

No Time for Us

Relationships between Parents who have a Disabled Child

A survey of over 2000 parents in the UK

Contact a Family: Acton.Shapiro

Final Report: December 2003

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*“A disabled child in the family strengthens a good marriage but shows up flaws in a way nothing else would in a bad marriage”
– a separated mother*

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Chapter 1 Introduction and Methodology

1.1 Introduction

Contact a Family provides support, advice and information to families with disabled children across the UK. Each year the help line and local information services support over 18,000 families, and a further million parents and professionals visit the website www.cafamily.org.uk.

This report describes the findings of a five-month consultation exercise on the theme of relationships in families where there are one or more disabled children. The work was funded by the Marriage and Relationships Support Programme, which has recently moved from the Lord Chancellor's Department to the Department for Education and Skills. It was carried out by Contact a Family with assistance from the consultancy Acton.Shapiro, who also analysed the data and produced this report.

1.2 Methodology

The consultation exercise incorporated four components:

- A postal survey
- A web-based survey
- A conference
- A workshop

The findings of an internal consultation exercise with Contact a Family's family support staff on the issue of domestic violence have also been incorporated into this report. In Section 5.3, comments previously made to Contact a Family's help line have also been used in the report, to illustrate concerns about how parents can feel abandoned when their child dies.

The postal survey

A short questionnaire (see Appendix A) was sent to all 2150 subscribers to the Contact a Family journal in June 2003. A total of 234 questionnaires were returned, giving a response rate of approximately 11%.

The web-based survey

The Internet survey was essentially a shortened version of the postal survey. It was posted on the CAF website from late August to the end of October 2003. This survey received 1850 responses, and some respondents sent emails with additional stories or comments.

Together the two surveys therefore generated a total of 2084 responses.

The conference

Contact a Family Northeast, in collaboration with Fathers Plus, Relate, Gingerbread, Parentline Plus and Barnardos, organised a 'Relationships and Family Day' on 13 August 2003. 240 parents and children attended. The families were asked to contribute their views on relationships and experiences of family life through a variety of media, including workshops, post it notes and a video 'soapbox'.

The workshop

The workshop, which was held in Cardiff on 21 November 2003, involved 15 parents and was facilitated by Contact a Family Wales. The majority came as couples. The group included two stepfathers.

1.3 The report

In summary therefore, this report brings together the views and experiences of well over 2000 parents with a child with a disability.

Chapters 2 and 3 are based on both the postal and web-based surveys. Chapter 2 describes the key features of the families who responded to the two surveys, including the gender of the respondents, their ethnic origin, the current family situation, and the age of the disabled child. Chapter 3 describes the respondents' perceptions of the impact on relationships of having a disabled child.

Chapters 4 and 5 are based purely on the postal survey, as these sets of questions were not included in the web-based survey due to space constraints. Chapter 4 explores respondents' views on what has helped, or could have helped, their relationships. Chapter 5 looks at their views on the role of counselling in relationships.

Chapter 6 is based mainly on the contributions of delegates to the conference and the workshop, and also draws on an internal consultation exercise with Contact a Family's family support staff. It explores the particular issues relating to fathers, siblings, single parents, domestic violence, work and housing.

Finally, the key findings, conclusions and policy implications and recommendations are presented in Chapter 7.

Throughout the report, the findings are illustrated with pie and bar charts. Quotes, comments and examples from the postal survey, the workshop and the conference, or from emails sent in by visitors to the web site, have also been incorporated in relevant sections throughout the report to illustrate the points under discussion

Chapter 2 The Families in the Surveys

This chapter is based on both the postal and web-based surveys. It describes the key features of the families who responded to the two surveys, including the gender of the respondents, their ethnic origin, the current family situation, and the age of the disabled child.

2.1 Gender of the respondents

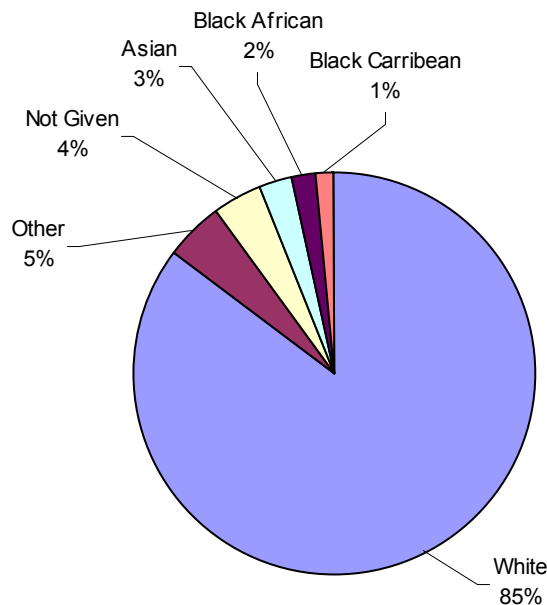
The vast majority of the respondents to the two surveys identified themselves as female (1759 = 84%). 242 (12%) identified themselves as male and 83 (4%) did not respond to this question.

Women comprised the majority in all ethnic groups, though the percentage of women varied from 93% of Black Caribbean respondents down to 58% of Asian respondents.

2.2 Ethnic origin of the respondents

The majority (85%) of the respondents described themselves as white (compared to the national population, in which 91% are white¹). The remaining 15% were distributed amongst the other 5 categories (including 4% not given). Fig 1 illustrates the distribution.

Fig 1 Ethnic description



2.3 The disabled child's current family situation

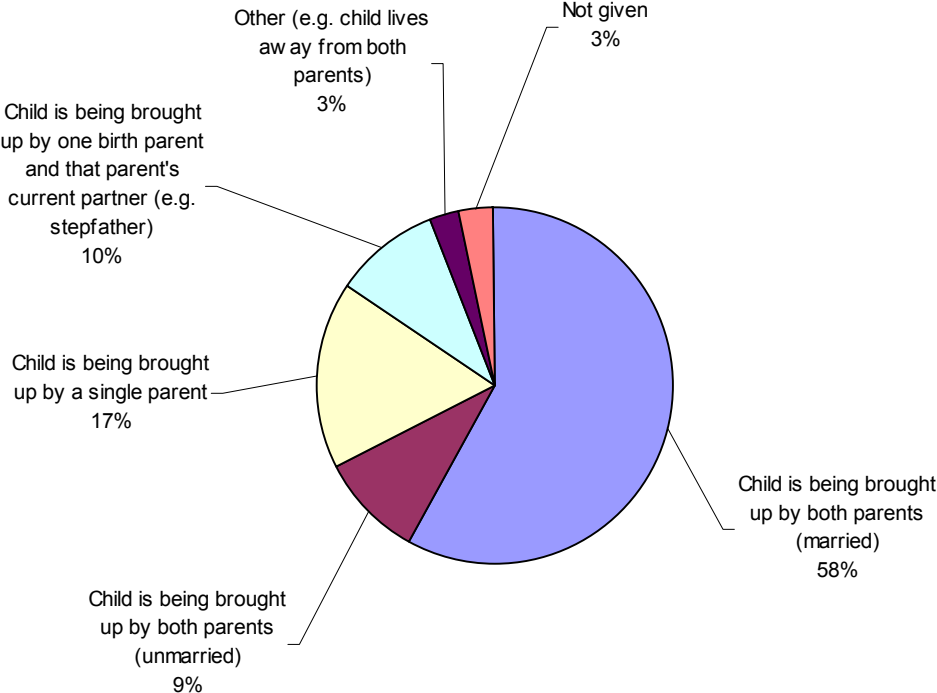
Fig 2 shows that, in two-thirds (67%) of the families of the respondents, the children were being brought up by both parents (either married or unmarried). In most of the

¹ Office of National Statistics (Feb 2003) *Data from 2001 census*

remaining families, they were being brought up by a single parent (17%) or by one parent with their current partner i.e. in a stepfamily (10%). A small minority (3%) were in another situation, for example, living away from both parents. The remaining 3% did not respond to the question.

Recent census figures² show that, nationally, 65% of children under 16 live with both parents, 23% live in single parent families, and 10% live in stepfamilies. However, because of the different age band applied in this survey, it is not possible to make a direct comparison.

Fig 2 – Disabled child’s current family situation



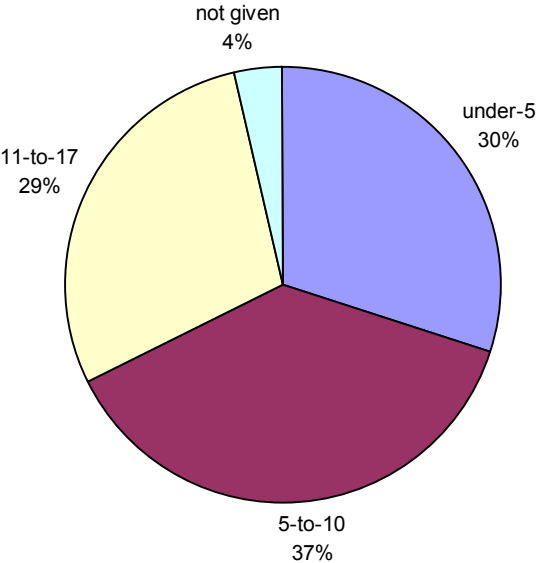
2.4 The age of the child

In cases where there was more than one disabled child in the family, respondents were asked to focus their answers on the *youngest* disabled child.

Fig 3 shows the distribution of the children’s age groups.

² Office of National Statistics (Feb 2003) *Data from 2001 census*

Fig 3 Children's ages



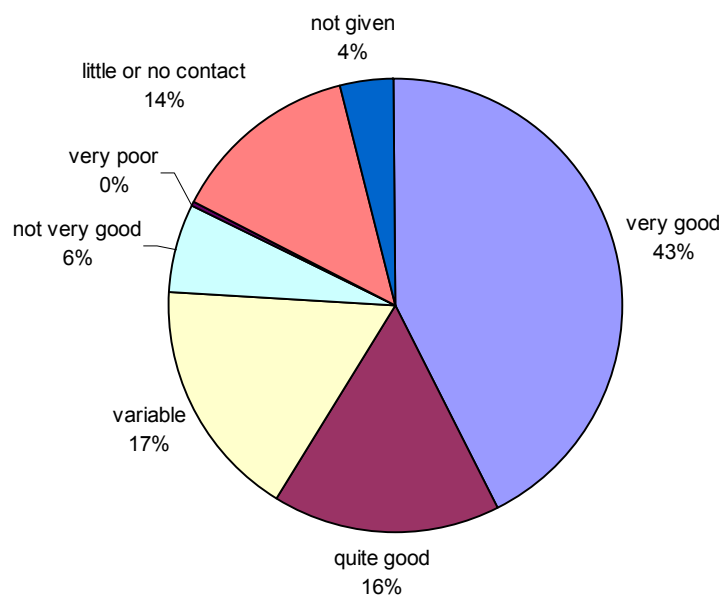
Chapter 3 The Impact on Relationships of Having a Disabled Child

This chapter is also based on both the postal and web-based surveys. It describes the respondents' perceptions of the impact on relationships of having a disabled child.

3.1 The current relationship between the parents

The respondents were asked to describe their overall relationship with the child's other parent. Fig 4 shows the distribution of the responses to this question. 43% of the respondents described their relationship as 'very good', 33% described the relationship as 'quite good' or 'variable', whilst 6% said that it was 'not very good' and fewer than 0.5% described it as 'very poor'. 14% said that there was 'little or no contact with the other parent' and the remaining 4% did not respond to the question.

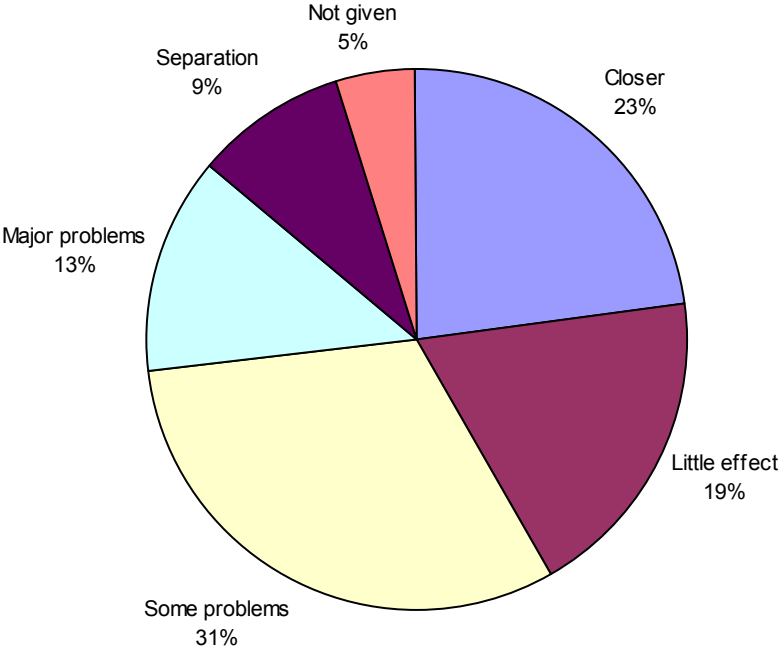
Fig 4 Current relationship between parents



3.2 The effect of having a disabled child on the parental relationship

As shown in Fig 5, almost a quarter (23%) of the respondents felt that having their disabled child had brought them closer together, and a further 19% felt it had had little effect on their relationship. However nearly a third (31%) felt that it *had* caused some problems in their relationship, and another 13% felt that it had caused major problems. 9% of respondents felt that having a disabled child had led to their separation as a couple and the remaining 5% had not responded to the question.

Fig 5 Perceived effect of having a disabled child on relationship between parents



The perceived effect on the parental relationship of having a disabled child differed markedly between those families where the child was living with both parents (whether or not they were married) – see Fig 6 - and those families where that was not the case – see Fig 7. Where the child was living with both parents at the time of the survey, having a disabled child was perceived to have brought the parents closer together in 32% of cases, whereas this was true in only 5% of the cases where the child did *not* live with both parents.

Where the child was not living with both parents at the time of the survey, the perceived link between having a disabled child and the separation of the parents was 24%. This compared to 2% where the child was still living with both parents. This latter figure appears at first sight to be a slight anomaly, but could be because the child lived with both parents even if the parents themselves were not living together.

Fig 6 Perceived effect of having a disabled child on relationship between parents (where the child is living with both parents)

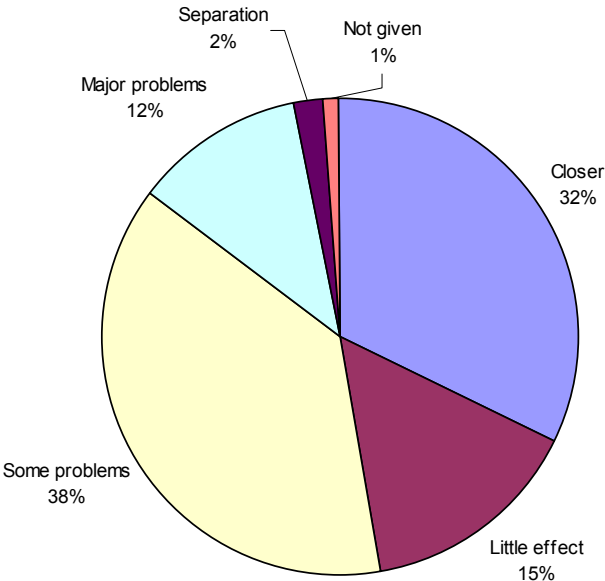
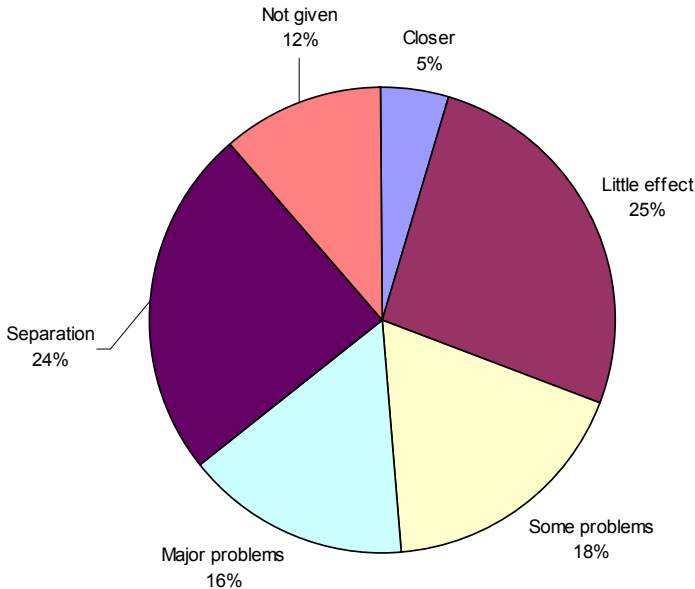


Fig 7 Perceived effect of having a disabled child on relationship between parents (where the child is not living with both parents)



3.3 Problems experienced since having the disabled child

Respondents were asked which, if any, of seven problems listed in Question 6 of the survey (see Appendix A) had been experienced since their disabled child was born. The problems listed were: stress or depression; tiredness/lack of sleep; financial difficulties; problems at work; housing problems; domestic violence; drug or alcohol problems. The respondents were asked to tick as many problems as applied to them or their partner. Fig 8 shows that the problems most widely experienced were 'stress or depression' (76%) and 'tiredness/lack of sleep' (72%).

Tiredness and lack of sleep

"Tiredness, lack of sleep and lack of emotional space, there are no calm places in our lives"

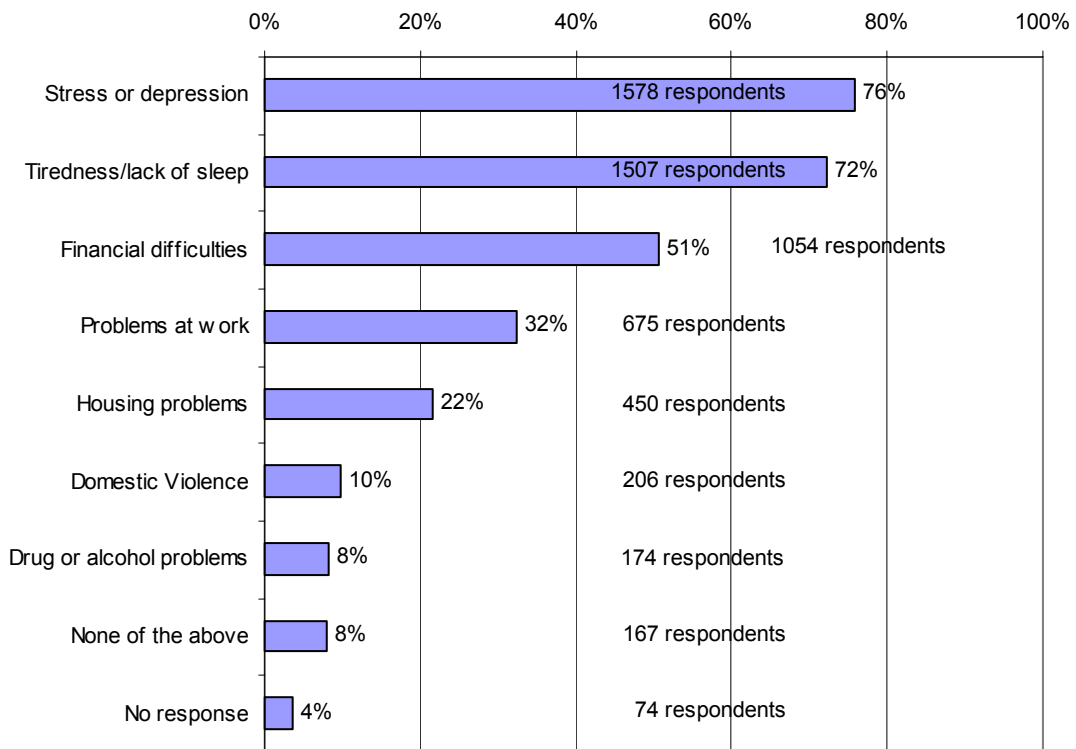
"You can't think straight if you've had no sleep"

"It's not because the child is disturbing you, but what goes on inside your head. You worry about the future"

"For thirteen years we have had disturbed and relatively little sleep. Our eldest, fortunately still small in stature, spends half the night in between us in our bed or she doesn't go back to sleep when she wakes at 2am... During holidays I am accustomed to taking the child/children out during the day and then working in the office all night when [my partner] gets home. By the end of a school holiday I am completely zombie-like with never any chance to recover"

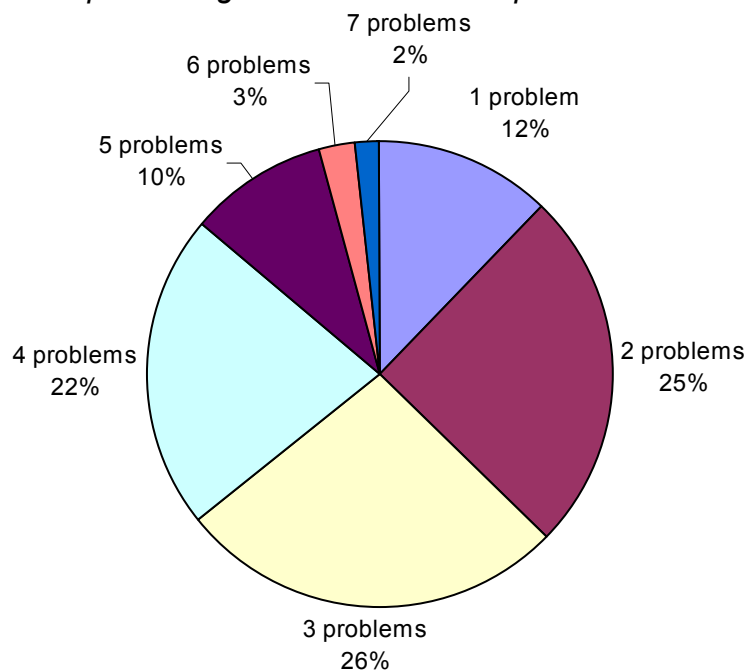
Fig 8 shows that over a half of the respondents (or their partners) had experienced 'financial difficulties' and nearly one-third 'problems at work'. One in five had experienced 'housing problems', one in ten had experienced domestic violence and one in twelve 'drug or alcohol problems'. Only 12% of the respondents and their partners had not experienced any of these problems since having their disabled child, including 4% who did not respond to the question.

Fig 8 Problems experienced since having disabled child



Many of the respondents or their partners had experienced several of these problems, as is shown in Fig 9 below. Three quarters of those who had experienced a problem had experienced at least two, and almost two-thirds had experienced three or more. A small minority (2%) of the respondents had experienced all seven problems listed since having their disabled child.

Fig 9 Respondents experiencing one or more of the problems listed

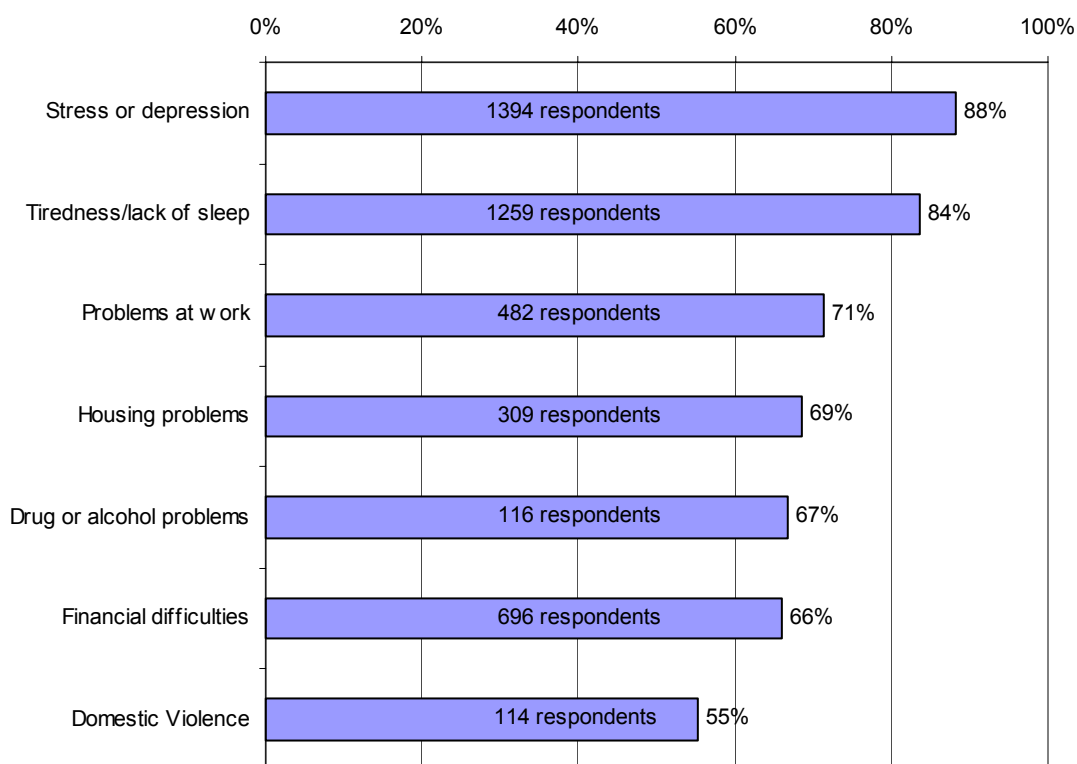


3.4 Problems perceived as being linked to having a disabled child

The problems listed above are found in many families, and it should not therefore be assumed that they are necessarily linked to having a disabled child. For this reason, respondents were asked if, in their opinion, those experiences could be *linked* to having a disabled child. Fig 10 shows the percentage of those who both gave a 'yes' response to experiencing a problem and also linked that problem with having a disabled child. So, for example, Fig 8 shows that 1054 respondents (51%) said they had experienced financial difficulties since their disabled child was born and Fig 10 shows that 66% of these (i.e. 696 of those 1054 respondents) linked that experience to having a disabled child.

The results in Fig 10 show that each problem was linked, by the majority of those who had experienced it, to having their disabled child. In the cases of stress or depression and tiredness/lack of sleep the links were as high as 88% and 84% respectively. Even the majority of those experiencing domestic violence linked it with having the disabled child.

Fig 10 Problems linked to having disabled child



3.5 The impact on relationships – separation, struggle, or adjustment

A number of parents involved in the consultation exercise responded to the invitation to provide more information about the effect of caring for their disabled child on their relationship. Some of these contributions have been included below to give a flavour

of the long-term impact on relationships, not only on the parents of the child but also on the wider family.

The first group of comments is from parents who have separated, usually because they found the stresses of caring for a disabled child too much. The comments show that this is sometimes because one parent (usually, but not always the father) cannot accept the child's disability, and frequently because the couple have no time or emotional space left for each other. Some respondents did however point out that they would probably have split up anyway, and that having a disabled child simply highlighted existing problems in their relationship. One respondent emphasised that, even though they had separated as a couple, they both still played an active role in bringing up their disabled son.

Couples who have separated

"I am constantly tired and run down. Relationships suffer because both parties require huge amounts of support, often in quite conflicting ways and times. There is little time, energy or emotion left for each other. My husband left me when our disabled daughter was very young. He said he wasn't leaving me but our daughter, as he could not stand living with her. I have given up on marriage and relationships"

"Having a child with disabilities is shattering, it changes your life. My husband and I split up last year. It gets to the point that it is too painful to talk about your child so you stop talking to each other completely"

"Her dad said that he did not want to bond with a child who was going to die. He refused to hold her and said 'either she goes or I do'. We split up when she was only a few months old. If they (health service) had had some sessions for dads in the evenings, he would maybe have found it easier to cope, to talk to someone else and maybe the marriage would not have ended. They (health service) frightened us by showing us terrible pictures of other children with this syndrome, but they didn't say all the positive things that my daughter has brought to our family"

"I had no time or energy for hobbies and interests and I think this made me a less interesting person to be with. I split up with my husband and my son went into residential care. His sister felt as though she had lost her home, her father and her brother all at once. At first she blamed me for this and relations between us were strained for quite a while. Now my son is very happy in his placement and becoming more independent. My daughter is returning to study and things are much better all round. But I would say to other people that you need to ask for help long before you get to crisis point"

"In my case my son's problems were inextricably part of a catastrophic relationship breakdown with my wife. He lives with me as she is not good at supporting him. I guess there must be many more fathers of disabled kids who have been through separation/divorce as a result of the family stress. But I think that those (few?) of us fathers who end up with majority or sole care of the child(ren) are in a very special situation and need support tailored to single parents of disabled kids"

“My ex used to be embarrassed by my son making a noise and people looking at him. He should have learned to be proud of his son and what he achieved, not embarrassed. His son didn’t ask to be disabled and like he is. My ex found someone else and left us - if I have a new relationship the person will have to take my son and me as a package”

“[Our child] is very close to me but he has a bond with his dad too. He sees his dad on a Saturday and even though he is disabled we both love him very much”

“It would have helped if I hadn’t been so depressed when I first had my child...If I’d been as strong and coped like I do now, I probably wouldn’t be on my own with my son now. It could have helped if I’d listened to my ex partner more but at the time I was too stressed and depressed”

While the survey showed two thirds of the children being brought up by both parents, it was clear from many comments that the quality of the parental relationships varied enormously. The comments below show that, for a second group of parents, staying together has not been an easy road, and has often in fact been a pragmatic response to the perceived impossibility of coping alone. The potential for saving the relationship often seems jeopardised by the couple’s shared, unresolved history of pain since the birth of the child.

Couples who have struggled

“When my child was born, we knew that he was born to be different. As time went on and our little boy’s needs grew we also required emotional support. At the time I received this from friends and family – I cannot speak for my husband who I know found it very hard to communicate his feelings. This is when the strain between us grew – often we would suffer from outbursts of emotion, a natural process when feelings that had been suppressed become unbearable! Believing we should cope on our own, we never turned to anyone for help (or even discussed the help available) but leaned on each other – I recognise today that we went through a grieving process, a ‘coping bravely’ process, even a healing process as a family and on our own! I wonder now how we coped and survived! Perhaps our family is one of the lucky ones as we have all stayed together – however the emotional scars and hidden memories of the darkest days still remain”

“If I thought I could manage alone I would have left years ago. It is the knowledge that I need my partner in order to be a good parent that has made me stay”

“We separated for six months, giving my partner time to come to terms with the disablement ...I’m still hurt and angry about his leaving”

“This has affected our relationship deeply, the shock of it all and living with the disability every day is a real burden, and sometimes I wish I could just walk out”

“I’m now menopausal and at the same time our youngest daughter is going through early puberty. Life is hell for my husband! Hormones rage and tempers flare! No

doubt this is normal-ish but the difference is that he (or I) can't storm out, cool off and then come back. So the atmosphere's unpleasant at times. We are under a lot of pressure and have constantly to rely on internal resources to get through. Sometimes life is very sweet – no, it's always very sweet, but most of the time we just don't seem to have time to savour it"

"I have no job, no useful relationship with my husband, and just about hang on to the threads of daily life"

"My partner is not physically violent but he verbally bullies me because he cannot cope with the situation and cannot cope with the demands placed upon us by having two disabled children"

"There is almost a 'backlog' of misery from the time when my son was very ill and no one wanted to give us any services or support. The relationship was the first thing to be kicked into touch when we were living in crisis and turmoil. My son is nearly 7 now and for the first time I feel there is enough 'space' in my life for me to think about my options. It would have been impossible to have dealt with the issues in our marriage until this point – there would not have been the time or the will to do it. Now there is both but I expect it will be a very difficult process and ultimately if we separate it will create additional issues about the care of all our children"

"I love our child but he gets in the way of everything. We don't talk anymore, we just manage him"

"[We] can't afford a divorce... you're locked in anyway"

"Any difficulties between my husband and I are exacerbated by the additional stress and time lost to caring for a disabled child. Neither of us gets enough time and attention for us as individuals and neither of us has the capacity to give more to the other. There is a great deal of resentment – he resents that I don't spend as much time with our disabled child as he does, and I resent that he doesn't recognise the colossal effort I put into co-ordinating schedules, visiting school and fighting continuous battles to get what our son needs"

The final group of comments are from parents who have found that, in spite of – or even because of - the many difficulties they have faced, caring for their child has enhanced and strengthened the relationship. These couples have been able to find real rewards from facing and overcoming daily challenges together.

Couples who have adjusted well

"We feel we are much more tolerant and understanding people"

"Just being with [our child], and watching him reach his goals in his own time, and achieving what we got told he would not"

"Reassessment of our values – what really matters in life"

“After earlier relationship difficulties, we are now much closer”

“We are terrific as a team in a crisis – we are the family that copes!”

“One parent in our relationship is the investigator/explorer/questioner/driving force, and the other keeps the ‘home fires burning’/brings perspective to ideas that can be outlandish/brings balance”

“Faith, love, grace, compassion.... all these are present and manifest and we are close and love each other and feel fortunate too - but it's still a hard journey to face”

“Neither my husband nor I can imagine life without the other - neither of us could cope with the children without the other's help. There is a bond between us that can never be shared by anyone else”

“[Our child] brought us closer together. We had to be strong [but] it's a hell of a strain - it takes you to your limit some times”

3.6 Summary

- Although many of the respondents described their overall relationship with the child's other parent in positive terms, at least one in five had a poor relationship, or even little or no contact.
- The majority of respondents felt that having their disabled child had caused problems in their relationship, and that, in nearly one in ten cases, these problems had led to their separation.
- Only a small minority of respondents had not experienced any additional problems (such as tiredness, stress, housing, work, financial problems, domestic violence, or drug and alcohol abuse), which would be likely to put their relationships under more stress. Most of these respondents linked these problems with having their disabled child. The majority had suffered at least one of the three most common problems i.e. stress or depression; tiredness/lack of sleep; and financial difficulties.
- The respondents could be identified as three main groups: those who have separated; those who are struggling in their relationships; and those who have adjusted well. Their comments suggested that one of the main differences between the groups is the level of communication and sharing of problems which the couples have been able to sustain. In the middle group, there is a lot of pain, but it appears that often these couples do not even have enough energy to address their relationship problems.

Chapter 4 What Helps – or Could Help – Parental Relationships?

Chapter 4 is based purely on the postal survey, as these sets of questions were not included in the web-based survey due to space constraints. It explores respondents' views on what has helped, or could have helped, their relationships.

4.1 What has helped parental relationships?

Respondents to the postal survey were asked to state what, if anything, had helped their relationship since having their disabled child, and to rank up to three answers according to perceived importance.

Respite care

Analysis of the responses shows that, overall, the single most important factor was seen as time away from the disabled child - time to be with the partner and/or other child or children. 47 responses referring to respite, breaks, time alone, evenings out together or 'time to be me' were all included in this category.

Many of the parents named local services which had enabled them to have a regular break, run by organisations such as Crossroads Care, NCH etc. Others had been enabled to have a regular break by other family members or by understanding friends.

Respite care

"RESPITE! ... makes us both feel human again"

"When our child is looked after we spend quality time together"

"Going out at night occasionally without the children [helped our relationship]"

"Having a supportive extended family nearby [helped our relationship] – when our child was younger we would only leave him with close family members who understood his needs"

"The reason my relationship has survived is due to the fact we receive a good respite care package. My then partner (now husband) was on the verge of breaking up due to the strains of caring for our profoundly disabled son when he was much younger...due to lack of sleep mainly. Respite care has been the key to our survival, it has allowed us to re-charge our batteries and have time for our other children and each other. This is necessary for any relationship but crucial for those with a disabled child in their family when having to cope with so many other pressures."

“Taking time to be with yourself, your partner and your ‘normal’ child can re-establish relationships that are buried under doctors’ appointments, being told what they can’t do, and hopes and disappointments of life”

“Find time for yourselves. Grab any help you can get!”

The ability of the parents to communicate

The ability of the parents to communicate openly with each other was referred to almost as frequently as respite care (41 responses). In fact this factor was ranked first by the highest number of respondents. A number of respondents described how they had had to reduce or at least modify their expectations of each other, while also making efforts to share rather than hide their feelings. Some respondents took the view that it was down to them to adjust to the situation in which they found themselves. As one parent at the Wales workshop put it: *“Prioritise your relationship - no one else is going to do it for you”*.

Several also made the point that having a disabled child had put the rest of their lives in perspective, had changed their priorities and had in some ways made them ‘better people’. As one parent put it: *“I would be a different parent to my children without [my daughter] – I am much more relaxed about things, things that would have got me down before just don’t – they are not important”*.

The ability of the parents to communicate

“Sticking together – talking to each other”

“Putting the other person’s needs and feelings first”

“Keeping talking to each other and not bottling up our feelings – being truthful about what we really think about our situation”

“Affirmation that our marriage is for life and we faced this and anything else together”

“Remembering the partner you married has feelings too and remembering why you married them”

Other ‘helping’ factors

Three other factors were also frequently identified as having helped the relationship i.e.

- Sharing the care and responsibility for the child between both parents (29)
- The support of family and friends (29)

- Support from other families in the same situation, often through local support groups or organisations such as Contact a Family (26)

The support of family and friends

“Physical help and acceptance from the immediate family lets you have an on-call baby sitter who will accept him and understand him. Plus he feels secure. Also it brings balance as to what is ‘disabled behaviour’ and what is ‘human behaviour’ which can be difficult to distinguish with your first one. In my case, my parents stopped me having too much self pity – it was of no help to anyone for me to sink into depression over the ‘vastness’ of the task”

Other factors highlighted with some frequency were:

- Benefits/lack of money worries (12)
- Support from professionals including hospitals, dieticians, therapists, GP etc (12)
- The ability of one or both partners either to reduce work to concentrate on caring for the child – or to keep working to maintain an outside interest and status (10)
- Having one or more other (non-disabled) children (10)
- Having the disabled child in full-time school (8)
- Religious faith and prayer (8)

Having one or more other (non-disabled) children

“Finding a balance between the disabled and non disabled world – which having a second one allowed. Letting the two develop their own relationship”

Separating

Finally, it is sad to note that a few parents felt that the most helpful thing for their relationship had been for them to separate:

When separating helps

“Him leaving ...allowing me to put in place methods for coping”

“The break up of my marriage was as a direct result of giving birth to a disabled child. But I consider this to have been a good thing in the long run. In my view a disabled child in the family strengthens a good marriage but shows up flaws in a way nothing else would in a bad marriage. Your findings may well indicate that there are more broken relationships where families have a disabled child, but that is not necessarily a bad thing”

“[What helped most was] leaving my partner after 24 years (strange but true)”

“Getting divorced and him moving away has greatly helped the family. [During] the few visits we do get he makes an effort to be positive and not angry”

4.2 What could have helped relationships?

Respondents to the postal survey were also asked to state what, if anything, *could have* helped their relationship with their partner since having their disabled child, and to rank up to three answers according to perceived importance.

The problems of getting a break

Again, the need for a break i.e. for some time alone with the partner, the rest of the family, or even by oneself, was by the far the most common response, with 84 (36%) of the respondents in the two surveys saying that this would have helped their relationship, and 60% of these ranking this first. The importance of breaks was reinforced by the parents who attended the Wales workshop, most of whom said they did not have access to any regular respite.

The problems of getting a break

*“Having some-one to look after both children for an evening perhaps once a month when we could go out and be a couple and properly talk... **not** just be carers”*

“It has taken ten years to get a six-night break this year”

“Our four hours once a month has just been cancelled”

“We get the hours 1.30 to 4 pm once a month, but [if we had more] respite it would have to be free from worry i.e. safe, no fear that our child would be abused in any way”

“[We needed] respite care on a regular basis to mend our relationship – it is very difficult to get childcare because of the children’s problems, and our family cannot handle them”

“Shopping is a nightmare. I have respite so that I can go shopping but I have to take the other kids with me – where’s the respite in that?”

“[We’ve had] no time to do things together as a couple. [It’s the] first time we’ve got respite, she’s now twenty-one”

Respondents highlighted a number of particular points relating to the provision of respite care:

- The impossibility of being spontaneous when respite has to be booked many months in advance
- The need for a free babysitting service
- Help in the home at night for children who do not sleep well
- The need for experienced respite care staff who can cope with difficult behaviour
- The stress caused by having to 'fight' for a break rather than being proactively offered it
- The need for an emergency break when the carers are exhausted
- The need for financial support for home-based childcare with carers trained by the family
- The frustration caused by long waiting-lists
- The need for services which can care for all the children in the family, not just the disabled child

A number of respondents called for more services that would both give them a break and their child more chance to mix with others. These included trained childcare/after school care, and baby-sitting (6 responses each) and playgroups/holiday activities (9).

The need for emotional support/counselling

Counselling, emotional support or some-one to talk to came second, with 30 respondents suggesting that this could have helped their relationship, and over half of these (17) ranking it first. A number suggested that counselling should be offered fairly soon after the diagnosis/birth of the child, when parents were typically faced with many questions, worries and uncertainties, and had to make many adjustments in their relationship and way of life. Several respondents felt that their partner (usually the father) would have benefited from being encouraged to express his feelings and worries rather than bottling them up, and one suggested that her partner's eventual suicide might have been avoided had he had access to appropriate counselling.

The need for emotional support/counselling

"[We need] someone professional to talk to outside the family, just to tell us we're doing well! The guilt one feels is tremendous - I feel I can never make things right for the children but I can never stop trying! Intellectually one knows all too well that this is "just one of those things", that no one was to blame, etc [but] emotionally that doesn't wash! The kids have massive problems not of their making. Their problems are our responsibility as well as the children themselves. The children will always have to face life through adversity - and so shall we... The shock of the children's births and of their stormy neonatal periods and early lives was so intense that the effect remains fresh, raw and quick to surface to this day. We both shed tears still on odd occasions that remind us: the sight of a young child walking hand-in-hand with one or two parents (the dream of carers of non-mobile children), or running around... the story of a tragedy in someone else's life... the death of a friend or another family

member... a support group seminar..."

"[We needed] some kind of family counselling – out of the home, a few months after diagnosis"

"Having someone independent to talk to, unload on...discuss feelings of guilt etc, without being judged and not having to put a brave face on the whole time"

"Her autism has made our family dysfunctional too... my husband is in danger of losing his job through depression"

Support and information around diagnosis

The third category in 'what could have helped?', noted by 26 respondents (and ranked first by over half of these (16), was the need for honesty, accuracy and speed in the diagnosis of the child's condition, and for timely information and support around this time. A number of respondents referred to the trauma they had experienced due to not understanding the cause of their child's problems, and the time wasted in accessing the support, benefits, services etc that they needed to help them cope. Again it was clear that this had, in some cases, had a very negative impact on the relationship between the parents.

Lack of support and information around diagnosis

"The hospital knew that my son had cerebral palsy from the minute he was born, but didn't tell us. So it came as a complete shock at 18 months when he had a brain scan"

"[We needed] the truth from professionals (doctors, hospital) from birth, as everyone appeared to know but us. As the only child, I was a bad mother who couldn't control her tot or stop him hurting everyone, and banging his head as he bounces off walls"

"We thought our child was just naughty and we argued over this"

"It would have been a lot better if we had received more support from the health professionals. We were told that our child had cerebral palsy and that was it, we were not given any information on the diagnosis, we were not offered any support. The response that we had from the doctors was just awful, as soon as we mentioned the word cerebral palsy, that was it – they did not want to know. We have found it a long hard struggle and we've had to cope with it alone, a lot of our friends cut themselves off also. The experience would not have been so horrific if we had received some sort of support and been told about the services"

"If you are diagnosed with breast cancer you immediately get access to a specialist nurse who sits with you and explains what's going on. Can't new parents get this service?"

Financial issues

The fourth category (with 21 respondents) centred on financial issues, and included easier and earlier access to benefits, lower costs, and fewer financial pressures. Several noted that, in many cases, one of the partners (usually the mother) was unable to return to work. This immediately had a significant impact on the family's finances, and often lasted until the child was adult, if not longer. Several also noted that their lives would have been considerably less stressful if someone had told them of their likely entitlement to benefits – some had only found this out through other parents.

Parents who attended the Wales workshop elaborated on some of the difficulties around claiming benefits. They explained how their guilt at claiming non-means-tested benefits, even if their income is relatively high, could be made worse by the comments of acquaintances who suggest they do not deserve benefits. However, as one parent put it: *“People saying ‘I wish I had all that money for nothing’ [hurts] - I’d give it all up just to see her walk”*. The point was also made that many families are very reluctant to accept help from charities: as one parent put it: *“I wasn’t bought up to ask –there’s enough guilt around having a disabled child anyway”*.

These parents also called for a more coordinated approach to financial support, with benefits being proactively offered to parents with a disabled child.

Financial issues

It is still difficult with hospital costs, our son has had many operations so my husband has had much unpaid leave”

“We didn’t get DLA until he was seven years old”

“Having more money – so not needing to work ...so spend quality time together”

“Getting DLA promptly would have helped – we had to save to get a second car due to our child’s restricted weight-bearing mobility”

“We have to pay privately for more physio which is an enormous financial drain”

“We spend thousands of pounds on therapies”

“Money is a continuous worry and this puts us under added strain”

“Grants/tax relief towards individually-arranged childcare [would help]. We don’t qualify for Working Tax Credit. We draw below-average salaries from our own business where we work 130 hours per week between us. This gives us flexibility - but because we have 2 incomes, puts us above the limit - or maybe it’s because our household receives 2 x DLA at the higher rate?”

“The indignity of the DLA/ICA forms and the poverty trap they are designed to keep

you in. They are designed to rub in your face what your child cannot do rather than celebrate what they have achieved – in case money is lost. The first time I completed a form I hoped it would be refused, so that I would not have to finally accept that my child – in the eyes of society – is disabled”

Help and support from family and friends

17 respondents said that more help or understanding from family members and relatives would have helped their relationship with their partner. In a few cases the relatives lived too far away to provide practical help, but the majority of the respondents seemed to be suggesting that relatives were either unsympathetic to their needs as carers, or else felt unable to cope with the child to give the parents a break.

Lack of help and support from family members

“The grand-parents have their other grand-children to stay but we are avoided and not invited to family ‘dos”

“At first, my parents gave a lot of help and support, but as my son got bigger and they got older and less able, they could not help”

“I guess it would be really, really great if, for just one weekend, friends or family came along and said, “you two go away for a night or two, we’ll look after the children for you at your home...”. In order to go away for just one night (yes, we have done it once or twice!) we have to arrange for two suitable adults to come and sleep in, normally a nanny and a relative”

Parents also pointed out that friends and acquaintances sometimes make comments which, even if unintentional, can be very hurtful. As one parent at the Wales workshop explained: *“You need a sense of humour –if any one else says we’ve been chosen, I’ll be up for murder!”*

What else could have helped?

Other issues raised by at least ten respondents in each case included:

- Access to professional support (18)
- Involvement and support for the father in particular (16)
- Recognition of the needs of the whole family, including the other children (11)
- Practical help in the home (11)
- General information about services and entitlements (11)
- Access to support from other families in similar situations (11)
- Fewer problems around education, ‘statementing’ etc (11)

A large number of respondents (15) described the stress put on their relationship by having to 'fight' their way through bureaucracy for support and services, and by the additional pressures of having to fill in forms. Several also explained that, if one of the parents felt they were having to 'fight' more than the other, this again put stress on the relationship: *"My husband's lack of engagement with the agencies and systems leaves me feeling very isolated - this issue is very pronounced in respect of our disabled child, whereas it would be barely noticeable in a 'normal' situation, for example in relation to our other children."*

Having to fight for services

"If I didn't have to fight for everything we get, our life would be much easier"

"Having two disabled children, education has been a major problem. The eldest child was verbally bullied on a near daily basis at school, the younger one we have had colossal problems in persuading the local education authority and her school to actually provide adequately for her needs - this is now a matter of a High Court Case and an exceptionally large disability discrimination claim at Special Educational Needs and Disability Tribunal (SENDIST). There is no support from the secondary school or the LEA for us, the social services refused to accept 3 referrals for us to receive help. It was only because I went public at a conference that they, after 2 and a half months, actually started to become involved with us and provide some support"

"You have to fight for everything for your child – it's wearing and takes its toll on relationships"

"Special equipment, grants, more services...they are all out there, but you have to go looking for them or we get nothing"

"This is just existing – we problem solve each new problem, sometimes quickly, sometimes slowly, but with no help from anyone else"

"[We needed] a key worker to help us through the layers of professionals who are supposed to help but don't necessarily do so"

4.3 Summary

The survey suggests that those parents whose relationships are good are likely to have achieved many, or at least some, of the following:

- Ready access to regular short breaks ('quality time together') away from all the children
- The ability to continue to communicate with each other and to modify expectations of each other
- The ability to share the care of, and responsibility for, their child
- The support and understanding of friends and wider family
- Contact with other families in similar situations, often through support organisations

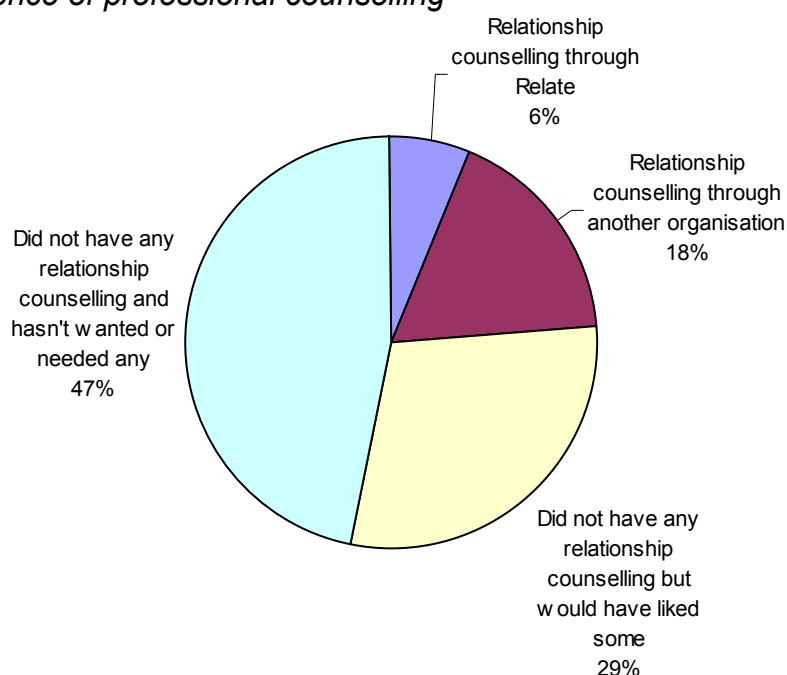
- Adequate financial resources, including the right benefits
- Support from professionals, including counselling support if needed
- The 'right' home/work balance for both parents
- Other (non-disabled) children
- A settled school life for the child
- A positive attitude to life, and perhaps a religious faith
- Good information, especially at the time around diagnosis
- Support and time for the other children in the family
- Practical help in the home
- Support proactively offered, rather than 'fought for'

Chapter 5 The Role of Counselling in Relationships

5.1 Experience of professional relationship counselling

Fig 11 shows that nearly a quarter (24%) of the respondents to the postal survey had had professional relationship counselling since having their disabled child. 14 of these (6%) had had counselling through Relate, and 37 (16%) through another organisation/counsellor. Of the three quarters (76%) who had not had any counselling, 38% would have liked some.

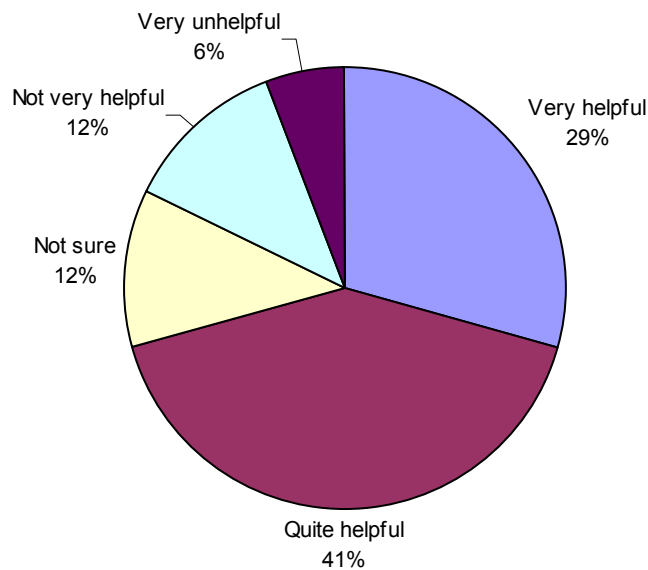
Fig 11 Experience of professional counselling



None of the fifteen parents attending the Wales workshop said they had received any formal counselling.

Fig 12 illustrates the responses of those in the surveys who had expressed a view as to the value of their counselling. It shows that 70% had found it to be very or quite helpful, whilst 12% were not sure, 12% said it was not very helpful, and 6% said it was very unhelpful.

Fig 12 Perceived helpfulness of relationship counselling



Of the 14 respondents who had received counselling through Relate, 9 (64%) had found it very helpful or quite helpful, 3 were not sure, and 2 had found it not very helpful or unhelpful.

Of the 37 who had received counselling through another organisation/counsellor, 27 (73%) had found the counselling very helpful or quite helpful, 3 were not sure, whilst 7 (19%) found it not very helpful or very unhelpful.

However, in both these cases the numbers of respondents involved are so small that it would not be appropriate to come to definite conclusions about the respondents' views on the helpfulness of counselling from different sources.

Counselling

"I think counselling should be made more freely available and, most importantly, before you reach crisis point. The attitude of many GP's/health visitors seems to be that, if you are aware that you have a problem and need help, then you must be alright. Why wait until a parent has a breakdown before arranging help? My husband left me, albeit only for one day. I had so much emotional stress at the time that the thought of my husband having the children every other weekend was actually very tempting. In the end, a local charity provided us with counselling and I'm sure that is the main reason we are still together as a family"

5.2 Where parents look for help

The parents who attended a workshop on relationships at the conference in the Northeast were asked to complete a questionnaire containing the above question. There were 25 responses; the most commonly cited response was 'family/friends'

(86%), followed by 'Relate' (40%) and 'GPs' (30%). Factors quoted as influencing the respondents' choice are shown in the box below.

Factors influencing where to go for help

"Being able to talk honestly in a relaxed informal atmosphere with someone who shows genuine concern, and is non-judgmental"

"(I would want) someone I know and trust"

"Confidentiality"

"Impartial advice/guidance"

"Supporting and listening, NOT telling you what to do"

"Being able to talk to them"

"Knowing the people personally"

"(Being) there anytime day/night"

"Compassion, willingness to listen (no time limit)"

"Ease of access"

The factors considered most important in a counselling service were (in rank order):

- The qualifications of the professional seen
- Location/venue
- Whether the service was free

It was clear that home visits for counselling would be much appreciated, although some parents made the point that even then it would be difficult, given the 24 hour demands of some of the children.

5.3 When a child dies

Several comments, including the one below, made it clear that the need for counselling and support does not necessarily disappear if a child dies:

"My little boy fell ill when he was 14. At that time [we had] no help or respite facilities. My lovely son passed away 4 years ago. I am still suffering from the trauma. I realise things have got a little better, but the government is still not getting to grips with the whole issue. Not only is it the children who suffer, but also their parents. I still get no help with my problem"

It seems that some service providers can be very insensitive to the needs of parents to come to terms with their child's death in their own time. One parent at the Wales workshop described how specialist equipment had been removed from the house even before the child's funeral (see Section 6.6).

To ascertain whether others shared the experiences of the parents quoted above, Contact a Family trawled recent enquiry files. It was found that, in the year 2002-2003, 64 families had telephoned or e-mailed with similar concerns. Families whose child (or children) had died were seeking support and counselling, as well as practical help with issues such as funeral costs following the bereavement. There is clearly a need to go on supporting those who are no longer parents following this kind of loss.

5.4 Summary

- Although many parents had had professional counselling, many others who had not, would have liked it.
- The majority who have had counselling found it helpful, although a small minority found it 'very unhelpful'.
- Parents would value access to free, impartial counselling services, which ideally would be delivered in their homes.
- Support and counselling may still be needed long after a child's death.

Chapter 6 Specific Issues

This chapter is based mainly on the contributions of delegates to the conference and the workshop, and also draws on an internal consultation exercise with Contact a Family's family support staff. It explores the particular issues relating to fathers, siblings, single parents, domestic violence, work and housing.

6.1 Fathers and relationships

Although fathers were in a minority amongst the respondents to the two main surveys (only 12% stated they were male), it was clear from many responses – from both men and women - that there are real issues for fathers of children with disabilities. Many mothers expressed frustration that their partner would not 'talk' about their child's disability or would not get fully involved in their care. For their part, some of the fathers found it hard to come back from a day's work only to have to 'pick up the pieces' of a stressed and tired partner. It was clear too that some fathers find it difficult or even impossible to accept their child's disability, and that their leaving is more about this than about ending their relationship with the mother. There was some suggestion that greater access to professional support would enable them to come to terms with the disability and view it in a more positive light.

One of the workshops at the Northeast conference offered fathers (and other male carers of children who have a disability) the opportunity to discuss such issues in greater depth, and to explore where fathers could get support. Ten fathers attended the workshop and all actively participated and shared ideas and feelings.

Time with partners

It was clear that the competing demands of caring for a child with disability and of work, impacted seriously upon the time available for the fathers and their partners to maintain any intimacy or to discuss issues. Fathers who go out to work can feel excluded from decision-making and contacts with health and social care professionals, and can feel too tired to share the caring at home. However, those who do not work full time risk exposing the family to greater stress from financial problems.

Issues for fathers

"There is no time for intimacy with my partner"

"I have little time to be with my partner. [Our child] takes up all our time"

"Work is a big issue, I use it for a break but it causes stress. I come home tired and then I have to face caring for ...[our child] and I have a stressed partner to deal with"

"I throw myself into work to deal with issues"

"My wife is there [at meetings and appointments] and makes all the decisions, then,

because of work, I am accused of not being there to help make the decisions”

“Some fathers split it [work] with their wives. They share the children’s care but end up with a financial struggle as a result”

“The child wants his mother for everything, this causes stress as it limits the help I can give her”

“I am walking on eggshells all of the time. I never know what to say that will be right, I can’t win”

“Having different ideas about how to manage [our child] can lead to fights”

Relationships with family and friends

Thirdly, the fathers raised the issue of relationships within the extended family or community. There was a significant discussion within the workshop surrounding disagreements they were having with their own parents or parents-in-law, who did not seem to understand that patterns of sleep, feeding and behaviour management had to be followed.

Relationships with family and friends

“Extended family breakdown can happen because they can’t understand the issues and problems”

“Mothers-in-law can cause problems because they can’t follow the patterns we have set for our son”

“It’s not worth letting her spend a night at her grandmother’s, because she changes the sleep pattern and it takes us up to five days to get her back the way she needs to be”

“Neighbours can be a problem, they can’t understand”

Sources of support

The fathers, as a group, required some encouragement to think of potential sources of support. While some felt that only their partner could understand, others had sought support from male friends or relatives: *“You find out who your friends are”*. On the other hand many had no other source of support, and were frustrated by attempts at sympathy:

“People keep saying ‘we know how you feel’, it makes me angry. No they do not!”

“No one knows what it’s like, no one who hasn’t been through it can know how we feel”

Some had received considerable support from their GP, while others had not.

Fathers’ support groups

The fathers all agreed that they found it useful to “meet others in the same boat and to talk to people who really understand how we feel”. They felt it was very positive to discuss and share their feelings with other fathers.

Fathers’ support groups

“It has been really useful talking to other dads who are in the same position as myself regarding disabled children”

“I enjoyed the fathers’ session. It should be more available to us. I know I am going to leave and feel more relieved in myself”

“Dads’ groups are very important to us fathers”

The participants had a number of suggestions as to how they could be better supported. These included:

- More compassion from professionals, and more training
- Sensitivity and counselling at the time of diagnosis
- Shorter waiting lists for professional counselling
- More activities for the children out of school and during the holidays
- Support for siblings: *“they can’t be normal kids because of the pressure in looking after...(the disabled child)”*
- Services that give parents time to just be together
- Trained and skilled childcare facilities that can be accessed day or night
- More flexibility from employers

6.2 The needs of siblings

Although the main focus of this survey was on the relationship between the parents, a number did comment on the impact on siblings of having a brother or sister with a disability. Many parents were acutely aware that having a child with a disability significantly affected their relationship with other siblings.

The impact on the whole family

“The other children don’t get the attention, so they behave [badly] to get more attention”

“There is little time for other members of the family”

“Relationships between partners/parents and well as between parents and other siblings can be much more difficult in a family with a disabled child. I think of us as a disabled family, because of the wider implications which my son’s disability has on every aspect of our family life”

Siblings were also able to express their views at one of the workshops at the Northeast conference. It was clear that some felt excluded and marginalised.

Siblings’ views

“My sister gets support in the hospice and gets to go on holiday. Me, I’m stuck at home. It would be nice if stuff happened with me”

“I feel left out”

“There is nothing for brothers and sisters of children with a disability”

“I can talk with my mates but other people may need someone else to talk to”

“I get nothing, he gets taken out, boring for me”

“You should get all the brothers and sisters together and treat them”

“You have to sit back all the time”

“You have to make allowances for your sister, it’s not fair”

6.3 Single parents

Single parents taking part in another workshop at the Northeast conference identified a number of additional stresses they faced in bringing up a child with a disability. These included:

- Negative stereotyping from society
- Undermining by others of discipline and routine: *“People let him get away with anything - they call him cute”*
- Perceived different approach from Social Services to single parents
- The difficulty of inconsistent messages from the two parents

In contrast however, one parent remarked that parenting was easier alone (reflecting several comments in the main surveys).

There was considerable interest in lone parent groups such as Gingerbread. These were perceived as being helpful not only for the parent but for the child or children too.

6.4 Domestic violence

As already stated, one in ten of the respondents to the two main surveys had experienced domestic violence since having their disabled child. The data does not tell us however, the identity of victim or abuser, or whether the violence involved the birth parents, a reconstituted family, or even other family members. It would be interesting to explore in further research the relationship between domestic violence and having a child with a disability.

Contact a Family has recently been invited to respond to the Government's proposals on domestic violence³. They asked their local project workers, and others working with disabled children, to summarise the issues and to give examples of families with whom they had worked who had faced this situation. Examples of mothers in abusive relationships of whom these workers were aware are given below (details have been altered to preserve confidentiality).

Examples of mothers of children with disabilities, facing domestic abuse

- A mother with six children, five of whom are mildly to severely disabled. She stayed with her partner, as she was not confident that a refuge could cope with her children.
- A mother who finally left home and is currently in B&B with a toddler with learning difficulties. One of her concerns was about losing services for her child. Her daughter went to a special needs nursery near her original home but the B&B they were moved to was outside the borough. The mother found it difficult to keep her child occupied in the B&B and to be away from all her support networks, so she started commuting to the nursery by bus, which takes hours. However, she has now been offered next stage temporary accommodation at the other side of the borough, so she may still have to endure a long journey with a child with behaviour difficulties. She feels she was in B&B longer than others without disabled children because the type of property she could be offered was limited. She was also worried about letting all the services know where she was in case appointments come through (a disabled child has many health and social care assessments and appointments to keep).
- A mother who came from abroad to be married to a man who subsequently turned out to have mental health problems. She has two disabled children. She receives specialist support services in her area (a Sure Start area) and is frightened to leave these behind if she goes to a refuge. Also she receives support from a male support worker who would no longer be able to visit her.

³ The Home Office (June 2003) *Safety and Justice* on <http://www.homeoffice.gov.uk/docs2/domesticviolence.pdf>. Consultation until 12 September 2003

The staff highlighted a number of issues which are very specific to mothers of children with disabilities. Many of these relate to the kind of accommodation and support which can be offered from refuges:

- Refuges cannot accommodate older male children – but where else can they go if they have learning disabilities?
- Care workers cannot keep coming to the refuge for security reasons (the location of the refuge is confidential)
- Male carers would not be allowed in the refuge
- Refuges are not always accessible for disabled people
- Families are often put in a shared room, which is very difficult for months at a time if the child has a disability such as autism
- Refuges lack special equipment. As one mother put it: *“How can a woman run away in the middle of the night if her child is halfway through kidney dialysis at home, or on oxygen, or needs a ceiling hoist to be lifted?”*

Contact a Family believes that there is unmet need in relation to support services and accommodation options for families with disabled children. Information supplied to women must include options which would allow women to stay in their current home, especially where this is adapted for use by a disabled person. Refuges must work on accessibility issues so that women with disabled children would not be excluded from using a refuge if other options were unsafe. The ‘refuges on line’ programme must be able to give details of accessibility of refuge accommodation.

Contact a Family would be happy to work with organisations which are domestic violence specific, such as Refuge and Women’s Aid, to increase awareness of the issues facing women with disabled children and to improve provision for them.

6.5 Working and caring

A number of parents at the Wales workshop echoed points made by the respondents to the main surveys in relation to juggling work and caring. For many parents it is clear that work offers an important ‘safety-valve’ and the opportunity to leave the worries of home life behind for a few hours to spend time in the ‘normal’ world. It is also felt that it is healthier for the couple and the wider family not to focus entirely on the needs of the disabled child. Work is also of course essential for many to maximise their income and minimise their financial worries.

Many however felt that it was not worth their while working for over fifteen hours a week, because they are then ‘penalised’ by the benefits system. Lack of appropriate childcare can also prevent parents from working when they wish to. Others had found it had helped if, as a couple, they could decide on one working and the other being a full-time carer for their child. For one couple, having the ‘excuse’ for neither to work full-time had allowed them more time together than they would otherwise have had.

For those who do work, this can bring further problems. Respondents pointed out that employers are not always sympathetic about their caring responsibilities, and that long hours or stressful jobs can leave the parent too tired to support their

partner. The parent left at home felt resentful and excluded from the outside world, while the working parent felt excluded from meetings and consultations about the child which usually took place in the daytime.

Working and caring

“Making sure I kept my professional working life going [helped us most], even though it has been a real juggling act. It has kept my sense of identity rather than being ‘only’ mum to my disabled daughter and kept me fulfilled - so I think I’m more interesting to live with!”

“I go to work to escape; I go to work to keep sane”

6.6 Housing issues

A number of parents in the surveys and at the Wales workshop raised the issue of housing as having an impact on their relationships. Finding accessible housing with adequate adaptations, or affording a large enough house to cope with difficult behaviour and lots of equipment, could be very stressful. For one parent in the survey, moving to a house in a less stressful environment had been the most important factor in helping their relationship.

Families being accommodated in council or housing association property also highlighted their feelings of vulnerability. Concern was expressed that they would have to move if their child died, but they would find it very hard to have to leave all their memories behind. One parent described how the hoist had been removed even before their child’s funeral took place.

Housing issues

“Larger living accommodation [would have helped our relationship]. We’re still in our first-time buy, a two-bedroomed ground floor maisonette with no gardens or garage and on-street parking... because it’s disability-friendly and we can’t find a good alternative in our price range. As the children are bigger and come with: buggy, 2 x walking frames, adult-size tricycle, standing frame etc, we have no room to move. We spend our time moving clutter around! It’s sending us all crazy especially as one of us has a severe hearing loss combined with her PLD and therefore constantly vocalises for self-stimulation. It is our medium-term aim (we’re awaiting a house price fall!) to move to a 4-bedroomed house with garage and garden... so that we can get a live-in au pair who can meet the buses, so that one of us does not have to be home by 3.30pm every school day”

“I was lucky to be made redundant, otherwise we could never have afforded our house”

6.7 Summary

- **Fathers** often feel themselves torn between the pressure to support the family financially and the pressure to support their partner in caring for the child. Some find it impossible to accept their child's disability, or the behaviour associated with it, and it is this, rather than their relationship with their partner, which may be the reason they leave. Fathers regret the reduced intimacy with their partners and the lack of time for them as a couple. They would like to be able to access 'dads' support groups in order to meet others in a similar situation
- **Siblings** often feel excluded and marginalised, and can resent the attention focused on the disabled child. They would appreciate support for themselves, including the occasional outing or treat
- **Single parents** also feel marginalised, and sometimes subject to negative stereotyping. They can also benefit from support groups
- **Parents suffering domestic abuse** are often unable to take advantage of refuges because the needs of their children cannot be met
- **Parents who work** can feel penalised by the benefits system, can suffer from unsympathetic employers, and can feel excluded from decisions about their child and contact with professionals. Parents who do not work may face additional financial stress and can also feel excluded from the outside world
- **Unsuitable housing conditions** can also add to stress in relationships within the family

Chapter 7 Conclusions and Recommendations

7.1 Key findings

The findings of our consultation exercise show that:

- Many respondents have a 'very good' relationship with the child's other parent, and almost a quarter feel that having the child has brought them closer together
- However, almost one quarter of the respondents feel that having the child has caused major problems in their relationship or has even led to their separation
- Over one in six of the respondents are bringing up their disabled child alone
- Around three quarters of the respondents have experienced stress/depression and/or tiredness/lack of sleep, and over a half financial difficulties – and the vast majority linked these with having their disabled child
- Many respondents have experienced other significant problems which are likely to have put stress on their relationship
- Respondents overwhelmingly cited respite care/the chance of a break as being the key factor which either had helped, or could have helped, their relationship with their partner
- Nearly a quarter of the respondents had had professional relationship counselling, and the majority had found this helpful
- However, many (29%) of the respondents had not had counselling but would have liked some
- There were indications that the overall attitude and philosophy of parents – the way they looked at life - may also be a significant element in the strength of their relationships and their ability to overcome problems

7.2 Conclusions

This consultation exercise provides ample evidence of the stresses on relationships within families where there is a disabled child. Although it is clear that many families do manage to maintain and even strengthen their relationships against all the odds, many couples do struggle to stay together, and may only do so because the alternative is so grim. For others, splitting up is the only way they feel they can focus entirely on the needs of the child.

It is clear that, in the perceptions of parents at least, many features of society and 'the system' serve to put additional stress on relationships. This is ironic, as their very 'raison d'être' must surely be to support and strengthen family relationships. However, the negative, or at least ill informed, attitudes of family and friends, and the bureaucratic structures of statutory services, often only add to the frustration of caring for the child. Where parents do receive the support they need, it is often only after a long 'fight' which can again take its toll on relationships within the family.

7.3 Policy implications and recommendations

Many of the findings from this survey should come as no surprise to policy makers. There is a considerable body of research evidence that disabled children and their

families routinely face isolation and exclusion from all aspects of ordinary life. We know, for example, that disabled children are more likely to grow up in poverty (Beresford 1995)⁴, and that three quarters of disabled children live in poor or unsuitable housing (Oldman and Beresford 1998)⁵. There is also evidence that their childhoods are impoverished of access to leisure and play (Shelley 2002)⁶. Families from minority ethnic communities face even greater exclusion than their white counterparts (Chamba 1999)⁷.

Our report echoes many of the findings of the recently published Audit Commission report⁸. The Commission described a 'lottery' of service provision, with the services that families are offered depending largely on where they live and how hard they are prepared to push. When help is provided, it is often too little and too late, and only comes after the family has been subjected to repeated assessments and telling their story over and over again.

'No Time for Us' is published at a time when supporting children and families is a key priority for government, as evidenced by the recent publication of its Green Paper 'Every Child Matters'⁹. Our consultation exercise suggests however that, to address the specific needs of disabled children and their families, concerted action is required, over and above the proposals contained in the Green Paper. Contact a Family is calling for an overarching strategy for disabled children and their families, which would span all relevant government departments. The strategy should contain specific, measurable targets and its delivery should be backed by adequate resources.

There are also a number of practical steps which could be taken now by central and local government, other service providers and the voluntary sector. In the light of our survey of over 2000 parents, we propose the following specific actions:

Providing better services

- Given the emphasis that parents place on respite care, it is vital that the Carers Special Grant should continue to be ringfenced after 2004/5
- Key-working services should be commissioned to support those families with high levels of need
- Additional investment in children's community nursing and therapy services is required
- Health and other appointments for children should be co-ordinated, so that parents can see health, social care and education professionals in the same location and on the same day

⁴ Beresford, B. (1995) *Expert Opinions; a national survey of parents caring for a disabled child*. Joseph Rowntree Foundation

⁵ Oldman, C and Beresford, B (1998). *Homes unfit for children: Housing, Disabled Children and Their Families* The Policy Press, Bristol.

⁶ Shelley, P.(2002) *Play and leisure for disabled children and young people*. Contact a Family

⁷ Chamba, R et al *On the edge: minority ethnic families caring for a severely disabled child* The Policy Press: Joseph Rowntree Foundation

⁸ Audit Commission (Sep 2003) *Services for Disabled Children*

⁹ Department for Skills and Education (Sep 2003) *Green Paper Every Child Matters*

- Working parents should be offered evening appointments so that both can attend any meetings or assessments at their own convenience
- Support services for parents should recognise their skills and expertise, rather than using a 'parent deficit model', which assumes that they are failing

Supporting parents in work

- The government should invest in suitable, affordable and flexible childcare for disabled children
- Tax credits should include additional, higher provision for childcare for disabled children
- Flexible employment provisions should commence immediately on starting employment
- There should be a right to work flexibly, rather than a right to ask
- Housing Benefit should be available for mortgage payments as well as rent, so that parents are never made worse off by working

Tackling family poverty

- Benefit levels, and in particular Disability Living Allowance, need to be raised in order to minimise financial stress
- The process for claiming benefits needs to be simplified
- The government should promote take up of benefits such as Disability Living Allowance and Carers Allowance as widely as it has promoted Tax Credits
- Additional payments towards winter fuel costs should be introduced for families with disabled children
- Families should be given financial help to cover the cost of visiting children in hospital, particularly now that many are treated a long way from home.

Addressing housing problems

- The means test for Disabled Facilities Grants requires urgent reform
- Children's Trusts should employ housing officers, so that a truly holistic service can be provided which also takes account of housing needs

Addressing the emotional needs of parents and wider family

- The DfES guidance document 'Together from the Start'¹⁰ should be adopted as the template by which diagnosis and early support is given
- Counselling should be available for both parents at the time of diagnosis, and easier access made available to counselling thereafter. Counselling should also be offered after a child's death
- Information should be available for wider family (e.g. grandparents) to enable them to better understand the child and family's needs

¹⁰ (2002) *Together from the start: practical guidance for professionals working with disabled children (birth to 2) and their families* London: Department for Education and Skills

- There should be easily available information alerting parents to the emotional effects of having a disabled child on their relationship, and signposting them to the support that is available
- Support groups (including specific groups for fathers and siblings) should be encouraged, supported financially and promoted. Families should be involved in developing models which best meet their needs
- Training of professionals should incorporate the experiences of disabled children and adults, as well as the needs and experiences of their parents
- Domestic violence organisations, marriage support charities and general counselling services should ensure that their services are accessible to parents of children with disabilities and sensitive to their needs. Home visits and telephone services should be available to those who cannot get out to attend 'traditional' face to face services
- The Parenting Fund, announced as part of the Treasury's 2002 Spending Review, should prioritise the needs of families with disabled children

Addressing the needs of those affected by substance misuse and domestic violence

- Contact a Family has a responsibility to widely disseminate these findings, so that service providers in these areas are made aware of the needs of families with disabled children, and are encouraged to seek funding to provide appropriate services

Appendix A

Relationships Survey

Do you think that having a disabled child has had an effect on your relationship with your partner? Has it brought you closer together, or have the stresses and strains driven you apart? The government has asked us to find out your views. If you have a disabled child under 18, can you spare a few moments to tell us what you think? *(If you have more than one disabled child, please relate your answers to your youngest disabled child)*

1) **What sex are you? (tick one)**

Male Female

2) **What is your disabled child's current family situation? (tick one)**

- Child is being brought up by both birth parents (married)
Child is being brought up by both birth parents (not married)
Child is being brought up by a single birth parent
Child is being brought up by one birth parent and that parent's current partner (e.g. stepfamily)
Other (e.g. child lives away from both birth parents)

3) **How old is your child? (tick one)**

Under 5 5 - 10 yrs 11 -17 yrs

4) **How would you describe your overall relationship with your child's other parent? (tick one)**

Very good Quite good Variable
Not very good Very poor
Little or no contact with the other parent

5) **How do you think having a disabled child has affected your relationship with the child's other parent? (tick one)**

- It has brought us closer together
It has had little effect on our relationship
It has caused some problems in our relationship
It has caused major problems in our relationship
It has led to separation

6) **Which, if any, of the experiences below has either parent had since your disabled child was born? (tick as many as apply)**

- | | | | |
|--------------------------|--------------------------|-------------------------|--------------------------|
| Financial difficulties | <input type="checkbox"/> | Housing problems | <input type="checkbox"/> |
| Problems at work | <input type="checkbox"/> | Tiredness/lack of sleep | <input type="checkbox"/> |
| Stress or depression | <input type="checkbox"/> | Domestic violence | <input type="checkbox"/> |
| Drug or alcohol problems | <input type="checkbox"/> | None of the above | <input type="checkbox"/> |

7) **Which, if any, of these experiences do you think are linked to having your disabled child? (please only select from those you have ticked above)**

- | | | | |
|--------------------------|--------------------------|-------------------------|--------------------------|
| Financial difficulties | <input type="checkbox"/> | Housing problems | <input type="checkbox"/> |
| Problems at work | <input type="checkbox"/> | Tiredness/lack of sleep | <input type="checkbox"/> |
| Stress or depression | <input type="checkbox"/> | Domestic violence | <input type="checkbox"/> |
| Drug or alcohol problems | <input type="checkbox"/> | None of the above | <input type="checkbox"/> |

8) **How would you describe yourself? (tick one)**

White Asian Black African

Black Caribbean Other

9) **Have you had any professional relationship counselling since having your disabled child?** *(tick one)*

- Yes, through Relate
Yes, through another organisation/counsellor
No (but I would have liked some) *(please go to question 11)*
No (but I haven't wanted or needed any) *(please go to question 11)*

10) **How helpful did you find relationship counselling?** *(tick one)*

- Very helpful Quite helpful Not sure
Not very helpful Very unhelpful

11) **What, if anything, HAS HELPED your relationship with your partner since having your disabled child?** *(Please rank your answers, i.e. put what you think as most important as number 1, the next most important as number 2 etc. If you need more space, you can attach another sheet)*

1)
2)
3)

12) **What else, if anything, COULD HAVE HELPED your relationship with your partner since having your disabled child?** *(Please rank your answers i.e. put what you think as most important as Number 1, the next as number 2 etc. If you need more space, you can attach another sheet)*

1)
2)
3)

Thank you for taking the time to fill in this survey. Please send it back to **Contact a Family, Freepost LON8801, London EC1B 1EE** by 31st July 2003

The results of this research will be available in January 2004 on our website www.cafamily.org.uk or from our freephone helpline 0808 808 3555. Our helpline can also put you in touch with services providing support and counselling in your area.