Just a Shadow?
A review of support for the fathers of children with disabilities

Sheila West
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A review of support for the fathers of children with disabilities

An adaptation of the dissertation submitted in part-fulfilment of the requirements for the degree of MA in Social Work and Social Care, Bradford University
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**Just a Shadow**

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I would like to acknowledge the contribution of the four fathers interviewed during this research.

I was aware, in my consideration of the ethics of carrying out this research that asking these fathers to tell their story yet again was an imposition. However I justified this by stating my intention to use the research to inform future practice. I also acknowledged that talking about their role as a father of a child with a disability would be a painful process. For some this pain was all too apparent, and I am indebted to all of them for sharing their experiences. What I was less prepared for was one of my assumptions to be proven false. Some of the fathers had not told their story many times before, or even at all. I acknowledge the privilege of being the first to listen.
Introduction

The roots of Just a Shadow

As part of her studies in Social Work and Social Care, Sheila West conducted a small-scale piece of research into the support needs of the fathers of children with disabilities.

Through her work with families and lately as a trustee with the Handsel Trust, Sheila realised that when parents are mentioned in carer and support terms, what is really meant is mothers. Often the reason is very simple - appointments and visits are invariably made in the day-time when the father may well be at work.

Just a Shadow discusses the views of four fathers, their experiences as parents and carers and the implications that their experiences have for future practice.

For those interested in the background of this research, Just a Shadow provides a comprehensive review of other relate research and a wide-ranging bibliography providing plenty of further reading.

About the author

A qualified social worker, Sheila worked as a keyworker with One Hundred Hours offering support to families in West Yorkshire from 1994 until One Hundred Hours ceased operating in 1999. In addition to her family work, Sheila became very involved with Scope’s Right from the Start campaign, conducted the first evaluation of One Hundred Hours (before becoming a keyworker herself) published as When the Bough Breaks in 1994 and organised the One Hundred Hours’ first UK conference on support for parents - Opportunity 98.

Sheila is now a trustee of the Handsel Trust and, as such, with Contact-a-Family, facilitates the Speaking Up series of workshops for parents. These workshops encourage parents around the UK to get together locally to discuss the needs and implications of a keyworker model of support.

Sheila currently works as a social worker in a children with disabilities team in West Yorkshire. Her work is in a Child Development Unit where the service to families is currently undergoing review.

The Handsel Trust

Just a Shadow is published by the Handsel Trust as part of our commitment to encourage the dissemination of original research which adds to the pool of knowledge about how we can best support parents. We aim for research to reach parents and practitioners - the people who can put it into practice rather than leave it in the realms only of other researchers.

The Handsel Trust is the UK organisation launched in 2000 to promote awareness of the support needs of parents and disseminate information about the keyworker model of support developed by One Hundred Hours in West Yorkshire.
About the research

Research aims

This is a piece of qualitative research investigating the experiences of fathers of a child with a disability. The aim of the research is to establish a picture of what constitutes support for fathers. It will aim to identify those elements of support that were or are important to them, based on their direct experience. It will also explore what, with hindsight, they would have wanted.

Research rationale

The researcher has been working with families with children with a disability for a number of years. Based on this experience, I have become increasingly aware that parents are, on the whole, unhappy with the services they receive to support them in the care of their disabled child. This is either a reflection of the quality of the service or a reflection of the unavailability of an appropriate service. It would therefore appear a valid exercise to investigate the reasons for this dissatisfaction with a view to suggesting ways to address the issues with recommendations for practice. This experience substantiates the findings of the research of the last two decades and leads me to believe:

- the majority of families feel unsupported from the point of diagnosis
- families have difficulty in accessing information about all aspects of their child's disability and services available to them
- families do not experience a co-ordinated pattern of service provision
- parents are not treated as equal partners in the design of the care package for their child
- mothers' and fathers' needs are not recognised as being potentially separate

I have become aware that whilst services to families have been researched and evaluated, little attention has been given to the separate needs within those families. There has been a concentration on mothers’ needs within a family, either explicitly or implicitly. Little attention has been paid exclusively to fathers. Hence the focus for this research.
Methodology

Semi-structured interviews with four individual fathers were used to generate the data. Here the emphasis is on individual as each parent is an individual; most of the previous research has treated parents as if they were of one mind. The structure for the interviews was provided by the use of a number of open-ended questions. The purpose of this was to ensure that each interview covered similar ground but because the interviews were not rigid in their format this increased the opportunity the interviewees had to talk about aspects of their child's care that were important to them. Silverman (1993) agrees that this approach is a valid one in the exploration of this particular social reality. He believes that when one is gathering an ‘authentic’ (as opposed to ‘reliable’) understanding of people's experiences the use of open-ended questions is the most effective method; Silverman uses the example of interviewing parents of handicapped (sic) children to illustrate his point. I agree with this viewpoint; because the nature of the topic being researched is a very emotive one it requires an unstructured approach. It would be entirely inappropriate to try to generate data about a parent's emotional response to caring for a child with a disability by using an interview schedule that does not allow the interview to flow according to the situation. Burgess' well known definition of the semi-structured interview as a ‘conversation with a purpose’ accurately describes what should happen in these circumstances. (Burgess, 1984 p102).

Each interview was taped and notes were also taken during the course of the interview. The analysis broadly concentrated on common themes emerging from the interviews. At the same time however being conscious that the depth of feeling about an issue for individual interviewees gave the issue just a much significance as did the frequency with which it was raised (Opie 1992).

The findings are presented with liberal use of the respondents' own words. I have grouped them under headings of common themes, with interpretations and summaries throughout. The use of quotations taken from the interviews has made the findings chapter fairly lengthy and for that I apologise. However I feel the impact of a piece of work like this is increased when the reality of each individual's situation can be directly communicated in this way. I would argue that using the fathers own words is the best method for achieving this impact.

I question how I can improve on or interpret someone else's perception of his or her reality. (Martin 1995 p71)

Finally, a note on how I have represented the quotations. Where the interviewee paused, or failed to finish a sentence, this has been indicated by two full stops. Where I have not included the full text of one piece of dialogue, I have indicated this with four full stops. Where an interviewee used a person's name, for example their wife (all the respondents were married) I have replaced this with [my wife] in italics. Where I have needed to add a small detail for reasons of clarity this has been inserted in parenthesis in standard type to signify that it was not part of the interviewees original words. In every instance I refer to the children as ‘he’. All the interviewees were fathers of sons.
A review of related research

There is a wealth of literature published over the last thirty years looking at a number of aspects of caring for a child with a disability. Some of this literature and research looks at the effects upon the family of caring for a child with a disability with a focus upon the coping strategies that parents employ to enable them to cope with these effects. Other research aims to evaluate a specific intervention designed to alleviate the stresses parents experience as a result of their caring role. It is my intention to look at the research to show how or whether it contributes to the overall picture of what constitutes support and whether they have differentiated between support for fathers and support for mothers. Later in the paper links will be made between the published research reviewed here and the findings of the research carried out for this paper.

Baldwin and Carlisle (1994) review the literature and give a good account of how there has been a gradual recognition that caring for a severely disabled child at home impacts upon the whole family. They quote the Younghusband report as highlighting the need for more and better organised support services and the Court Report (1976) identified the nature of the problems being faced by parents. These lay not necessarily with the lack of support services but in their design and delivery. The Warnock Report (1978) was amongst the first to identify what form this support should take. The committee concluded that what was needed was one person to whom parents could relate for advice on services available to them.

Glendinning (1983 and 1986) has done much to further an understanding of the experiences of parents and the how these experiences have impacted on the many aspects of daily life associated with caring for a disabled child, but clearly neglects the issue of fathers' needs. In her earlier study she devotes one whole section to Effects on Parents with a sub-section for fathers, however father's feelings were very under-represented (only 18% of the interviews included fathers as well). Glendinning acknowledges that the interviews took place during the daytime - thus presumably excluding employed fathers from the research. She then goes on to describe a highly dubious data collection method:

>If they (the fathers) were not present, their wives were asked for their views on their husband's responses to the demands of a severely disabled child.

(Glendinning 1983 p 82)

Other research attempts to quantify support experienced by parents by measuring the frequency of contacts each family had with a helping professional. (Fox, 1974, Bradshaw, Glendinning and Baldwin, 1977, Armstrong, Race and Race, 1979, Glendinning, 1983, Baldwin, 1985) The conclusions of these had a number of common elements. A high percentage of parents reported having infrequent contact with either social workers or health visitors; many parents would like more advice and support, or they found what they did receive either too passive or too routine. The overall emerging picture from the research at this time is that parents felt generally unsupported by the services set up with the purpose of providing that support. The researchers seem to assume that ‘support’ is something that should be provided by either a social worker or a health visitor. What is not clear however is who is responsible for identifying the source of the support. (Glendinning 1983, Mutch 1987). The focus of the research questions asked in these two pieces of research were heavily influenced by the organisation from which the researcher came which I would argue influenced the findings of the research.

Another potential problem of research lies in the focus of the questions asked. Quine and...
Pahl (1989) looked specifically at issues around stress and coping within the family. The research is very child and problem focused. The researchers defined the problem as they perceived it rather than allowing the parents to define it for themselves. There is one telling comment in the conclusion that illustrates this point. The researchers found that feelings of loneliness were related to

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\text{perceived inadequacy of social support. Whether such feelings are related to actual amount (their emphasis) of social support is not clear, however.}
\]

(Quine and Pahl, 1989, p.128.)

I would argue that the only valid measurement of support is the amount of support that the recipients perceive themselves as receiving; any other criteria would be meaningless.

Parents or mothers?

It is well documented that there is a plethora of research into various aspects of the care of a child with a disability within the family (Beresford et al 1996). Much of this research has been carried out with the use of questionnaires or interviews with parents. It is interesting to note however, that many of these pieces of research have failed to acknowledge the fact that parents should mean a mother and a father as separate individuals. Neither is it acknowledged that these two people might well have different views of the same situation. Middleton (1998) addresses the question of the relationship between parental views and those of social workers with regard to service provision for families with a disabled child. She talks about gaining a picture of ‘families’ views through interviews without making it explicit who in the family had been interviewed. She only acknowledged that the views of the disabled children themselves had not been sought.

This criticism could be levelled at a number of pieces of research. Pelchat et al (1999) reviews many research findings (Holroyd and McArthur 1976; Bendell et al 1987; Stein and Jessop 1989; Hanson and Hanline 1990) which are discussed under the general heading of \textit{parental} stress and adaptation (my emphasis). All of the research that Pelchat reviews only talk in terms of measurements of the mother's stress and psychological adaptation. Similarly Harada and Pye's (1981) research drew conclusions about training needs for midwives in the communication with parents of babies defined as the abnormal neonate. However all the discussion focuses on the needs of mothers. Fathers' needs are not mentioned. Hornby et al (1987) describe a parent support service in Auckland but again there is no clear differentiation between mothers and fathers as part of the scheme, either as parent counsellors or parent users. This is not to say that in reality it did not happen but for the published work to be of greater value these issues need to be made explicit.

Sloper and Turner (1992), in their attempts to find out about service needs for families with a disabled child, sent questionnaires to both parents to fill in independently of each other, but followed this up by only interviewing the mothers. Stallard and Lenton (1992) looked at parental satisfaction of services they received for their child with special needs. Parents were approached via their opportunity playgroup (playgroups resourced specifically to meet the needs of pre-school children with special needs). They were then requested to volunteer for the survey and interviewed at the playgroup. Although the research findings refer to parents' responses, given that the majority of children are taken to playgroups by their mothers it would be reasonable to assume that the research, once again, reflects the views of mothers.

Cotterell and Summers (1990) investigated parents' experiences of communication of their child's disability when the diagnosis and prognosis is unclear. Again the concentration was
upon mothers. Some of the data was gathered from what occurred at a support group for mothers and some of the data came from information gained by the staff during contact with parents whilst their children were receiving therapy. Firstly fathers were excluded from one part of the research and secondly it is not made clear which parent took the child to the therapy sessions. It is reasonable to assume that the majority of parents in this instance would have been the mother.

Responses to stress

Much of the research focuses on the stress of caring for a child with a disability and parents' responses to that stress. This raises a number of issues. The first is the one that has already been raised, which is that the research does not look at mothers and fathers separately. There is also considerable evidence, which my own experience and practice would substantiate, to show that parents and professionals have a divergence of opinion about the needs of families with children with a disability (Sloper and Turner 1991; Baldwin and Carlisle 1994; Hall 1997; Middleton 1998). I would argue that professionals need to address this issue and establish not only what families want and need from services but also what each individual member of the family wants from them. It is possible to argue that focussing on the stress of caring for a child with a disability distorts the real picture. Research shows that it is erroneous to assume that all parents inevitably experience their child's disability as a source of stress (Sloper 1999). Beresford (1994a & 1994b) particularly emphasises the positive aspect that parents report in the care of their disabled child.

Most of the research reviewed so far can be seen to be flawed as it talks about ‘parents’ views’ when what it means is ‘mothers’ views’. However there is published work that does acknowledge that fathers have been overlooked. (Beckman 1991; Hornby 1992; Rodrigue 1992; Barr 1999).

There appears to be a bias in sample selection for studies with an almost exclusive focus on the views of mothers, and correspondingly limited attention to the views of fathers or other family members. (Barr 1999 p 34)

Research that does address fathers’ needs

McConachie (1982) carried out research into fathers' involvement with their disabled child and attempted to define more clearly what fathers actually do. Although this work was written some time ago, some of the issues it raises are still very relevant. I would contend, based on my own experience of working in this field, that the situations described in the McConachie article and the research that she cites, reflect a situation that has not much changed in the intervening years. She also raises some points that are of particular interest to the research being piloted in this study.

McConachie found that there was a paucity of material looking specifically at fathers of children with a disability. Carpenter (1997) found the situation not much improved fifteen years later when he carried out his research into the reactions of fathers in the early months following the birth of a baby with a disability or diagnosis of disability. McConachie makes the point that the research is often based on interviews with mothers about fathers' views. There is often no differentiation between parents or indeed when 'parents' are mentioned the term really refers to mothers only. This will have an effect upon the ways that services respond to the family. McConachie argues that services and information are directed at mothers as they are seen as the primary carer and fathers' involvement is often viewed as
peripheral, a view supported in a study carried out by Carpenter and Herbert (1994). Wing (1975) identifies fathers as the source of emotional support for mothers in her research into families' experience of disability. She found that emotional support from their husbands was mentioned by nearly one third of the research sample (all of whom were women of course!) This begs the obvious question - who supports the fathers? A video recently produced by Capability Scotland (1999) looks at support needs for parents of a child with complex needs. Five parents were interviewed (two of whom were fathers) and one of the fathers highlighted this very problem. He stated that he recognised that his wife was their child's main carer and she received no emotional support aimed specifically at her as a carer. He also stated that he received no support as the husband of a carer, indicating that he sees his needs and those of his partner as distinct, different and unmet.

McConachie (1982) also addresses the myths (as she sees them) surrounding fathers' needs, abilities and roles within the family. She argues that the stereotyping of these roles has influenced the way fathers have been viewed in their relationship with their child. She also recognises a number of contradictory assumptions that are made about fathers. For example, it is expected that fathers of a child with a disability will be more involved with their child by the nature of the increased care load. On the other hand alternative perspectives place fathers more removed from their disabled child as the child will be less likely to reach the level of achievement at which fathers can be involved in the traditional ‘father-role’ activities. She sees these contradictory assumptions as being one of the factors that makes research into family dynamics problematic.

Other stereotypes of the father being the strong one can also be seen to affect the response of the professionals in their dealings with a family. This stereotyping has profound consequences for the expectations that fathers feel they may have to live up to in their dealings with professionals. Wrigglesworth (1975) contend that fathers are seen as being more detached and less intimately involved emotionally with the child. In a study of parents responses to the diagnosis of disability Hannam (1975) reported one father as seeing himself as the ‘tough’ member of the family. The mother however

\[
\text{was cast in the weak and feminine role as was allowed at least the ‘luxury’ of breaking down. The man had to carry the burden. (Hannam, 1975, p 29)}
\]

Hornby (1992) reviews fathers' accounts of their experiences of parenting children with disabilities. He identifies a number of common themes emerging from these accounts whilst at the same time acknowledging the differences between each of the fathers and their personal experiences. He identifies that fathers experience a great intensity of emotion connected with fathering a child with a disability. These emotions range across the spectrum of negative to positive feelings about their child and their response to fatherhood. In an earlier study Hornby (1991) describes this range of emotion as the ‘process of adaptation’. He suggests that fathers experience emotions that move from shock and denial, through anger, sadness and detachment towards reorganisation and adaptation.

Some studies suggest that fathers are more affected by their child's disability and take longer to adjust than mothers. It is argued that this is due to the fact that men are more concerned with the potential achievements and independence of their children. This argument is founded on a view of fathers based on socio-cultural values of manhood, competitiveness and attainment (Cunningham and Davis 1985). Further investigation will examine whether this stereotypical view of gender differences is substantiated or refuted by the research. Beckman (1991) focuses specifically on the differences of mothers' and fathers' perceptions of the effect of their child's disability upon them. Beckman quotes some of the earlier research, which found that fathers generally reported more stress than did mothers and had
few constructive outlets for that stress (Cummings et al, 1966, Cummings 1976). Conversely other research found the opposite to be true, that mothers reported more stress than did fathers (Goldberg et al, 1986; Bristol et al, 1988; Beckman 1991; Pelchat et al 1999). Beckman suggests one explanation for the difference between these and Cummings' findings was that not all parents in Cummings' study were couples. Pelchat's review points out that Cummings was among that aforementioned band of researchers who concentrated exclusively on mothers (Pelchat et al 1999). They define how mothers experience stress:

Compared with fathers, mothers experience more stress related to their role restriction, they feel more threatened and stressed by their parental role, and they report a greater level of psychological distress. (Pelchat et al 1999 p391)

They emphasise however that this finding is not peculiar to parents of disabled children but was found to be true for parents of all children of the study, including parents of non-disabled children. Beckman's results also show that mothers and fathers have different perceptions of the effect of their child on their lives:

Mothers reported more depression, more difficulties with their sense of competence, more restrictions on their parental role, more effects on their relationship with their spouse, and more effects on their health, fathers reported more problems with attachment. (Beckman 1991, p592)

One argument for the fact that mothers' and fathers' experiences are different is related to their differential access to support services. Services tend to deal with mothers who would consequently have greater access to appropriate support networks. (Cunningham and Davis 1985; Marks and McLaanahan 1993). Carpenter and Herbert (1995a) focus on the issue of fathers not having the same access to support services as mothers. This not only puts fathers at a disadvantage but also puts extra stress upon mothers as ‘it is assumed by the professionals that all the ongoing dialogue can be sustained in the main through the mother.’ (Carpenter and Herbert 1995a p10). It has been argued that the support services can add to the burden of care in other ways:

for many parents dealing with services was the most stressful part of caring for their child. (Beresford 1995 p 39)

Beresford identified that some families experienced a negative relationship with professionals which was not conducive to effective support.

Beckman (1991) differentiates between sources of support - informal support (from friends, neighbours, spouse) and formal support (from professionals and agencies). She argues that informal support is ‘an important factor as a potential mediator of family stress’ (p 593) and found that fathers did not report significantly less informal support than did mothers. The research does seem to indicate however that fathers express greater dissatisfaction with the formal support services than do mothers (Beckman 1991, Wishart et al 1980)

Sloper (1999) reviews a number of research papers (Knussen and Sloper 1992; Beresford 1994a; McConachie 1994; Wallander & Varni 1998) which look at the factors related to parental well-being. One generalisation that she makes from these is

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 and Pahl 1991; Sloper et al 1991). (Sloper 1999, p88)
Some of the literature examines what factors might influence the different responses of mothers and fathers to their disabled child and investigates their processes of adaptation. Bristol et al (1998) found that mothers reported more depressive symptoms and family disruption than fathers. These results were replicated by Rodrigue et al (1992). This latter study examines how the nature of the child's disability may affect father's psychosocial adaptation. They conclude that the more demanding the child (by implication the greater the severity of the disability) the less competent the fathers felt, which in turn led to increased levels of stress. It is possible to argue that this cause and effect is unlikely to be restricted to fathers. What might be of more significance would be to examine the difference between mothers' and fathers' perceptions of 'demanding'.

Rodrigue's study made a comparison of fathers of children with autism and fathers of children with Down Syndrome. Their expectation was that autism (being seen as the more severely disabling condition) would contribute more to paternal distress than Down Syndrome. However the research showed that whilst this was true for mothers, fathers reported 'similar concerns and equally low levels of stress, regardless of their child's type of developmental disability.' (Rodrigue 1992, p259). The suggested explanation for this result is that fathers are less involved with the day-to-day care of the child than mothers and therefore perceive (rightly or wrongly) that the fathers' personal and family lives have not been significantly disrupted. I would argue that this suggestion adds fuel to the widely held but erroneous idea that fathers are the peripheral or secondary partner in the parenting role (Carpenter 1994 and 1997).

Other research identifies differences between mothers' and fathers' responses to their child's disability (Affleck et al, 1990, Cunningham and Davis, 1985, Sloper, 1999, and Vadasy et al 1986). Both fathers and mothers reported decreasing levels of stress over time. However differences between parents emerge when it is shown that fathers' pessimism about the future increased over time (Vadasy et al 1986). It is argued that the amount of involvement fathers have with their child will have an effect upon their responses to the situation. Fathers who are out at work, leaving the majority of the care burden to the child's mother, will not be as involved in all aspects of daily life. These factors will include the child's demands, interaction with support services and the day-to-day care with all the accompanying stresses and rewards that this will bring. This will inevitably have an effect upon their responses to their child's disability. However I would argue that stereotyping fathers (or mothers) in this way is not necessarily valid.

**Coping strategies**

Affleck et al (1990) interviewed mothers and fathers of infants who had spent a considerable time in a neonatal intensive care unit. This is a stressful experience for any parent with the combination of prematurity with all the threats to the baby's future development that this brings with it, alongside the baby's medical fragility. The research found that fathers reported less emotional distress than the mothers of the study. They give alternative interpretations of this finding - the first being that mothers may be in a more vulnerable state physically and emotionally due to the fact that they have just given birth. Also they acknowledge fathers' possible reluctance to admit distress. This highlights the fact that mothers and fathers may have different coping strategies. Many of the respondents in this survey referred to their husband's coping strategy as 'keeping his feelings in'. None of the fathers used this description of their wife's coping strategy (Affleck et al 1990).

_I would cry and he would yell at the dog. He kept busy at work and I was there with the problem all of the time. This put quite a strain on the_
relationship. I'd wonder why he didn't react like I did. Didn't he love him too?

My husband and I coped very differently. I made myself go to the hospital every day, but he would stay away. Once I realised how discouraged he would get by not seeing much progress, it didn't bother me. Actually I came to understand him better, and that brought us closer together. (Affleck 1990, p22)

Sources and elements of support

Some of the literature suggests elements of service provision that form part of an effective source of support for families with a child with a disability. (Glendinning 1986; Davis and Rushton; 1991; Stallard and Lenton 1992; Sloper and Turner 1992; Dale 1992; Beresford 1996; Hall 1996; Marlow 1998; Sloper 1999). Whilst there is often not much attention paid to the needs of fathers in this research, some exceptions do exist. In Beckman's study (1991) she found that fathers found formal support (as opposed to informal support) their preferred source of support. However, as has already been discussed earlier in this paper, fathers often express greater dissatisfaction with formal support services than do mothers.

Some research has looked at parent groups as a particular source of support. (Hornby et al 1987; Cotterell and Summers 1990; Stallard and Dickinson 1994) In one study the aim was to set up a support group for mothers. Those mothers that attended reported that this was effective as a source of support for them and speculated upon the likely response of their partners:

all the mothers thought their husbands would benefit from a group, but all felt that their husbands would refuse to come. The husbands, when interviewed separately, were indeed against the idea of attending a group.

(Cotterell and Summers 1990, p215)

Stallard and Dickinson's research involved the setting up of a mothers' group as well as a fathers' group. The fathers' group was less well attended. There also emerged different themes to the discussions in each group. The mothers focussed on information exchange and discussions about the future for their children. They explored the emotional issues connected to the impact upon them as the mother of a child with a disability as well as the impact on their partners, siblings and other family members.

Fathers' concerns differed slightly as they concentrated on themes such as their marginalisation and sense of isolation from the professionals involved with their child as well as their isolation from other parents. They spent time finding out about each other and their children's relative strengths and weaknesses. They examined their emotional responses to their child's disability and discussed the future for their children with a growing awareness of the widening skills gap between their disabled child and those of their siblings. It is also interesting to note that joint parent groups were considered and dismissed as it was felt that separate groups would allow each person to act as an individual rather than the dominant partner talking on behalf of the couple.

Other research advocates for services that include the provision of a link worker or keyworker - a concept suggested as early as 1978 in the Warnock report (1978) (Cotterell and Summers 1990; Stallard and Lenton, 1992; Sloper and Turner 1992; ‘Right from the Start’ 1999; McConachie 1999; Mukherjee et al 1999). So many of the support services
concentrate on meeting the needs of the child, that the emotional needs of the rest of the family are neglected.

A number of families expressed concern that whilst the professionals were focussing upon their child, their own needs as a family were not being met. Thus the tremendous impact upon the family of coming to terms with their child's difficulties, the inevitable feelings of guilt, anger, blame, whilst they adjust to the loss of their 'healthy' child, clearly needed to be acknowledged and addressed. Once again the establishment of a specialist 'link worker' with specific counselling skills would be one way of ensuring that this need is being met. (Stallard and Lenton, 1992 p201)

The specific characteristics of a keyworker have been variously described (Buchan et al 1987; Sloper and Turner 1992; Dale 1992; Davis 1993; Mukherjee et al 1999) and include a combination of approachability, openess and honesty, combined with information giving, empathy and treating parents as individuals. In my own contact with groups of parents, they identified flexibility and communication skills as desirable characteristics of a keyworker (Right from the Start 1999). This flexibility they identified, would need to include the ability of the keyworker occasionally to work evenings and weekends so that working partners (fathers or mothers) could be part of the relationship between parent and keyworker. Two evaluations of a keyworker model established by One Hundred Hours concluded that fathers and mothers valued its flexible parent-led approach and appreciated the understanding and listening skills of the keyworker (West 1994; Spencer 1999).

The voluntary organisation One Hundred Hours has demonstrated a model of early support to families of children with multiple disabilities and health needs, making a limited contract with a family within which they control how much of what kinds of services they would like to use and receive, a model which statutory services would do well to emulate. (McConachie 1999 p106).

Other research investigated how far fathers were a source of support for mothers. The conclusions drawn were that many more fathers than mothers said that they focused their attention on supporting their spouse (Affleck 1990).

In many families a delicate balance seemed to have built up where mother cared for the child and father cared for the mother. (Cotterell and Summers 1990 p 216)

This situation is also highlighted by Carpenter - himself a father of two children born with a congenital disability.

The fathers in this study described such situations as the 'calm after the storm' when, once the family returned home from the hospital, the fathers received no specific help from the professionals. All help was focused on the mother and the baby. The fathers’ needs were not addressed or, perhaps, even noticed. They were seen as the 'supporters’ and as such adopted the role that society expects - that of being competent in a crisis. (Carpenter 1995b, from personal communication).
The findings - fathers’ views

Child's abilities and disabilities

Each of the fathers were asked to describe their child. I specifically avoided any reference to disability as I wanted to begin by establishing a picture of how they viewed their child. Two of the fathers' first comment was a positive statement about their child, their relationship or their son's character. The other two fathers referred to their child's disability first.

He is very sociable. To strangers he is a very endearing character. (B)

He is my son, he is three years old. He has got awful ginger hair and he has got Down Syndrome. Charles is just my son. (C)

David is 6 he has severe to moderate learning difficulties and he is also hyper- tonic, that is floppy muscles; he is a well behaved boy (D)

A severely disabled little boy but in spite of his disabilities I think he has a great personality (A)

As an overall comparison the references fathers made to disability compared to other things like aspects of their character and personality, the latter outweighed the former in number. Two of the fathers (the same two who did not refer to disability straight away) attempted little or no description of the disability or how it affected their child. In the case of C references were limited to comments about the various health concerns connected to their child's syndrome - heart problems, feeding problems and recurring chest infections. In the case of B the nature of his disability was only referred to fleetingly:

So it was confirmed about two weeks after that - they did tests and it was confirmed that he did have a chromosome anomaly. (B)

This comment had been preceded however with a number of positive statements about his son:

He's very sociable and he can make his needs known very well indeed. Really, around people and sociably he's very very good indeed. As I say, he is a very endearing character. (B)

A number of references were made to the behaviour of the child, two fathers noted for instance the lack of temper tantrums, another father, conversely, the presence of the 'terrible twos' at age three. In A's interview there was a clear description of the disability balanced with references to ability and normality. In D there was more description of how the disability manifested itself in restricting David's abilities as well as describing how it affected his behaviour.

underneath all the disability, they are ordinary people .... Alex is underneath everything a normal very happy little boy .... he has cerebral palsy, he is quadriplegic so it affects all of his limbs, affects all his movements, he is blind but he is very perceptive and his hearing is very good (A)
we have noticed that as he is getting older he is becoming more frustrated because of his poor speech quality and we can't understand what he is saying sometimes .... he's taken to actually banging his head now .... But he is a well behaved little boy, he sleeps well, sleeps all night, no problems .... he smiled but didn't do anything else, he didn't crawl, he was very floppy, his head, he would always lean his head to the right. (D)

**Fathers' needs**

Each of the fathers were asked what they needed in the early days of learning about their child's disability. There was also an exploration of whether their needs have changed in the intervening years (a time span varying from three to ten years). A later section of the findings examines what they would have found helpful in an attempt to identify aspects of service provision that would have met their needs.

For three of the fathers there were two main needs identified - someone to talk to and information. The fourth father (B) talked about his need for practical help.

*I was at work and what I really wanted I suppose was more time off work to help [my wife] with the three boys .... I didn't feel I needed anybody to talk me through it. I didn't need any counselling because we talked about, [my wife] and I talked about it anyway. She was, as I say, very good, she was a good counsellor. I didn't feel any need for that help. (B)*

One father mentioned his need for support and information a number of times, and that this need was there right from the very first point of diagnosis.

*I needed someone to say, come on [D] it is OK, come and sit down for five minutes or to be taken outside for half an hour and said I'll see you in a bit and I'll have a chat about it, think about what questions you want to ask, come back in and we will talk about it. We can talk about what next .... I needed information and I needed somebody to talk to, other than family members .... I really did need someone to talk to .... I needed an external, somebody different, it wouldn't have mattered what race, colour, creed or gender it was. Somebody that I could sit down with and say "look I'm having a really bad time, I'm really worried about the future, am I doing this right, is it my fault?". I needed someone just to analyse the baggage out of it. I really did need it .... you need to sit down and talk to someone not over the phone .... At first it was I need information, I need to know this, I need to know that and I need support now. (D)*

Another father (C) had never given his own needs much thought, nor had he ever been offered the opportunity to talk about his needs.

*I don't really know because I have never actually spoken about this to anybody else other than yourself. I don't know I suppose I would like more reassurance like from that family that we met [another family with a child with Down Syndrome] or someone to say hey [C] come on out for a beer so you can discuss things on that sort of level with another dad. (C)*

The third father identified his need for information particularly about financial benefits as
well as his need for support. He talked about the isolation that ensues from being launched into the world of disability.

So I think you need something to redress that maybe someone just to talk to. Because you are not only talking to the person you are actually talking to yourself. (A)

How did the needs change?

All four fathers recognised that their needs had changed. That they were not as great, or as paramount. The need for support still remained but without the same intensity. It was also recognised that the focus of need might have shifted from the needs of the individual family members to the needs of the family as a whole. There was some recognition that the process of caring for a child with a disability had changed them to make them stronger.

They are different, [the needs] they are not as acute but they're still there and I think there's a possibility that they will become acute again and perhaps more specific and not just centred on Alex but the whole family relationships - which have become very strained at times so I would still feel the need to be able to talk it over with somebody (A)

C was the father who, as indicated earlier, had not been offered any opportunity to talk about his needs. He expressed the benefit he was feeling from the interview process itself, as it was his first opportunity to talk about his needs and his feelings since the birth of his son. Nevertheless given that he had not had someone to talk to before, he recognised that this need (albeit previously unmet) had lessened.

I don't think I now need the initial support that I needed when he was a few months old although it is really good to have a good talk now. (C)

What was helpful?

Each father was able to identify one or two individuals they had found helpful. This perceived helpfulness was based either on the person's attitude or on the practical help they were able to offer.

I think the most helpful thing has been the positive attitude of the paediatrician. As I say we saw him on a six monthly cycle basis when he was first born and then after that on an annual basis. He would ask us how he was doing and we would tell him and he would keep saying ‘is there anything else you need?’ and he put into motion anything we thought we needed .... He seemed to have a lot of time for us and a lot of time for Ben and although he wasn't able to give us any definitive answers to any of our questions he would do his best to help us, so I think his support, though we didn't see him very often, his support was as good as any that we've had because he obviously has come into contact with all sorts of other children with disabilities .... I think he was one of the key people that helped us. He gave us a lot of support. (B)

This theme of helpfulness of the paediatrician occurred in all of the interviews. In addition to
this, other helpful professionals identified were pre school teachers, a speech therapist an outreach nurse and an independent keyworker. For some of these individuals it was their practical advice that was considered the helpful aspect, for others it was their general attitude.

*a pre-school teacher that came when he was only months old. I thought it was really good she just came to sort of teach us really and showing us how to stimulate him and using bright colours and what have you. (C)*

*then we had another change of speech therapist and the new girl was brilliant. She couldn't do enough for us, she came round to the house, she told us what to get and she supplied the flashcards and she told us to get this and get that …. she [a teacher] was the only one like spoke to me as a parent rather than as a male or female. It was a parent.* (D)

*so I would say the big thing is someone to talk to. That's why [the keyworker] coming to us was one of the biggest things recently that really helped us (A)*

One father saw helpfulness relatively, in so much as he had experienced the health professionals as particularly unhelpful. This had been followed by contact with education professionals when his son started school whom he perceived as helpful:

*School. The school environment is different than when you are seeing all these other [health] professionals. (D)*

Other examples given were support from friends and the contact they had with other parents, either through a support group, the Down Syndrome Association, or at conferences where they were given the opportunity to talk with other parents.

The overall picture from each of the fathers was that they each felt that they had experienced at least one relationship - and in some cases more than one - that had been helpful. Exploration of how that had made them feel threw up a set of different responses. The father, who identified that his only involvement with a helpful professional was when he saw the paediatrician every six months, did not feel unsupported. Two other fathers however felt very strongly that they received no support for themselves at all. For D this was a theme to which he returned several times throughout the interview, that there was no support for him and it was something he felt he really needed. For C he described himself as 'unsupported' and felt he had missed out on having someone to talk to, but also recognised that he may not have wanted this immediately after diagnosis:

*but as for someone to find out how I was feeling - I didn't speak to anybody.*

Interviewer: *Would you have wanted to?*

*C: I don't know to be quite honest. I really don't know on that point. In those first few weeks I basically just wanted to shut myself away and pretend it wasn't happening.*

The experience of the fourth father was that he felt supported; this is evidenced by his comments of how having a keyworker helped him and how it made a difference.

*it unburdens you, you feel as though you have organised yourself in a*
certain way, all that jumble of experience in your head you have managed to explain it to yourself and tried to see some way of organising .... he [the keyworker] is not doing it for you, you are doing it by yourself but by him being there it is helpful for you to organise your own thoughts .... [the keyworker] helped us regain our confidence and think that we're running this game, we can be in charge and so that spun off into other areas. Now we have good relationships with our GP and a good relationship with the consultant in the hospital and it's a relationship of equals and I think they appreciate that as much as we do but that's all come from that regain of confidence you know, from that initial hands on support. (A)

What was least helpful?

This area of exploration showed a lack of consensus across the interviews. It was also the question to which two of the fathers had to give long consideration before answering. This would imply that these two (C and A) did not have an example that immediately sprang to mind and also suggests that it was not an aspect to which they attached great significance. The answers ranged across examples of particular professionals who were not helpful or inappropriate services.

The Family Support Centre ... when [my wife] went there, there weren't any other children there with disabilities. It was basically like for disadvantaged families. They totally got ours and Charles' and [my wife's] need wrong. [My wife] felt really uncomfortable - there were like mothers there with drug habits. It totally wasn't appropriate but that's all that they were offering us a that time .... Basically it seemed like Social Services were just not listening. We obviously just fitted into their budgetary requirements. (C)

The one exception to this hesitation came from the father who knew instantly what aspect of service delivery had been most unhelpful. He often referred to the fact that he, as David's father, was not being listened to. It was as if he was not an equal or contributing partner in the care of his child.

The totally bad attitude shown to me by other members of the health professionals and not just the health professionals - the speech therapist, they were an absolute nightmare ... they didn't listen to my views at all. (D)

For B the unhelpful aspect was the attitude of one of the specialists he and his wife saw. Although this was one isolated incident the impact it had upon him was very evident in the apparent distress shown in his recollection of the occasion.

In the first year when we went to the ________ Hospital to speak to the genetic people they were very very pessimistic about his chances because he was so small, so tiny it's unlikely that he will be get his first birthday. [At this point, B became visibly upset.]

After some pause he continued]. Well we got him christened and he seemed to be okay after that. [This was said with B holding back the tears]. (B)
What would have been helpful?

The message that all four fathers gave was that they would have wanted someone who would listen to them. There were slight variations to this theme but the underlying message was that they wanted a relationship with one special person to whom they could talk. B felt that although there was nothing he could think of that they would have liked that they did not have, when asked what he would describe as a good pattern of support his response reflected his need for practical help:

I suppose somebody coming in on a regular basis like a keyworker to just talk about things like, for example, the nappy situation. (B)

He felt the value of a keyworker would lie in his or her ability to recognise common concerns arising in different families (his was a problem of the supply of nappies) so that the problem could be addressed collectively. He also recognised the value of having a quality relationship with one person.

you could actually talk about everyday things if a keyworker came in and if you had a good relationship with that particular person it would be a good thing. (B)

This was echoed by D who wanted someone who would listen to him. His experience had been that he had had no-one to give him advice and information about how to cope with his son's disability. He had also felt that he had not been valued as a parent; all the attention had been focussed upon David's mother.

you need to talk to someone because we are entering a big world now that is going to affect the rest of your lives and you need someone to tell you what happens, what are you entitled to, what can you do, what can't you do, what should I do, what do you think? Give me your experiences. Because you are opening the door of something that is just well, unreal. When you start off it just overwhelms you, totally overwhelms you …. To be actively involved, to be asked questions and when questions are asked, direct them at me …. recognising the fact that the father's role is just as important as the mother's role and that I do take an active part. (D)

For another father however he felt he would have welcomed this support from a group of fathers, acknowledging the importance of getting it right for each person:

It's important to have the right environment as well. Like if with a load of blokes if there's women there as well, well they're not going to come out of their shell are they? They're not going to say what they really want to say. I think that's what's needed - a special group for dads. It would be nice to know whether it would work or not cos I imagine even if you do give dads some opportunity they won't all take it, because it's got to be like a special relationship for most people to let their feelings out. It'd be nice to be offered the opportunity to talk in a group or a one to one or whatever. (C)

Another father was in the position of being able to talk about what he felt constituted effective support from his personal experience of receiving support from a keyworker. He
described the keyworker's role as including being a mentor and advocate.

\[
I \text{ think that the initial support is essential, someone to talk to someone to work through the problem in your own mind. (A)}
\]

Expression of feelings

The fathers all talked about their emotional response to their child in varying degrees. One father was very forthcoming about his feelings. He obviously found the interview itself a cathartic process enabling him to express his emotions, something he had not previously had the opportunity to do. At the other end of the spectrum another father made almost no reference to his emotional response to the fact of his son's disability. However he was the father who exhibited deep distress when speaking about the time they were given a bleak prognosis for their son.

The interviewees talked about shock, mourning, anger, guilt, denial, isolation, despair and adjustment.

they said ‘Well have you ever thought about Down Syndrome?’ and well the blood just drained out of me. I didn't know what to think. In all honesty I was totally ignorant because I didn't know what Down Syndrome was. I had not got a clue.

Interviewee: But you had heard of it?
C: Oh yes. Oh yes like I'd heard of it and knew about the facial features but I didn't really know what it was. So you don't know what that involves at all. So basically all I thought at that moment was Oh my God my life is over. I thought, What have I done wrong? Why? Just total shock. (C)

I remember they were very good, when he actually said he has a learning disability, the nurse came in with a box of tissues and she went straight to the wife, who was crying and I was thinking, I was trying to ask questions but when it hits you it is like the big Frank Bruno punch, it knocks you for six. Trying to talk but I couldn't. (D)

One father referred to the sense of loss he felt in the early days.

So it's a complete shock. I often talk about it as a trauma, it's a trauma that's very .. it's not expected, so you mourn for the child you thought you were going to have, because that child's not there, and you are coming to terms with the child you have got. (A)

Often anger appeared to be present in some of the fathers but was not directly alluded to as a feeling of anger. It could be seen as mixed with other emotions such as guilt.

So basically all I thought at that moment was Oh my God my life is over. I thought what have I done wrong? .... I mean everybody is selfish up to a point and you are thinking What's my life going to be like now?' It's my life over .... just thought of like I'm going to be looking after somebody disabled for the rest of my life .... Totally being selfish like we thought what are we going to do? Like there is going to be no life left for us. (C)
Again, as I said earlier, the range of emotions are often difficult to separate out, and the way the fathers expressed themselves showed that guilt and denial were often inextricably mixed together. C recalled a time that was very painful for him when he and his wife were unable to accept the burden that caring for their son would bring.

*I feel like I totally alienated myself from him. It felt like its not my baby. I know it seems daft to say it but I said, do you think they have made a mistake? but no, no they hadn't. I mean now I feel absolutely totally guilty but that's the initial feeling that you get .... at that point when he was two days old [my wife] actually .. er .. we left him there, we didn't actually know whether we had to go through all the options what you can do, you've got the choice of like, do you want him or whether we could give him up to foster carers or .. and that's what we were initially thinking, we were both thinking like we can't cope with it so we actually left him there. We went to see him every day but we actually left him there for a week. We couldn't make our minds up, could we take on all this responsibility? (C)*

For another the denial was simply expressed:

*It was hard, I mean, as a Dad. He will be alright, little boys they are always lazy, it was in the press at the time, little girls are shooting ahead of boys and boys are always slow. I thought it will be OK, he will catch up. He will get a bit of help with school, he will be fine, don't worry about it. (D)*

They talked about the isolation they felt, how they felt cut off from the world had previously been familiar.

*Well it's like your whole life has took a different course hasn't it? You have all these plans and ideals for the future just like a normal family, you get your house nice, a couple of cars, holiday abroad twice a year, everything is hunky dory then something like that happens well it turns your world upside down for a bit anyway .... It makes you feel isolated. I don't talk about Charles so much, I haven't really got any friends that I can talk about him to. (C)*

then suddenly the child is born and the circumstances have completely changed so all your attention is turned inwards so all the connections outside become dependent upon the people themselves outside and you just can't devote your time to that so that's partly how you become isolated and you become mentally isolated as well cos all the time you are devoting to the big problem and so you lose the connections (A)

They also talked of adjustment indicating that this is an ongoing and largely positive aspect of their lives.

*I've soldiered on I've gone through like the pain barrier .... It's made me a real strong person. I was a strong person anyway but I'm even stronger now and I'm determined I'm not just going to take anything .... I've relaxed a lot more now. I'm a lot more easy going about it partly through studying I've learnt what I can do and what I can't do. (D)*
C acknowledged the fact that the emotions involved were painful ones but that it was possible to adjust to them, up to a point.

I wouldn't wish that on anybody but I mean like just talking about it now I'm getting, I get worked up about it now yeah that was tough then. It's all right now [he laughed] .... Now like I feel as if you come to terms with it so far but I don't feel you ever come fully to terms with it. (C)

A, on the other hand, recognised that his adjustment involved a certain amount of denial and control of his emotions.

So I find myself being unemotional because I feel my instinct is to be unemotional .... I find that I have got to the point when I can't be emotional about Alex. That's the unnerving thing. (A)

Whereas B spoke easily about his adjustment in his son's life:

Well now I'm quite at ease about it over time which, as I say is ten years so .. he is very special to us. We're quite happy with him.

The future

Several references were made by the fathers to the fact that they worried about the future for their child. One father spoke of his worries about what the future would hold for his son as soon as they were made aware of the diagnosis. Another spoke of the difficulty that professionals face when giving information as they have to weigh up how much each person wants to know about the future.

I don't envy doctors at all or any of these people, because different people are different. Some people don't want to know. While some people want to know but they want to know when its appropriate for them to know, so it's all a big problem and really you are relying on the medics for the information initially at least anyway. (A)

Two of the fathers spoke about the fact that they worried quite a bit about the future for their sons.

I still like lay awake at night and think what's Charles going to be like when he's 18. Will he be wanting to hold my hand walking up the road? .... That's a big worry for me about the future. I was thinking the other night about his development. Will he still be living at home with us when he's 21 or will he be saying 'Dad do you want to go out for a pint?' (C)

I've got to look to the future. I've got to make sure that David will be okay so that when David's older he can say 'no', he can demand his rights, so I'm now more looking to the future and his goals rather than the past and the emotional support I needed before .... I'm always casting my mind around the things for the future beyond primary school so I'm looking to his future cos his needs have changed markedly really. (D)

This planning for the future was not however every father's experience:
you don't think what it is going to be like when he is 10 or 15 or 20 or so on but I don't think there is any one point .... whether that is a psychological block because you have got enough to cope with so maybe your brain just accepts certain things. It's not too helpful to be too realistic in those circumstances (A)

Differences in response

Analysis of the data indicated that the fathers perceived differences in response to their situation between themselves and their wives. B talked about the differences in the ways in which he and his wife adjusted to their son's disability. He made a number of references to the fact that his wife 'came to terms with it' much quicker than he did. This he attributed to a number of factors including her experience as a special needs teacher, the differences in their personality and differences in their approaches to a problem. He talked about her ability to talk about their son's disability in the first weeks of birth with openness and without 'breaking down':

at the beginning she was quite happy to acknowledge it straight away which I wasn't. I didn't feel able to because I'm a different type of person I suppose. It took me a while, it took me much longer to come to terms with it than what [my wife] did .... I don't think I would have done for quite some time. That was really quite a big difference for me .... so yes I told colleagues at work that he'd got a problem. I was able to do it a lot better because [my wife] had already showed me the way how to do it so that was quite good really. I'd have found it more difficult otherwise probably if she hadn't have done it to the family and neighbours, I'd been there with her at the time and I was all churned up I couldn't really have done it without breaking down....

Interviewer: Was [your wife] able to go through the process of telling everybody without breaking down?

B: Yes, yes it was quite strange really. Yes she did, I don't know whether it's because she's used to having a lot of these sort of children and working with them. (B)

There was other evidence of acknowledgement of the differences in response that the interviewees attributed to gender differences. D talked about the response he felt he would get from his friends if he were to talk openly to them, or, as he put it, if he were to 'break down'. He felt he would be avoided by them in future. He also felt he would have been able to talk to the female members of his family but not the males:

I really did need someone to talk to because my brothers, well they weren't very good at all. Sister-in-laws were great, but I didn't want to keep bothering them because they were looking after [my wife] .... my brothers they clam up they don't want to know and then they change the subject, but I can't push it. They are obviously uncomfortable with it .... I think women open up more yeah, I think women are a bit more open but men can't, they just put the shields up: 'I can't talk about this'. (D)

Father A saw how their differing responses were having an effect upon him and his partner. He felt that he had to keep his own emotions in check in order that his wife could allow hers full rein, although he was beginning to realise that this situation might have to change for it to remain a healthy one.
The man is simply dragged down. I sometimes feel that I am losing myself because I can’t afford the emotional output or a similar emotional output as [my wife] but … it might be better for me to be more emotional at the same time to allow her to be less emotional. … me being that way [less emotional] has allowed [my wife] a free run of her emotions, to work through the trauma of what has happened. … It wasn’t a strategy which was chosen, it was just evolved. I don’t know whether it is a good strategy to continue. I think I need to start winning back some of that area that I have given up as much for myself as for [my wife]. I can’t allow her the luxury of all this emotional outlet because I don’t think it is good for her. It is not good for me and it is not good for her. (A)

Expectations and coping strategies

There was some evidence that the fathers interviewed were aware of an expectation that they be strong and supportive to their wife. It was difficult however to establish if this was an expectation that they had of themselves or whether it was one that was imposed upon them by others. However there was acknowledgement that whatever the source, it did exist:

the man doesn't have the same opportunities perhaps as the woman has because of gender expectations which aren't based on anything, anything real I don't think. … men are expected to keep quiet and just do their job, if you don't you're not a man. (A)

Father D clearly felt that the strong supportive role was one that was expected of him:

It was like the stiff upper lip syndrome. It was like, ‘he is the Dad - he will have the Dunkirk spirit’ and I felt that I needed to be strong. By talking I needed to keep it going and appear strong but really deep inside it was like I was on fire, my head wanted to explode but there was nothing, no words, no support, nothing. Looking back now, I know that that shouldn't have happened but at the time, I was in awe. … if you cry it’s well it’s like a weakness and I think it still is seen as a weakness. (D)

Conversely another father recognised it was his wife that was the source of strength for him. He also acknowledged that her return to work was a strategy that she adopted to enable her to cope with the situation of caring for their son:

she is a great source of strength. I'm sure she was a great source of strength than ever I was to her. … I'm sure it did work both ways, but looking back she was a tower of strength cos we were both working at the time, well she was on maternity leave but she went back to work. She didn't feel she wanted to stay at home and look after them [Ben is one of twins] she wanted to go back. Yeah she wanted another outlet. I remember the social worker saying to her that it would be good for her, for her to get away from it and I think that was the right decision because I think she probably would have absorbed herself too much in it and it was a release for her to get out and pursue other interests. (B)

Working, as a coping strategy, was also one that C identified he adopted to help him cope or
even, to use his words, to escape. He saw that his opportunity to cope in this way was not one that was available to his wife.

Well I cope with it because I don't really get time to think about it. When I think about it I keep myself busy and I don't think about it that's probably why [my wife] suffers from depression. She's here with the kids and she has time to dwell on it. Sometimes I lay awake at night and worry about what the future holds for Charles and that's when it gets upsetting for me. But I think that's the way I cope with it, although I always complain about working so many hours. I think that's the way I deal with it, I keep myself busy so I haven't got time to dwell on things. I always complain about working that's my escape I suppose. (C)

Involvement

There was evidence therefore that the expectations were very real, they affected how fathers behaved, what coping strategies they adopted and it also affected how others responded to them. This had a direct impact on how far they felt involved with the care of their child and how connected to the sources of information and support they felt. Father C acknowledged that he wanted to be more involved with his son, his care needs and decisions being made by others about him. However he felt he did not have as much opportunity to do this as his wife. He felt that this lack of involvement was partly his responsibility:

I'd like to be a bit more involved, I'm my own worst enemy when I get involved with work, so I'd like to know what options there are with education .... but I have to put my hand up there, I should be more involved. (C)

Father D's experience was very different however. He made every effort to be involved with all aspects of his son's life but felt that he was viewed in a different way by the professionals to the way his wife was viewed. He felt he did not have the same access to support as his wife, he was not being listened to, and felt generally undervalued. He made many references to this feeling throughout the interview. These are just a selection from the number of comments he made:

I didn't feel valued. I'm thinking I going in here but I'm just the taxi driver and I'm just the emotional support for [my wife] .... I religiously went to as many meetings with the doctor as I could. It was partly to support my wife but also for me, I needed to know. It would have been so easy to have said I will let her go to that but he is my son, I want to be a part of his life. I want to be party to shaping his future and helping him get what he needs. I went to as much as I could, every single one. But there was still the female bias, every doctor, every speech therapist addressed [my wife] saying ‘Now Mrs D you must do this and this is a programme we have for you, try and get him to play with this’ and I thought I'm the dad, I do my bit too. It is as if they perceive that dads with children with special needs don't get involved, but that is wrong .... it felt like, although I was the husband, I was there to taxi drive, to take him there and take him back again .... I keep going because you have to keep going but I can easily see why some blokes think ‘you take him, I've got to go work’, but I have thought no, you have got to keep going, you have got to know what is going off. But you do feel devalued and useless and a feeling of worthlessness. (D)
Access to support

For some fathers there was a direct relationship between how much they were seen as part of the family unit and how this affected their access to services. Father A recognised that the fact that he was with his son and wife for the first few months of Alex's life made a difference to how involved he felt, but that it was not an experience every father would have:

*we were together all the time and so I think our experience was quite unique in a way and I don't think that would be a common theme for most people, say in England, probably most of them would keep their jobs and most men would be fairly isolated and don't get the benefit, same benefits that I had really.* (A)

Another father saw that the difference between his contact with the professionals and his wife's was directly attributable to the fact that he was working and she was attending all the appointments.

*[My wife] was going to other appointments and she had like more opportunity to talk about it and she was meeting more of a variety of people …. *[My wife] was getting all the information first hand as she was making all the appointments. I got to some appointments but with work I had already had a month off and I didn't want to test their patience too much …. I didn't get to many of the appointments to be quite honest.* (C)

Other fathers felt that the fact they were often not seen to be involved in their child's care meant that they and their needs were often overlooked:

*I don't think most professionals think about it, the man is just a shadow, something in the background, we are of very little consequence really.* (A)

*[My wife] she could have had support, she could have had counselling but there was nothing for Dad. The need just wasn't recognised for me.* (D)

This data showed that being involved with your child will not necessarily guarantee access to professionals and support. The experience of one father illustrates how the picture may not be as simple as this. He was a father who reported he made a considerable effort to be involved but he felt frustrated by the attitude of some (not all) of the professionals:

*when they are saying ‘How's David doing? Has David passed this landmark? Is David doing this?’ It was always looking at [my wife].*  
*Interviewer: As if you weren't there?*  
*D: yes that's right as if they are saying ‘What do you know about it?’* (D)

There was also some evidence that mothers and fathers had differing access to informal support as well. Father C talked about not having any friends to whom he could talk about his son and another father felt that the support his wife received from her family was unavailable to him. He felt that he could not access this support as the family had enough to deal with supporting his wife.
Implications for practice

These research findings have given a clear picture of the support these fathers received. It enables conclusions to be drawn about what constituted effective support for them and what would have constituted effective support. From this, proposals for implications for practice can be made. In this ensuing discussion similarities and differences between this research and the research covered in the literature review will be highlighted.

Disability

The research findings presented here have shown that fathers do not only see their child in terms of his disability. More reference was made to their child's behaviour and this appeared more significant to them than the degree or nature of the child's disability. This finding supports those of Rodrigue (1992) and Sloper (1999). Research and my own practice confirms that parents wish for their child to be seen holistically and as a child first. However the message from the research is that this does not always happen (Right from the Start 1999). This is the ethos underpinning the Children Act and is one for which practitioners should continue to strive.

Fathers' needs

There were two main needs identified: information and someone to talk to. They expressed the need for information about their child and his disability and what services were available to help them in caring for him. Three of the four fathers had not had anyone they could talk to. Of these, one father had not felt unsupported and felt he received all the support he needed from his partner. He nevertheless expressed the wish to have had a keyworker to offer him practical support. The father who had had someone to listen to him - a keyworker - was clear that this had been invaluable for him. This finding clearly bears out the research that advocates for a keyworker (Cotterell and Summers 1990; Stallard and Lenton, 1992; Sloper and Turner 1992; McConachie 1999; Mukherjee et al 1999; Spencer 1999; Sloper 1999; 'Right from the Start' 1999).

There seemed to be a general consensus from the fathers interviewed that their needs had reduced over time. The need for information was less acute. One of the explanations offered by one father for this reduction of need for information was his increased knowledge of strategies for acquiring information. They all spoke about their feelings of needing less support - irrespective of whether they had received any support in the first instance. The literature found that fathers reported decreased levels of stress over time, which could also be interpreted as fathers experiencing less need or less unmet need. Other research (Vadaszy et al 1986) identified that what, for fathers, did increase over time was their pessimistic view of the future. This research found that the three out of the four fathers did worry about the future although only a longitudinal study would be able to indicate if this worry led to increased pessimism.

What constitutes support?
The overwhelming message was that for fathers to feel supported they needed to be listened to. They all identified that a helpful attitude of one professional was one element of feeling supported. The profession, and therefore the role that the professional played in the child's life, was not the important factor. The important factor was the perceived attitude of the professional. Again this returns to the idea of a keyworker. The research reviewed in the early part of this study showed that a keyworker model is founded on the formation of a good relationship between the worker and the professional and is based on listening. This is one element the fathers of this study identified would constitute support for them.

For support to be effective fathers have to be able to access it. Three out of the four fathers mentioned not having as much access to either formal or informal support as they would have liked. This closely mirrors the published research evidence. The fourth father was the exception to this in that he felt he was receiving as much support as he currently wanted. He also contradicted the picture of the published research (Cotterell and Summers 1990; Affleck 1999) as he received his support from his wife. All the other fathers spoke of being the source of support for their wives. This should not be considered as a contradiction in the research findings. The implications for practice remain the same. Whoever it is within a partnership that is the source of support, it should be recognised that the support provider may have unmet support needs themselves which would need addressing by someone from outside the partnership.

As for other forms of support, at least one father mentioned the need for a support group for fathers and another talked about the benefits he had gained from having contact with other parents. The relative infrequency of the references to this type of support coupled with the lesser stress that these fathers placed upon the idea of this type of support, would indicate that the efficacy of this type of support would vary according to individual fathers' needs. This is supported by the research; some of it indicates that support groups are effective (Hornby1987; Carpenter 1997) whilst yet others have shown limited value in having support groups for fathers (Cotterell and Summers 1990; Stallard and Dickinson 1994).

Service provision - help or hindrance?

Some recently published research has recognised that services can be a source of stress rather than a mediator of it (Beresford et al 1996). Certainly the feeling that I perceived from these interviews was that often it was inappropriate or insensitive service provision that was a serious source of stress for fathers. One clear example was the way in which one father felt he was considered an insignificant member of the partnership involved in the care of his son. Other research has shown that fathers are viewed as the peripheral parent (Carpenter and Herbert 1995a; Carpenter 1997). This they attribute to fathers usual absence from professional appointments due to work commitments. This feeling of being considered peripheral was substantiated in these research findings. It was apparent even given that two of the fathers in this research were either the main carer or shared the role equally with their partner. Whilst the two fathers who were not working felt more involved and had more contact with the support services than did the two fathers who were working, the fathers felt the professionals did not treat them as equal partners with their wives.

Expression of emotion

The researcher was left in no doubt whatsoever that talking about their disabled child evoked very strong emotions for every father. Some talked about this more easily than others; two
exhibited outward signs of distress during the interview process. The emotions that these fathers had experienced over their child's lifetime covered the whole range that other research has documented (Carpenter and Herbert 1995a; Hornby 1992). Acknowledgement by professionals that these emotions are present is an important step towards dealing with them. Most fathers experience was however that they were either expected not to show emotion, or they were reluctant to display emotion and developed strategies accordingly. This expectation that male emotion not be allowed appropriate expression is not one that will help fathers in their caring role. Evidence of this approach - that male emotion is an area into which a lot of people are wary to tread - is all too apparent both in the findings of this research and in other published material. This attitude of being almost afraid to face men's emotional expression is exemplified in the description of how fathers were approached for one piece of research (Carpenter and Herbert 1995a). This research project was designed for the express purpose of looking at fathers and their response to their child's disability. I would argue that it appears that the researchers approached fathers differently from the way they had previously approached the mothers.

Before embarking upon this in-depth study, careful thought was given to the method of approaching the fathers and indeed, if the approach would intrude into areas of their lives that were wholly private. This concern arose because during the interviews with the mothers, some became very distressed when discussing the events of the early weeks, and it was felt that fathers may exhibit similar feelings and become embarrassed. (Carpenter and Herbert 1995a p5)

This highlights a number of issues. Firstly it would appear that more care was taken over the approach to fathers than the approach to mothers. The researchers gave consideration to intrusion into areas of fathers' lives that were ‘wholly private’. This begs the question as to whether these areas are considered private for mothers as well or whether they simply have to become accustomed to being intruded upon. Secondly there is an obvious difference between acceptable levels of emotional expression that is different for men and for women. It is not clear whose levels are being catered for, the father or the researcher. This research, and the literature reviewed, clearly identifies that fathering a child with a disability is a very emotive area. I would contend that it is vital that outlets for dealing with these emotions are available, in whatever way is appropriate for the individual and is essential for the future well-being of any parent, male or female, who is caught up in the trauma of caring for a child with a disability. This again brings the implication for practice back to the need expressed by these fathers for someone they can talk to; someone who has the listening skills that these fathers are clearly saying they wanted and valued when they had experience of it.

Carpenter and Herbert in their research talk about the father as the ‘hard to reach parent’ alluding to the fact that fathers are often only available (to professionals and researchers alike) out of working hours. I would argue however that this situation is exacerbated if fathers are approached by professionals who have this wary attitude to facing male emotion. It will only compound the picture of fathers being the hard to reach parent because they have been warily approached in the first place and in such a way that signals to them that their emotions are not to be expressed. The findings of this research would support the idea that fathers want to be able to talk to someone. This, I feel, is the most significant conclusion from this research and is the area that service provision should address. Professionals must not be afraid to venture sensitively into the world of male emotions, otherwise fathers will remain just a shadow.
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Father of a boy with disabilities