about groups. You are to decide which statements are true of your group and which are not.

If you think the statement is True or mostly True of your group, circle *T* (true). If you think the statement is False or mostly False of your group, circle *F* (false).

(Circle one)

1.	*There is a feeling of unity and cohesion in this group.*	T	F
2.	*When members disagree with each other, they usually say so.*	T	F
3.	*There is very little emphasis on practical tasks in this group.*	T	F
4.	*Personal problems are openly talked about.*	T	F
5.	*There is very little group spirit among members.*	T	F
6.	*It's hard to tell how members of this group are feeling.*	T	F
7.	*This is a down-to-earth, practical group.*	T	F
8.	*Members are expected to keep their personal hang-ups out of the group.*	T	F
9.	*There is a strong feeling of belongingness in this group.*	T	F
10.	*Members often say the first thing that comes into their minds.*	T	F
11.	*The group rarely has anything concrete to show for its efforts.*	T	F
12.	*Members sometimes tell others about their feelings of self-doubt.*	T	F
13.	*Members of this group feel close to each other.*	T	F
14.	*Members show a good deal of caution and self-control in the group.*	T	F
15.	*This is a decision-making group.*	T	F
16.	*Members sometimes talk about their dreams and ambitions.*	T	F
17.	*Members put a lot of energy into this group.*	T	F
18.	*Members tend to hide their feelings from one another.*	T	F

19.	*This is a planning group.*	*T*	*F*
20.	*Members hardly ever discuss their sexual lives.*	*T*	*F*
21.	*A lot of members just seem to be passing time in this group.*	*T*	*F*
22.	*It's OK to say whatever you want to in this group.*	*T*	*F*
23.	*Relatively little work gets done in this group.*	*T*	*F*
24.	*Members' religious beliefs are never discussed in the group.*	*T*	*F*
25.	*The members are very proud of this group.*	*T*	*F*
26.	*There is a lot of spontaneous discussion in this group.*	*T*	*F*
27.	*This group concentrates on dealing with everyday problems.*	*T*	*F*
28.	*Members can discuss family problems in the group.*	*T*	*F*
29.	*This is a rather apathetic group.*	*T*	*F*
30.	*Members are careful about what they say.*	*T*	*F*
31.	*This group does not help its members make practical decisions.*	*T*	*F*
32.	*In this group, you can find out what other people really think of you.*	*T*	*F*
33.	*The group is a good place to make friends.*	*T*	*F*
34.	*People here think things out before saying anything.*	*T*	*F*
35.	*The group helps its members learn new skills.*	*T*	*F*
36.	*This group is a good place to "let off steam".*	*T*	*F*

Please state the extent to which you agree or disagree with the following statements about your group:

37. *Different members are in charge of different aspects of group functioning.*

1	2	3	4	5	6	7
Disagree strongly			Neither agree nor disagree			Agree strongly

38. *You have developed a close friendship with another group member.*

1	2	3	4	5	6	7
Disagree strongly			Neither agree nor disagree			Agree strongly

39. *You regularly provide emotional support to group members.*

1	2	3	4	5	6	7
Disagree strongly			Neither agree nor disagree			Agree strongly

40. *Members regularly provide emotional support to you.*

1	2	3	4	5	6	7
Disagree strongly			Neither agree nor disagree			Agree strongly

41. *How often do you have contact with other group members between meetings?*

Never   Once a month   Once a fortnight   Once a week   More than once a week

(Circle one)

Section 2:   **The overall benefits of the group**

Please answer the following questions about <u>the benefits of the group overall.</u>   .

42.   *Please state the way(s) in which this group has helped you.*
       (Continue overleaf if necessary.)

To what extent do you feel that you have benefitted from:

43.   *Helping others?*

1	2	3	4	5	6	7
Very unhelpful			Neither			Very helpful

44.   *Receiving help from others?*

1	2	3	4	5	6	7
Very unhelpful			Neither			Very helpful

45.   *Sharing coping strategies?*

1	2	3	4	5	6	7
Very unhelpful			Neither			Very helpful

To what extent do you feel that you have benefitted from:

46. *Having a sense of community?*

1	2	3	4	5	6	7
Very unhelpful			Neither			Very helpful

47. *Sharing ideas about coping with public attitudes?*

1	2	3	4	5	6	7
Very unhelpful			Neither			Very helpful

48. *Sharing factual information?*

1	2	3	4	5	6	7
Very unhelpful			Neither			Very helpful

49. *Sharing a spirit of hope?*

1	2	3	4	5	6	7
Very unhelpful			Neither			Very helpful

50. *Increased self-confidence?*

1	2	3	4	5	6	7
Very unhelpful			Neither			Very helpful

51. *Meeting others with similar problems?*

1	2	3	4	5	6	7
Very unhelpful			Neither			Very helpful

Section 3:   Satisfaction with the group overall

Please answer the following questions about your overall satisfaction with your group.
(Circle one)

52.   *To what extent does the group meet your needs?*

1	2	3	4
None of my needs are met	Only a few of my needs are met	Most of my needs are met	Almost all of my needs are met

53.   *Does the support you receive help you to deal more effectively with your problems?*

1	2	3	4
No, it seems to make things worse	No, it really doesn't help	Yes, it helps somewhat	Yes, it helps a great deal

54.   *If a friend were in need of similar support, would you recommend the group to him/her?*

1	2	3	4
No, definitely not	No, not really	Yes, generally	Yes, definitely

55.   *In an overall, general sense, how satisfied are you with the support you receive?*

1	2	3	4
Quite dissatisfied	Indifferent or mildly dissatisfied	Mostly satisfied	Very satisfied

56.   *What do you think has been the most helpful in the group's meetings? It might have been something you said or did, or something that someone else said or did. Can you say why it has been helpful?* (Continue overleaf if necessary.)

57.   *What do you think has been the most unhelpful in the group's meetings? It might have been something you said or did, or something that someone else said or did. Can you say why it has been unhelpful?* (Continue overleaf if necessary.)

58.   *Please rate how helpful or unhelpful to you the group is overall.*

1	2	3	4	5	6	7	8	9
Extremely unhelpful				Neither helpful nor unhelpful				Extremely helpful

---

Section 4:   Demographic details

Please answer the following questions about yourself. All information is anonymous and will be treated confidentially.

59.   *Male/Female* (circle one)

60.   *Age:*

61.   *Occupation:*
(If you do not currently work, please state your last occupation or the occupation of the main income-earner in your household)

62.   *What is your ethnic background:*

63.   *What is your religion, if any:*

64.   *How long have you been attending meetings of this group?*

65.   *How many children do you have?*

66.   *How old is your child(ren) with special needs?*

67.   *How would you describe the nature and extent of your child's (children's) disabilities and special needs?*

Thank you very much for completing this part of the questionnaire.

Section 5:   Summary sheet on the impact of group membership

You have just taken part in a discussion about the impact which being a member of this group has had on people's lives. Please answer the questions below summarising the impact which being a member of this group has had for you. (Continue any answers overleaf if necessary.)

68.   *What difference has being a member of the group made to you?*

69.   *Have you changed in any way since you started being part of this group? If so, how?*

70.   *How would things be different for you if there were no group?*

71.   *If you were recommending this group to someone else in a similar position, what benefits would you describe to them?*

72.   *Is there anything else which you would like to say about your experiences in this group which you have not had an opportunity to say?*

Thank you very much for taking part in this project.