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Models of service support for parents of disabled children. What do we know? What do we need to know?

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Summary

Research carried out over a number of years provides a consistent picture of the experiences and needs of parents of disabled children. Recent studies, based on models of stress and coping, have identified factors which relate to high or low levels of parental distress. Whilst this research can provide useful information for service development, there appears to have been little change over the years in parents' reports of unmet need. It is clear that parental need covers a wide range of aspects of family life and holistic models of service support are required. Although evaluation studies which identify models of services that can change this situation are few, there are positive examples of models of support. The paper reviews the findings of such evaluation and identifies a number of important characteristics of effective service models.

Keywords: coping, disabled children, parents, services, stress

Introduction

Over the last 25 years, the ideas and models which inform policy, research and services for families of disabled children have undergone a number of changes. These changes appear to have been prompted by many factors, amongst these are: the growth of the disability and human rights movements (Oliver 1990); the growing focus on the rights of children (United Nations 1989); generation

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of theoretical models of stress and coping and family systems approaches (Lazarus & Folkman 1984; Dunst, Trivette & Deal 1994); and the development of the carers movement, for instance the Carers National Association.

Debates around the differences between the medical and social models of disability, although mainly focused on the rights and needs of disabled people, also have implications for changes in the ways in which the needs of families of disabled children are viewed. The British Association of Community Child Health defines the distinctions between these models as:

The medical model views all disability as the result of some physiological impairment due to damage or to a disease process. Within a social model, individuals who are different by virtue of an impairment find that they are oppressed by a society obsessed with concepts of normality.
(BACCH/DoH 1994:p.31)

Within the medical model, the needs of the family and child are mainly viewed as requiring interventions focused on the child's impairment and prevention of disability resulting from this impairment. Stresses on families are seen as occurring as a direct result of the child's impairment. A social model as applied to families predicates a broader view focusing on the social and environmental factors that affect families of disabled children, social attitudes towards impairment and inadequacies in support.

Recent changes in policies within health, education and social services (Children Act 1989; NHS & Community Care Act 1990; Education Act 1993; Children Act [Scotland] 1995; Carers [Support and Recognition] Act 1995) reflect these developments and contribute to the need to assess the current position with regard to what we know about support for parents of disabled children and what the outcomes of changes over the last 25 years have been. The emphasis within current policy development (e.g. DfEE 1997; DoH 1997) on the importance of obtaining the views of users of services, and the requirement on social services departments to draw up children's services plans in consultation with other agencies, also provides opportunities for service providers to review the ways in which they support families of disabled children.

This paper will review research examining the effectiveness of different models of service support for parents of disabled children. Such research is sparse, considerable difficulties are apparent in measuring the outcomes of social welfare provision (Nocon & Qureshi 1996), and there is little evidence of active evaluation of services for families of disabled children (SSI 1994).

The review will first look at information which can be gained from research on parents' needs and the factors which are related to problems in parental functioning, before examining evidence on effects of different models of service provision.

The importance of parent support services

Research tells us that parents of disabled children are particularly vulnerable to stress, for example, high levels of distress have been found in up to 70% of mothers and 40% of fathers of severely disabled children (Sloper & Turner 1993). In addition, both the general psychological literature and specific studies of disabled children show that parental distress and family functioning impacts on children in numerous ways, affecting their cognitive, behavioural and social development (e.g. Richman, Stevenson & Graham 1982; Wallander & Varni 1998). Thus, whilst supporting parents to alleviate distress will not inevitably result in well-being for the child and does not negate the need for child-focused support, the converse position, that is a lack of parent support and high levels of parental distress, will affect the child's well-being (Middleton 1995).

Whilst the risk of distress has long been recognized, an early major change in approach was the move from a pathological model, which viewed high levels of parental distress and problems in family functioning as an inevitable reaction to having a disabled child, to the recognition that there were large variations in families' responses with positive outcomes for a substantial number of families, and a corresponding need to understand the factors which influence differences in outcome (Byrne & Cunningham 1985). This change accompanied recognition of the need for services to provide more broadly based family support, rather than focusing solely on treatment of the child and remediation of the effects of the impairment (Cunningham & Davis 1985). It generated a search for models which could inform research on family needs and functioning and encompass the many different factors involved in how families cope with having a disabled child.

Theoretical models of stress and coping and parent well-being

The most influential model in research on families of disabled children has been Lazarus and Folkman's (1984) cognitive model of stress and coping. This model views people as actively interpreting, responding to and, if necessary, dealing with, a potentially stressful situation. A key feature of the

model is that individuals differ in their appraisals of similar events and circumstances. Thus, we cannot presume that any parent inevitably experiences the child's impairment as a source of stress. Individuals' appraisals and options for action are affected by the resources available to them, which include material, physical, psychological and social factors. The actions people take to deal with stressful situations are termed 'coping strategies' and include both efforts to regulate or reduce the stressful emotions engendered by the situation (emotion-focused strategies) and efforts to change the situation itself (problem-focused strategies). A considerable number of research studies now point to the utility of this model and the particular importance of resources in influencing the well-being of parents of disabled children (Knussen & Sloper 1992; Beresford 1994a).

Whilst the model has sometimes been seen as focusing excessively on the individual, rather than the social and environmental factors which affect parents of disabled children, this is more a criticism of the sometimes narrow ways in which it has been used than the tenets of the model itself. Clearly, the emphasis on the importance of resources available to parents demands investigation of material and environmental factors, such as income, transport, housing; social resources, such as informal and service support; and personal factors, such as attitudes and beliefs, which are also influenced by prevailing social mores.

What do we know about factors related to parental well-being?

A number of reviews of research on this topic already exist (Knussen & Sloper 1992; Beresford 1994a; McConachie 1994; Wallander & Varni 1998) and it is not the purpose of this paper to deal with this in detail. However, some generalizations can be made from the research. Firstly, families vary considerably in how they appraise the situation of having a disabled child, and this variation is not explained by severity of disability. Problems of the child's behaviour or sleeping problems are more likely to be appraised as stressful than severity of disability (Quine & Pahl 1991; Sloper *et al.* 1991). Secondly, life events that impinge on family well-being, such as family illness, separation or divorce, affect parents of disabled children in the same way as any other family (Sloper & Turner 1993).

Material, personal and social resources have all been shown to relate strongly to parental well-being (Frey, Greenberg & Fewell 1989; Quine & Pahl 1991; Sloper & Turner 1993; Sloper *et al.* 1991; Wallander *et al.* 1989). Inadequate income is a source of anxiety in itself and also prevents parents from accessing

other resources, such as purchasing help. On average, families of disabled children have lower incomes than other families (Gordon, Parker & Loughran 1996) and face extra costs not covered by existing disability benefits (Dobson & Middleton 1998). Mothers of disabled children are less likely to be in employment than their peers (Beresford 1995), yet research shows that employment provides both material and social resources and is associated with lower levels of distress (Sloper *et al.* 1991; Walker, Ortiz-Valdes & Newbrough 1989). Many mothers would like to work outside the home but are prevented from doing so by the lack of provision of services to cater for the child's needs during working hours, and the inflexibility of service systems such as hospital appointments and school transport (Kagan, Lewis & Heaton 1998). Inadequate housing and transport are also associated with higher levels of distress (Bradshaw & Lawton 1978; Sloper & Turner 1993; Sloper *et al.* 1991). Informal social support, especially that available from within the immediate family has been shown to be related to well-being in many studies (McKinney & Peterson 1987; Frey, Greenberg & Fewell 1989; Wallander *et al.* 1989), and unmet needs for support from services are also important factors (Sloper & Turner 1993). An important personal resource is parents' sense of control: feeling that they are in control of events and can obtain appropriate help for the family and child (Frey, Greenberg & Fewell 1989; Friedrich, Wiltturner & Cohen 1985). Sadly, parents often report problems in relationships with services which erode this sense of control (Beresford 1995).

There are indications that parents who use active problem solving coping strategies to deal with stressors show less distress than those who use more passive strategies of avoidance, self blame or wishful thinking (Frey, Greenberg & Fewell 1989; Sloper *et al.* 1991). Parents who take a passive approach have also been shown to have more unmet needs for services (Sloper & Turner 1992), indicating a need for services to be more proactive in contacts with parents. Research also shows that many parents are reluctant to use services for themselves: they will go to great lengths to obtain appropriate help for their children, but may view support for themselves as an admission of failure as a parent (Beresford 1994b). This emphasizes the importance of the interpersonal factors in parent support and the need to maintain parents' own sense of control and build upon their strengths.

It is clear from these findings that the factors related to well-being in parents of disabled children are mostly those common to all parents, with social factors being paramount. Yet, research on service provision and parents' views of their unmet needs shows considerable problems in the provision of services which can provide appropriate parent support.

Evidence on unmet need

Research over the last 25 years has continued to indicate substantial levels of unmet need in parents of disabled children (Baldwin & Carlisle 1994). Beresford's recent national survey of over 1000 families showed little change in parents' views about whether services met their needs when compared with similar surveys carried out many years ago (e.g. Glendinning 1983). Other research with parents of children with different disabilities, and carried out in different parts of the country (Quine & Pahl 1989; Sloper & Turner 1992) also presents a consistent picture of parents' views of their needs, and those needs that are most likely to remain unmet. Areas where over one third of parents report unmet need are: information and advice about services, the child's condition and how to help the child; financial and material support with housing and transport; and practical help with breaks from care.

Certain groups of families are likely to have particularly high levels of unmet need. These are: families of children with very severe impairments and families of older children (Beresford 1995); families from ethnic minorities (Beresford 1995; Chamba *et al.* 1999); and families with more than one disabled child (Lawton 1998).

Problems encountered with services

Disabled children and their families have needs that require interventions from many different services, such as health, education, social services, housing and benefits agencies. They experience numerous contacts with different workers, and one of the biggest problems lies in the lack of co-ordination of the work of these different agencies and the resulting confusion for and demands upon parents (Gordon, Parker & Loughran 1996; Sloper & Turner 1992). Many parents describe a constant battle to find out about what services are available, to understand the roles of different agencies and workers, to know who to go to, and to get services to understand their situation and their needs (Beresford 1995).

Why should this be so? First, fragmentation of support and the lack of any overall view of the family's needs are exacerbated by the lack of a single point of contact and co-ordination for families. Thus, provision may be piecemeal and service- rather than needs-led. Although, recommendations that 'key' or 'link' workers should provide this single point of contact for families of disabled children have appeared regularly in policy since the Court Report in 1976, research continues to show that less than one third of families have a key worker (Beresford 1995). Secondly, a failure to consider a holistic picture of family needs is indicated by Gordon, Parker and Loughran's (1996) finding

from analysis of OPCS data that the distribution of services received by families reflected the severity of the child's disability rather than the social factors most strongly related to parental well-being. Families who received least service provision were those likely to have the greatest social needs: lone parent families, large families, and those with the lowest 20% of income.

Despite the negative tenor of these findings, it is clear that not all parents have high levels of distress or unmet need. It is useful to consider what we know about service models that *do* meet parental needs.

What do we know about 'successful' services to support parents?

The research findings reported above indicate that to provide support to parents, services need to assess parents' own appraisals of their situation, the resources available to the family, and the coping strategies used, to respond to identified need and to help parents mobilize resources and build upon their strengths (Dunst, Trivette & Deal 1994). This paper will therefore concentrate on service models, that is ways of providing parent support, that cover a broad range of parent need. Specific services, such as respite care, which may form one part of a package of support after assessment of needs, are omitted. Whilst, as noted above, research that has evaluated the effectiveness of parent support services is relatively rare, a number of service models that have been shown to 'work' have been identified. These will be briefly described below (for a more detailed account readers are referred to Beresford *et al.* 1996). Services selected here are those whose main aim is parent support and those for which evidence of effectiveness is available. The issue of disclosure of diagnosis is not included. A number of reviews and guidelines on this issue are already available and the parameters of good practice are now relatively well established (e.g. Cunningham 1994; Leonard 1994).

Key worker models

A 'key worker' or 'link person' is a named person whom the parent approaches for advice about any problem related to the disabled child. The key worker maintains regular contact as needed with the family, and has responsibility for collaborating with professionals from a range of services, and co-ordinating support for the family. Particularly important aspects of the service are the key worker's knowledge of and ability to access information and services from a range of agencies. Examples of models of key worker services are described by Dale (1996) and Appleton *et al.* (1997).

There have been few evaluations of key worker services for families of disabled children, but more general research on family needs does indicate positive effects of key workers. Sloper and Turner (1992) found that families who did not have a key worker had significantly more unmet needs, and that this was particularly the case for families with the most problems and the fewest resources. Beresford's (1995) survey indicated that whilst only a minority of families received a key worker service, those who did reported better relationships with professionals, but they did not necessarily report fewer problems with services. There are a number of reasons why this should be so: first, parents' descriptions of their key workers often suggest that this role is taken on in an *ad hoc* way by a particular person, rather than it being an official part of their role (Sloper & Turner 1991). Thus, changes in service personnel or increasing demands of 'official' roles may result in a cessation or decrease in the key worker function. Secondly, problems with services are dependent upon other factors, such as interagency collaboration and availability of services. Glendinning's (1986) detailed research study of the effects of providing designated key workers, termed 'resource workers', showed a number of positive effects for resource worker families compared with a control group: higher parental morale, receipt of more practical help, greater satisfaction with respite facilities, and less isolation. The greatest value of the service was seen as having someone to talk to, whom parents could turn to for help whenever they needed.

Parent counselling models

Dunst, Trivette and Deal (1988, 1994) have carried out a number of studies of family support services in the USA. Their findings suggest that many elements of effective support services centre around interpersonal aspects of the relationship between families and service providers:

It matters as much *how* professionals assist families in mobilizing resources as it does *which* supports are mobilized.

(Dunst, Trivette & Deal 1994: p.ii)

Features of effective help-giving are identified as: relationship building; communication, honesty and clarity; understanding of families' own concerns; and responsiveness to family values and goals.

Research in the UK on parent support services based on counselling models has shown positive effects. Davis and Rushton (1991) report on a randomized controlled trial of a service provided by parent advisers trained in a basic

counselling approach. The advisers' role was to explore any issues raised by parents, including material resources, relationship problems, and problems related to the child; to help parents to clarify problems, set goals, formulate plans and carry them out. The results of the study showed that, compared with the control group, mothers in the intervention group rated themselves as better supported by professionals and felt more positive about the child, and the children's developmental progress was greater. Results for the group of socially disadvantaged Bangladeshi mothers were even stronger, with additional effects on feelings about self and spouse; increases in measures of social support; improvements in child behaviour problems, and decreases in levels of maternal distress. Davis (1993) provides a more detailed description of the counselling models informing this study.

Parent partnership models

As noted above, the relationship between parent and professionals is a crucial aspect of service effectiveness. Much has been written in recent years about the change in approach of professionals from 'expert' models to those based on partnership, with recognition of the complementary knowledge and expertise of parents and professionals, accommodation of different perspectives, and a flexible and individualized approach (e.g. Cunningham & Davis 1985; Appleton & Minchom 1991; Dale 1996). Evaluation of such an approach employed by the KIDS Family Centre (Dale 1992, 1996) points to positive effects. The Centre employed a named worker approach, with multidisciplinary staffing, and provided a range of services from which parents could choose. Professional practice was based on a negotiating model of partnership (Dale 1996) whereby time, listening, openness and discussion are used to help parents and professionals to reach consensus on needs and actions. Evaluation results showed that the majority of mothers felt that they had control in choosing services, and rated the Centre as very helpful and supportive. The provision of emotional and practical guidance, accessibility of the service, and the partnership approach were particularly appreciated.

Coping skills models

Reports of interventions focused on parents' coping skills are more common in the American literature than in the UK (Zeitlin, Rosenblatt & Williamson 1986; Kirkham & Schilling 1990; Gammon & Rose 1991; Kirkham 1993). Nevertheless, positive results from such interventions suggest that such

models may have lessons for UK services. In general, these interventions have used the ideas from stress and coping theories to inform parent training in problem solving and decision making, communication skills, skills in accessing and utilizing social networks, and coping strategies such as positive self-statements, self-praise and relaxation. Training has often been carried out in groups, although Zeitlin, Rosenblatt and Williamson (1986) report an individual programme. Kirkham (1993) reports on post-training and two-year follow-up effects on mothers who took part in such a programme. Compared with the control group, intervention group mothers showed a number of effects on post-training measures: greater improvements in communication skills, coping skills, satisfaction with family support and intimate support. At two-year follow-up, intervention group mothers showed lower levels of depression, and maintenance over the two-year period of improved communication and coping skills.

An intervention focused on a specific aspect of coping skills, parents' ability to deal with sleeping problems in their disabled child, was reported by Quine (1993). Health visitors and community nurses were trained in the use of behavioural approaches, and then taught parents behavioural techniques and supported them in implementing programmes for their children. An intervention with 25 families showed significant reductions in both settling and waking problems, with improvements maintained three months after the intervention. Improvements in maternal well-being were also shown.

Other services

The models reported above focus on services that take a holistic approach to parent support. One of their strengths lies in their ability to work with parents to determine their needs, and to provide opportunities for parents to access a range of other services as appropriate. Examples of such services that are particularly valued by parents include types of respite services, particularly family-based care schemes that provide positive experiences and opportunities for the child (Stalker 1990; Platts *et al.* 1995); parent-to-parent groups and befriending schemes (White 1996; Hornby, Murray & Jones 1987); and early intervention schemes. The latter are a good example of services which, although originally aimed at supporting the child's development, have been shown in practice to provide support to parents. Parents appreciate the long-term, regular contact with the same worker, acknowledgement of their own knowledge of the child, and the opportunity to learn how best to help their child (Beresford 1994a). In contrast with the equivocal findings with regard to

child development, evaluations of early intervention have highlighted positive impacts on parents (Cunningham *et al.* 1986; Eayrs & Jones 1992).

Conclusions

Research on parental needs and support suggests that a number of problems still exist in service provision, but there are encouraging examples of service models which can meet parental needs. Whilst there are differences between the models cited above, they have a number of features in common. They take a holistic approach to assessing and meeting family needs; the importance of relationship building between parents and professionals is recognized; they provide a consistent, single point of contact for the family; they have a flexible, individualized, needs-led approach; they focus on parents' own concerns and recognize the importance of understanding parents' own perceptions of the hierarchy of their needs; support provided empowers parents rather than taking control away from them; parents' own expertise with regard to their child and family is recognized and acknowledged. Such models are not specific to any one agency or service. They can be implemented within different settings, with multidisciplinary teams, such as child development teams, providing a good basis for implementation (e.g. Hall 1997).

What do we need to know?

Research findings on factors related to parental well-being can be informative for service development (McConachie 1994), and information from well-designed evaluation of interventions and service initiatives can do much to promote appropriate service models. Research over the last 25 years has provided detailed information on parents' needs and experiences and, more latterly, explicative research on parental functioning has helped to clarify ways in which support could be more usefully targeted. However, the requirement now is to put this body of knowledge into practice, to influence service development, to evaluate these developments, and to highlight and disseminate good practice. There needs to be a change in research priorities from finding out what the problems are to finding out the solutions, with full involvement of both parents and professionals at all stages of the process.

It is notable that setting up and evaluation of service models has often taken place within small-scale research projects. Evaluation of both the process and outcome of implementing such models within mainstream services is important. Such researched development work could address questions of

whether the models can be implemented on a larger scale, what barriers are faced in implementation, what are the effects on other aspects of services, and what larger scale evaluation can tell us about effectiveness. Such work should ideally involve multicentre studies. Our current experiences, at the Social Policy Research Unit, of carrying out a small-scale researched development project on the implementation of a key worker service in two areas suggests that researchers, service managers and practitioners are all keen to address these issues.

Current policy emphasis on the importance of evidence-based practice in both health and social services sets a challenge for researchers and practitioners to work together in this endeavour. The value of researched development work needs to be acknowledged and promoted. It is notable that one of parents' main complaints is of the difficulty in finding out about services. This complaint is also echoed by professionals with regard to ways of finding out about the many examples of good practice that undoubtedly exist, so that service development in each local area does not have to 'reinvent the wheel'. Over its lifetime, *Child: care, health and development* has played an important role in dissemination of research and practice on support for parents of disabled children. In the next few years it is to be hoped that a much more extensive literature on service effectiveness will develop to inform good practice.

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