



**THE VIEWS OF PARENT CARERS ON SUPPORT AND SERVICES
IN SURREY**

**Produced by
Geraldine Bolam
Independent Consultant
For Surrey County Council**

**On behalf of Action for Carers (Surrey)
February 2011**

In partnership
...



"...Enabling carers to have a voice and realise a life outside caring..."

**Action for Carers (Surrey) is a company limited by guarantee with charitable status
Charity Reg: 1116714 Company No: 5939327 Registered in England and Wales
Registered Address: Astolat, Coniers Way, Burpham, Guildford, Surrey, GU4**

**1
Affiliated to
CARERS**

Contents

	Page No
Introduction	3
Structure of the report	4
Some of the key themes for parent carers in Surrey (focus group reports)	5
An overview perspective of the themes emerging from the focus groups	8
A brief focus on research findings	12
Key themes for parent carers in Surrey (1-1 interviews)	16
Professionals feedback – parent carers and their outcomes	27
Conclusion	28
Recommendations	32

THE VIEWS OF PARENT CARERS ON SUPPORT AND SERVICES IN SURREY

Introduction.

This report has been produced for Action for Carers (Surrey) to provide specific evidence from the views gleaned by parent carers about how well the Council is currently supporting them. The focus of the engagement with parent carers has been to consider parent carers experience of the carers' assessment process and to consider what outcomes have been achieved for them. The report will also examine the support given to young carers where this has been highlighted by parent carers and revisit some of the salient messages in an earlier report on young carers produced for Surrey County Council and on behalf of Action for Carers (Surrey). The report author has used a mix of telephone interviews, and focus groups with parent carers in November and December 2010 to inform this report and an online questionnaire is being developed to provide further information. Contact has been achieved with 7 carers via the format of telephone interviews and a further 17 carers via focus groups making a total of 24 carers canvassed. This report and its recommendations should therefore be read with some caution. It is a small scale qualitative study of parent carers and cannot be said to be largely representative of parent carers as a whole in Surrey. It does however provide us with some interesting insights about those parent carers interviewed in Surrey and there are some key messages to give further consideration to.

This report will also look at additional research available from a more in depth literature review on parent carers. It is very worthwhile to think about emerging research for this cohort (journals, reports, papers) and to reflect further on new developments such as the Short Term Breaks Regulations 2010 and consequent impacts for this group. Taken together, the small scale snap shot review of parent carers' views about how well carers' assessments have supported them (and the outcomes achieved) as well as other findings, should provide a more complete picture about their needs and concerns. Given this context then, that there are limitations to this research, that it is small scale, related specifically to parent carers in Surrey, we have an appreciation of the context within which key messages can emerge.

The report author is grateful to a range of key organisations in Surrey that support parent carers. I refer in particular to Crossroads, White Lodge and Partnership with Parents for their practical assistance and advice with regard to this research. I am also grateful to the Carers Support Workers in Surrey that have assisted with the work particularly in providing access to carers for the purposes of telephone interviews or for inviting me to attend existing parent carer focus groups. I am also indebted to a range of professionals that have provided guidance and advice both within Action for Carers (Surrey) and most notably within Surrey Young Carers, Action for Carers and Employment (ACE) and the Action for Carers Moving and Handling Back Care Advisers. My thanks also extend to Surrey County Council for their IT expertise with regard to publicity and information/advice. All the parent carers deserve special recognition and thanks for their assistance with this research. They attended focus groups despite the difficult weather in December and challenging circumstances arising from their caring role. Their insight and recall of recent experience of assessment and support/outcomes achieved has been remarkable and without their input this research would not have been possible.

Structure of the Report

This report will commence with the feedback from the focus groups held in late November and December 2010. An overview perspective of the themes emerging from these groups will also follow. A focus on wider research with regard to parent carers is also included for a more detailed picture of the needs of this group. Some of the key issues that parent carers have to contend with are given a fuller examination in the individual interview format. This provides yet further clarity about how well Children's Services in Surrey are currently supporting the parent carers in this consultation. The report author has also included the input of a range of professionals that are currently in touch with parent carers in Surrey.

The report provides a final analysis of the key themes in the report's Conclusion. There are also a series of Recommendations for further consideration.

Some of the key themes for parent carers in Surrey

The Focus Groups:

Elmbridge – Recorded in November 2010

- The primary needs of the parent carers at the focus group was for short term breaks provision
- Parent carers stressed that for those currently in receipt of respite care, the allocation was not currently sufficient to meet their existing needs. Additional short term breaks are required at weekends.
- For those parent carers supporting their children through Transition, perceptions were that parent carers will not be offered the same level of support from Adult Services as compared with previous allocations from Children's Services
- Support received from Third Sector services were highly valued e.g. Surrey Young Carers
- The value of short term breaks provision for some carers was seen in terms of being able to spend more time with other family members
- The perception was that if the disabled child does not meet Children's Services Eligibility Criteria, this becomes a bar to the parent carer receiving a carer's assessment
- An aspect of the carer's assessment process that a carer found stressful was finding her parenting style being brought into question.

"I have been quite tearful. I found the process of preparation for the carer's assessment quite exhausting. The way they approached me about the carer's assessment was very negative, they talked about "assessing parenting styles". I found it very intrusive, not at all positive. They were not clear about the purpose of the assessment or the benefits or the possible outcomes."

- That overall the carers perceived that they are constantly fighting for things, that getting feedback is very difficult and slow.
- That there are often delays from the Transition Team. *"They write to you to tell you that they haven't forgotten about you. It seems that you are left with big gaps in your support."*

Merrow Focus Group - Recorded in December 2010

- Carers agreed that school holiday times were particularly difficult and it is then that short term breaks are particularly needed.
- Carers were upset by the notion of "parental competencies" being introduced into any assessment or dialogue with a social worker (noted too in the Elmbridge focus group).

- Of the three carers present, two are struggling to get an assessment and one had an assessment which resulted in no specific outcomes for her. The carer stated that a respite package had been in place prior to her carer's assessment and she'd hoped to increase the respite available to the family. This was not made possible.
- One carer seeking an assessment stated that she was screened out at the Contact Centre stage. When ringing the Children with Disabilities Team (West), the carer was told: *"You must not ask for much because you won't get anything, ask for something small and we might be able to get you something."*
- One carer spoke about the paucity of short term breaks provision (her son has severe learning disabilities and autism). The carer cited access problems, and funding cuts causing difficulties. In pursuing alternatives, the carer stated: *"It was a waste of time for someone who has no time"*. The carer has now pursued breaks options funding these herself.
- Another carer spoke about an array of medical problems that she has had to confront in caring for her child. She spoke about a litany of health conditions and a diary packed with medical appointments. This carer's experience of trying to get a carer's assessment is one of long delays and phone calls not responded to within acceptable time frames. In the meantime the carer has severe health problems of her own.
- The carer in receipt of her own carer's assessment did not feel that her social worker was particularly helpful or understanding of her family's circumstances. *"As well as looking after my daughter, I am also a mother to her sisters and that useless donkey of a social worker has suggested that what would be helpful would be some courses for my daughters to learn how to become care workers."*
- Another carer expressed dissatisfaction with delays in getting suction equipment for her son. The carer described having to go through an appeal process and having to experience unacceptable delays in decision making.
- All the carers expressed a lack of knowledge about their rights and entitlements. One carer explained that she had only found out about carers' assessments after caring for several years. All the carers found a great deal of support from each other and expressed the view that often the most useful information and support comes from other carers.

Spelthorne Focus Groups – Recorded in December 2010

- Carers discussed the experience of trying to get a carer's assessment as a "battle". *"My child didn't meet the criteria for help and that was that"*.
- One carer described the carers assessment as follows:

"I wanted help to access to a normal life, I was under a lot of stress at the time and my marriage was deteriorating and eventually we split up. I was not in good health either I had a very bad back too. I had a good job previously, I worked in finance but caring put paid to that and I had to go part time. Caring for two children with autism

isn't easy and they don't sleep well. My carer's assessment didn't help, I felt belittled by it all. My social worker wasn't very professional and I don't think that they are trained in disability issues, they just don't have a clue. In the end I found out the information I needed by myself and I went to the GP and got a gym membership. I am coping on my own, the children are ok."

- For another carer, her chief concern is for breaks cover and help in an emergency. Her carer's assessment however has not been updated:

"I do not feel that my carer's assessment had any purpose, any money for additional help was not achieved through the carer's assessment but through my son's plan."

- The consensus from the group was that carers spend many years fighting for support – they feel that no one is listening, that no one is doing anything. *"There are lots of pressures on families and there is not much care for the carers!"*
- There was a feeling from the group that it is up to carers ultimately, to sort problems out. There was a feeling that there are many restrictions on carers and that it affects carers' ability to get a job or hold down a job.
- One carer in the group, caring for her grandson was able to relay the experience of having had regular carer's assessments but that there is a rapid turnover of social workers. *"They get to know you and then they leave."*

"The last social worker was very good. She was supportive to the whole family. She funded the family to have a break, a holiday break. The holiday was for me, my husband and grandson, we all went together. My grandson also gets 12 days respite at a respite facility."

- None of the five carers at the ADHD group for parent carers had a carer's assessment. Images of embattlement were to the fore when parent carers talked about trying to get support. The parent carers thought that social care did not readily recognise their children's disability and hence that made it difficult for their children to meet eligibility criteria.

An overview perspective of the themes emerging from the focus groups

The primary focus of this engagement exercise with the parent carers in this study is to consider above all what outcomes have been achieved for them following their carer's assessment. From the focus group discussions at least we can determine that the most desired outcome for the parent carers is for short term breaks and where breaks have been allocated, for an increase in such provision. What the parent carers have told us is that access to such support is problematic and where such an allocation exists, it is not currently meeting their needs. Additional short term breaks are required at those times where the carer and/or their family is under particular increased pressures such as at weekends or during the school holidays. Many carers fed back that it was their perception that where their child did not meet Children's Services Eligibility Criteria, this has become a bar to the parent carer receiving an assessment in their own right. From a study where the chief line of enquiry has been to consider what outcomes have been achieved following carers assessments, a major issue has emerged which has acted as a barrier for some parent carers in achieving an assessment in their own right. This issue therefore needs to be fully explored.

People with parental responsibility for a disabled child (i.e. a person under 18) are (if their caring role is substantial) entitled to an assessment under Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000. As Luke Clements ¹ makes clear:

"It is self evident that most parent carers provide a regular and substantial amount of care on a regular basis" Neither the 1995 nor the 2000 Acts includes a stipulation (found in social security law) that the care provided to the disabled child must (for instance) be "substantially in excess of the normal requirements of persons of his age"

As well as parent carers having a right to a separate assessment under the 1995 and 2000 Carers Acts, in addition to their needs being fully addressed in the child's Children Act assessment. In general Luke Clements advises that this should not be necessary, provided the local authority fully addresses (in the Children Act assessment) the parent's employment, training, education, leisure and other needs. As a result of the passage of the Carers (Equal Opportunities) Act 2004, the assessment should take account the parent's ability to provide or continue to provide care for the child and consideration of whether they work, or undertake any education, training or leisure activity or wish to do so. Local authorities therefore have a duty to ask carers about these activities and take their wishes into account when planning the care package.

Luke Clements advises that if the local authority is failing to implement its duties to parent carers in this regard, then parent carers may have to insist on having a separate assessment under the 1995 and 2000 Acts.

"It will be maladministration for a local authority not to undertake such a separate assessment or to suggest that it is merely a "good will gesture" when it is in fact a statutory responsibility. The right to such a separate assessment was put beyond doubt in R (LH AND MH) V Lambeth LBC (2006).

¹ Luke Clements Carers and their Rights 4th Edition 2010

The Ombudsman has also come to a similar finding in a 2009 complaint. In this case, a family's son with autism put an enormous strain on his parents and younger sister. The local authority merely focused exclusively on the needs of the son without properly addressing the devastating impact his behaviour was having on his parents and sister. The Ombudsman held that it was maladministration not have undertaken separate carers' assessments in this case.

Rather usefully, Clements in his chapter on Parent Carers (Carers and their Rights) also refers to cited guidance to the 2000 Act namely that if a carer's assessment identifies a risk to his or her employment, this is to be recorded as a "critical risk" and one that requires positive intervention by social services to address this risk. The importance of adequate childcare for parent carers is also discussed in this section and there is an acknowledgement of the importance of adequate and timely short term breaks which has been specifically acknowledged by the English Government. The discussion of parent carers' entitlement to a carer's assessment was prompted at the beginning of this section of the report by parent carers' desire for short term breaks and the need in some instances for increases in such provision.

The lack of clarity by parent carers about their rights to a carers' assessment was clear in the focus groups and their stated belief that eligibility to children's services was a bar to that entitlement. The report author's assumption is that an assessment of need for short term breaks is made on the basis of the level of disability as well as family circumstances to determine how well a family is able to cope with caring responsibilities.

Having sight of recent correspondence on the Eligibility Criteria for Disabled Children, the report author understands that the Eligibility Criteria for children's services has recently been refreshed and reissued but that these criteria does not cover services for children with disabilities. The criteria for access to services by disabled children and their families is currently under review and the A,B,C Priority Criteria that was previously in use across Surrey is still in place for this group. The document is not widely available as the Council will be issuing the new criteria soon and does not wish to cause confusion. The report author is informed that the new criteria will take into account carers' legislation and the right of parent carers to request a carer's assessment. There is still a great deal of uncertainty about entitlement but it is envisaged by the Council that the new criteria will be clear and understandable for parent and carers as well as staff.

That there needs to be greater clarity about the criteria for access to services by disabled children and their families is at once obvious and particularly the need for this criteria to make absolutely clear to parent carers how it will take into account carers' legislation and the right of parent carers to request a carer's assessment. The recent introduction of Carers Breaks Regulations 2010 surely reinforces parent carers' rights to an assessment as the duties imposed on LAs by the draft regulations also includes this requirement to:

- Provide short breaks to those who care for disabled children when it would improve their ability to care for their disabled child, or when they could not continue to provide care without a short break
- Provide a range of breaks including day time and overnight breaks in the home of disabled child or educational/recreational activities outside their homes, and breaks in evenings, weekends and holidays

- Publish information to parents about the services available in their area and for accessing it.

The Explanatory Memorandum to the Breaks for Carers of Disabled Children Regulations 2010² comments as follows:

“The provision of short term breaks that are regular, reliable and appropriate is a key service priority for parents of disabled children. The lack of such services was the biggest single cause of unhappiness with service provision and the single greatest unmet need in parental submissions to the 2006 Parliamentary Hearings on services to Disabled Children undertaken as part of the HM Treasury/Department for Education and Skills review. A break from caring is one of parents most frequently reported needs (Beresford, 1995, Contact a Family 2003) and families also require support that enables them to do activities together as a whole family..... There is a considerable body of research showing that parents with disabled children have higher levels of stress and lower levels of well being than parents of disabled children.”

These are issues reflected in the focus groups with parent carers in December 2010 and the report author began this section by commenting that access to short term breaks or indeed an increase in such provision was the single biggest outcome that parent carers wished from their carer’s assessment. The lack of clarity about entitlement to services and the lack of understanding about entitlement to carers’ assessments is a huge issue for parent carers in Surrey. The Explanatory Memorandum referred to above comments as follows:

“The eligibility for short breaks means that only a subset of the disabled children population is able to receive them. ... Since assessments are made on a case by case basis and different LA’s interpret the criteria differently, it is not possible to estimate how many children are eligible for breaks.”

The policy objective underpinning the 2010 regulations is to ensure that local authorities recognise the provision of short term breaks services as an essential service to be offered to carers of disabled children. Regulation 5 in particular requires local authorities to publish information for carers to access, about the range of services in their locality and the local authority’s eligibility criteria for accessing them. This has to be welcomed along with greater clarity about how new criteria for children’s services in Surrey will take into account carers’ legislation and the right of parent carers to request a carer’s assessment.

Other themes in the focus groups that have significance for parent carers is the perception that they and their families will not be offered the same level of support from Adult Services as compared with previous allocations from Children’s Services. This is a point made in the “Transition Guide for all Services³.”

The report comments:

² Explanatory Memorandum to the Breaks for Carers of Disabled Children Regulations 2010 – prepared by the Department for Education

³ Transition Guide for all Services (Key information for all professionals about transition for disabled young people) Department of Children, School and Families and DOH)

In adult social care a community care assessment is used to determine which services should be provided. It is therefore common to find disabled young people losing ongoing support once they reach 16 or 18 (this differs across the country). Those who do make the transfer to one of the adult teams are often not offered the same levels or types of support they have received in the past. For example, access to a short term break service may not be available from adult social care. Children's and Adults services need to work closely together to offer the best support to disabled young people moving into adulthood. They need to ensure this support is ongoing, doesn't end abruptly, and meets the need of the disabled young person".

Other carers have commented on the delays by the Transition Team in getting back to them at key stages during this process. The carer felt that despite protestations to the contrary that she had been forgotten about. Clearly it is essential for Adults and Children's services to work together with partner agencies to ensure that carers and disabled young people get the support and information that they need as young people transfer across services. For many disabled young people and those with special educational needs (SEN) having access to timely and comprehensive information, advice and guidance can be enough to help them reach their goals. For others clearly, more support is needed from a range of services. Research in terms of the national picture suggests support available locally for disabled young people and their families varies widely. A key problem has remained and that is the lack of continuity in provision across transition stemming from the different entitlement to criteria and definitions between Adults and Children's services.

Parent carers in the focus groups have commented on the irritation at having to repeat information to a range of professionals: *"I have to constantly repeat information to a range of professionals. Silly questions are often posed to my disabled son by professionals who don't know him well."*

For other carers, the key issues remain constantly having to battle for support, that no one is listening to them and that ultimately "there is not much care for the carers" In general, carers feel that they are left to sort out problems for themselves. A key theme for parent carers is also the distress felt by believing that their parenting skills are under scrutiny. This is also a point borne out by young carers in an earlier consultation as they spoke on behalf of their parents. Feeling tested and sometimes made to feel that their competency was in question, carers found this experience to be negative. This is contrary to the Practice Guidance to the Carers and Disabled Children Act 2000 which states that *"the assessment is not a test for the carer. It should not be prescriptive but recognise the carers' knowledge and expertise"*. On the whole parent carers were doubtful that their carer's assessment had achieved meaningful outcomes, for some the experience of the assessment had lacked purpose and value.

A brief focus on recent research findings. – what does this tell us in general about the needs of parent carers?

- The latest analysis of the 2001 census that 7% of all children are disabled. This means that there are 770,000 disabled children in the UK. That equates to one child in 20
- It is estimate that around 14% of the 6 million carers in the UK look after a disabled child
- There is however an absence of reliable current national data on prevalence, trends and the socio-demographic characteristics of disabled children and their households
- Over 90% of disabled children live at home and are supported by their families
- 55% of families with a disabled child live in or on the margins of poverty
- Disabled children are 13 times more likely to be excluded from school
- Three quarters of families with a disabled child live in an unsuitable home
- Only 16% of mothers with disabled children are in paid employment (compared to 61% of other)
- A greater proportion of households with disabled children have a lone parent

Source – Contact a Family - About Families with Disabled Children – UK

- Parents with disabled children tend to use less child care. Is this choice, or because of a lack of appropriate and affordable places?
- There is a strong socio- economic dimension to caring. People from lower socio-economic groups are more likely to need care and to provide it, at any age. Better off people are more likely to use formal child care, and people on low incomes, non working parents and single parents are less likely to use formal child care
- A range of small scale studies point towards some specific challenges experienced by parents with disabled children. In 2007 the Day Care Trust conducted a small scale study in England that found that child care for disabled children varies considerably depending on the child's disability and that there were very little or no use of formal child care. Some parents were critical that child care providers were not appropriate for some disabled children such as those with autism and that staff were not appropriately trained to deal with disabled children. It also found that finding appropriate care can become increasingly difficult as children get older
- A second small scale study looking specifically at the experiences of ethnic minority families caring for a disabled child in the UK found that the main barriers to child care use for disabled children were: the lack of places appropriate for disabled children, the lack of trained workers competent to care for disabled children and the cost

- The same research found that parents with English as their second language face even more barriers accessing appropriate services, as they may be less able to understand the system. Compared with the white population, families from ethnic minority groups were found to be less well informed about childhood conditions and disabilities and services available for parents and children
- The evidence suggests that parents of non disabled children are at present more satisfied with the way in which paid work and caring for children are balanced, and encounter more understanding from employers, than people looking after adults and disabled children. More people who provide unpaid care would like to do unpaid work too, but do not always feel that the necessary support is available
- A survey of families with children with profound and multiple disabilities found that 60% of parents spend more than 10 hours per day on a basic physical care level, a third of those were providing 24 hour care
- Caring for a disabled child impacts on a parent's ability to undertake paid work. Analysis of the 2001 Census found that 38% of families with a sick or disabled child contain two working adults, compared with 55% of families generally. As Contact A Family have also noted, only 16% of mothers of disabled children were in paid employment compared with 61% of all mothers.

Source – Equalities and Human Rights Commission – Chapter 13 on Care and Support.

- Parents of disabled children want practical flexible help and a break from the physical and emotional demands of caring for their child. They often wish that their relationship with their disabled child could be more “ordinary” and they did not have to perform caring for nursing roles
- Traditionally, services providing short breaks have focused on residential care solely for the disabled child. New types of short break are better at meeting the needs of the whole family. They are flexible and offer many different kinds of support.

Source – Having a Break: good practice in short breaks for families with children who have complex health needs and disabilities – Children and Families' Services SCIE⁴ Guides 25

- The Every Child Matters website reports that only 4% of children get any kind of help from social services, although the latest figures indicate that this has increased to 6%. Therefore only 90% of families with disabled children get no regular support or help at all
- There are limited short break options for children especially those with challenging behaviour. Services may not be flexible enough to fit in with parents lives, work patterns or may not meet their cultural needs – **Source – Contact a Family information sheet 2010.**

⁴ SCIE – Social Care Institute for Excellence.

- The low income of families with a disabled child is compounded by high costs, with disabled children costing three times as much to bring up compared with all children. One in seven families with a disabled child are living in debt and are four times more likely than other families to have debts in excess of £10,000
- Families of disabled children report a lack of childcare in their area. While there are extended school services that could cater for disabled children, they do not have transport that would make them a viable form of childcare for working parents
- A survey of 350 families with a disabled child found that 90% of families reported that the costs of child care were a major deterrent to work. In this survey 60% of families had been asked to pay a premium to cover additional support in childcare services
- The costs of childcare for a disabled child are often substantially higher due to the needs for higher staff ratios or more specialised care

Source – Every (disabled) Child Matters Campaign Briefing – between a rock and a hard place

- Overall families from minority ethnic groups caring for a severely disabled child were more disadvantaged than white families in similar situations. Families' experiences, needs and circumstances varied across ethnic groups
- Parents wanted more information about their child's disability and in particular, services for their child and themselves. However, poor interpreting support and limited availability of translated materials could make access to appropriate information difficult, particularly for Bangladeshi families
- Indian and Black African/Caribbean families reported least support from their extended family, with levels of support lower than that found among the survey of white families. Mothers from all ethnic groups reported lower levels of support from their partners than white mothers had reported.
- Parents were asked about what needs were not being met for their children, the following key areas were identified:
 - ❖ Skills for future independence
 - ❖ Help with learning disabilities
 - ❖ Access to social/leisure activities
 - ❖ Help with communication/help with physical abilities/help with learning about new culture/religion
 - ❖ Emotional/counselling support

Source – Findings Minority ethnic families caring for a severely disabled child (Joseph Rowntree Foundation)

On Combining work and care:

- Problems with child care, having to take time off and a lack of understanding and flexibility at work, are three key problems faced by parents of sick and disabled children who combine paid work and unpaid caring
- Most parent carers find caring has an adverse impact on their own employment, this can include a negative impact on relationships with colleagues, and a feeling that opportunities to develop or progress are denied parents in their situation
- Although some succeed in reducing their hours or changing their work patterns to suit their needs, many feel forced to look for a different type of work or to change their jobs
- Because of the additional demands of caring for a sick or disabled child, tiredness and stress are especially difficult aspects of their situation
- At work some have been met with ignorance, disrespect or hostility because of their need to work flexibly to meet the needs of their sick or disabled child
- Some feel a degree of guilt or regret about being away from their sick or disabled child

Source – Caring for a Sick or Disabled Children: Parents’ experience of combining work and care (A report for Carers UK and Contact a Family from the Centre for Social Inclusion, Sheffield Hallam University, Bernadette Stiell, Lucy Shipton and Sue Yeandle 2006

- First and foremost, parents thought of themselves as parents. Most rejected the notion of being a carer
- The pleasure and satisfaction gained through the relationship with the disabled child was the fundamental reason why parents felt able to continue to care for their child
- Most parents found the stresses associated with the care of their disabled child to be wide ranging, unrelenting and sometimes overwhelming
- Parents actively sought to deal with these stresses, using a range of strategies to overcome or manage their problems and the difficulties that they encountered
- Parents valued services which allowed them to retain the normality of family life and were reluctant to use services which seemed to disrupt this
- Support from informal and formal sources, money, practical resources and personal qualities were important in helping parents cope. However if parents felt that the services provided for their child were inadequate or unsatisfactory, this could be a major source of stress
- Other aspects of the parent lives were sometimes more stressful than having a disabled child.

Source Caring for a Disabled Child – Joseph Rowntree Foundation

Some of the key themes for parent carers in Surrey

The individual interviews - Recorded in December 2010

Consistent with the findings of the focus groups discussions, parent carers also confirmed through the format of the 1-1 interviews that their single most important priority is access to short term breaks. For all the carers interviewed, the experience of trying to access support was likened to a battle in which the outcomes of the assessment process were variable. Some carers were able to access respite but not at the level that they felt fully met their needs. Sometimes respite was achieved through their child's care plan, others were in receipt of respite for a time limited period e.g. as a one off carer direct payment. Others simply resorted to paying for breaks through their own personal resources. It was notable too that a carer commented that the breaks ended when her son turned 18 and that equivalent provision was not forthcoming from Adults services. This was also a point made by parent carers in the focus groups.

It is interesting to note that in the HM Government "Recognised, valued and supported: Next Steps for the Carers Strategy"⁵, the Government notes that in the call for views under the five outcomes for carers contained in the strategic vision in the 2008 Carers Strategy, the theme raised most often is the need for breaks from caring in order to sustain carers in their role.

"Whilst the majority of responses focused on the availability of breaks, a number focused on the type of breaks on offer. In order to be beneficial, breaks need to be more personalised to meet the specific needs of the carer – many felt that breaks are currently offered on a "one-size-fits-all" basis".

For the parent carers available for interview, the breaks were necessary for a number of reasons and the type of break sought varied according to their individual circumstances. For a fuller analysis it can be useful to look at the matter in hand through a case study format:

Case Study 1

The carer explained that he was a highly paid professional, juggling work with his caring role. The carer has a caring role for two children and his wife. The carer stated that his biggest need was for regular breaks from his caring role. He explained that because of the challenges of his caring role, he had to reduce his work hours to part time and a year later his company made him redundant.

"I did not realise that my employment was at risk, it is only looking back at the situation that I realised the impact of caring".

The carer commented that he sought a carer's assessment but did not think that it resulted in much. *"My daughter was not considered eligible and so we were taken off the books".* The carer thought that the only outcome was access to a one off summer play-scheme but that fizzled out. The carer explained that having taken advice he did refer to his wife's depression and as a consequence the family got caught up in child protection issues. The carer explained that the most support received was via his children's schools, his son now

⁵ HM Government Recognised, valued and supported: Next Steps for the Carers Strategy. Annex A: Response to the call for views on priorities.

has a residential placement and his daughter has some boarding at her school. “With respect to my carer’s assessment, I would have been better off keeping quiet about my wife’s health needs, the whole process has kicked off some unsavoury things”

Case Study 2.

This carer cares for a child with autism. The carer explained that in her case the main issue was that her child fell between two teams. The teams referred to were the Children with Disabilities Team and the Assessment and Children in Need Team. The salient issue appeared to be that her child did not fit within the criteria for the Children with Disabilities Team and not having the specialist needs that fitted the framework and services provided by the Assessment and Children in Need Teams. This carer was granted a one off payment carer breaks funds from the CWDT and was disappointed to find that this would not be an ongoing support. The breaks allocation was for a break from caring but the carer opted to take the break with the whole family, this included her husband and two children. The carer had the option of using the funds for a mini break or other activity, e.g. gym membership, she opted for the mini-break.

During the interview the carer explained that with respect to the CWDT, she had been informed that her child did not fit the criteria because: *the team works with children and young people whose development is significantly impaired and needs to receive significantly more personal care and supervision than a child without disabilities of a similar age and circumstances... any typical 3 year old would need a fairly significant amount of supervision, behaviour management, personal care and so any parent would be expected to provide these things..”*

The reader at this point is asked to refer once more to Luke Clements (leading Community Care Lawyer) comments about carers’ rights on page 6 of this report.

For this carer, in describing her caring role, she stated that the “*stress has been unbearable*”, she clearly does not feel that in attempting to manage her son’s behaviour, the consequent impact on family life and juggling life as a mother, that the breaks allocations have been sufficient for her needs.

Case Study 3

This carer is a disabled person and cares for two children and has a long distance caring role for her father. The carer received her assessment in 2009, she felt that she needed to request it as it had been some time since it had been updated. When asked about what outcomes the carer would have liked from her assessment she replied:

“Everything is up in the air as my son was moving to transition. The assessment was done and nothing extra was achieved though I have now received a direct payment through a lot of lobbying and this is 18 months on since the assessment. It was a bit difficult to think about my needs. I have been caring for three people, my father and two children. My father lives long distance from me. I think I should have more support as should the wider family. There are co-caring issues too as I am a disabled person. The assessment process posed a number of issues, caring in the immediate family, my extended family and my life outside of caring. I tended to think just about the caring issues”.

The carer stated that her primary need was for breaks. “*Having children close in age, it is difficult to disentangle the complexity of needs”.*

This carer made some very useful comments about Transition but this will be explored later in the report. In terms of breaks, the carer commented that her children receive breaks via Family Links (Friday evening to Monday morning) and in addition the family gets breaks one day a month via Disability Challengers. The carer commented:

“The social worker suggested that I use the Family Link breaks to travel to see my father and use the break to look after him! Of course this would not have given me time out from caring or a chance to spend some time with my husband. The social worker also kept saying to me “I am here for the children” and yet during my carer’s assessment he never once asked me about my son. He also did not inform us when he moved on, he just left.”

Case Study 4

The carer has a 12 year old son with cerebral palsy, visual impairment and epilepsy. He doesn’t sleep well. The carer explained that she’d had a carer’s assessment but had been told that there was no money for support. This was a bad time for her, as she had mild depression. The carer just described giving herself a pep talk, she had other children to consider, having an older sibling to her disabled child made her focus. *“I have gone through low points, but I have not gone back to that dark space again”*. Things did improve for the carer, she got a mother’s help partly funded by her in-laws but this was for a limited time. The carer then got access to an agency via social care but this came some time after the carer’s assessment. It provided help at tea times. The input freed up the carer to prepare meals and do household chores and see her other children while the agency worker fed her son, prepared drinks and assisted with drugs and personal care.

The carer explained that one of the agency workers really connected to her son and applied to become a Link Family worker and the worker now looks after her son for one evening mid week. The nights rest has been essential in keeping the carer going. It is a flexible arrangement and in addition there are 12 days of care per year.

“In an ideal world I would like a floating night at a local respite facility, when the Link Worker cannot have my son” The carer mentioned another facility that social care now cannot afford to run and this has had a devastating effect on families.

In terms of her own carer’s assessment, the carer did not think there had been much point to it. *“Life outside of caring was not really discussed and any health issues I might have had were seen only in the context of keeping the family together. It was more about keeping the family cohesive than about thinking about me as a carer or my needs.”*

This carer thought that parent carers are disillusioned in general and that most parent carers don’t have a named social worker to support them. In her view, social workers are trying to manage two roles that are incompatible, namely identifying need and resource management.

Case study 5 (telephone interview)

This parent carer has a son with autism, he is 7 years old. The carer stated that she has been struggling to get a carer’s assessment for some time. She explained that she had been told the difficulty was because her son is not eligible for services. The carer has sought some assistance from her MP and through that intervention her son receives a break at a local respite facility. The carer’s view is that *“Not everyone who needs help gets it”*. This carer had been advised that because her son is not at risk, so the family is

not eligible for support. My son is not at risk, so I can't have a carer's assessment" The carer also commented that a Disability Living Nurse had told her that she should not go for an assessment in case she loses what she gets. *"I do need the extra help and whilst my employer has been sympathetic up to now there are increasing strains there"*.

Case study 6

This carer had her carer's assessment last year, this was when her son turned 18 but she has had frequent carer's assessments since the last 5 or 6 years. In terms of the carer's assessment, the carer thought:

"There is always a lot going on in your life and the whole process of the carer's assessment is confusing. You are always caught up in the middle of another process, the assessment of your child. I also felt like I was being judged, i.e. that it is a test that you pass or fail. You feel that your parenting skills are being assessed, you really have to trust the system. The system I thought though was really only there to help my son".

One of the outcomes of her carer's assessment was direct payments, she could have chosen to go to the gym and swim but she chose the option of mini-breaks. Her last holiday had been two years previously. The breaks gave her a chance to have 2-3 nights at a hotel with her husband. The carer mentioned that her son had previously had breaks at White Lodge but that these had stopped when her son turned 18. Her son had breaks for 12 hours a week but this had now all stopped. The carer now feels that she is very much on her own without support. Her son is now in a residential placement.

"With the carer's assessment, I just thought, oh I just don't want to go through all this again, I often used to feel ill after doing it. You feel sick, it is very draining, it is because you are dealing with a lot of negative feelings. You have to put the worst case scenario because you simply have to get help. Assessments are really depressing and draining. You do become a bit more used to it over time though. With respect to the carer's assessment, my remarks were sometimes taken out of context, you have to be so careful."

When asked about outcomes, the carer stated:

You do need outcomes for your son and yourself. I was grateful for the carer's break monies, but in retrospect I probably needed more help. I didn't ask for more as I felt guilty about what I had got. I think given my health issues, I would have benefited from a gym membership. You do need access to more information about what you are entitled to as a carer. I can see now that I would have benefited more from discussions about employment which I did not get. I would like to have done some courses to have helped me with my future. I needed help with access to funding and I do believe that I am still a carer and should be entitled to help. I see my son frequently and even though I don't see him everyday the impact of caring is still there. The worrying you do, the effect of sorting out problems/worries. I worry about what will happen when I die.

So regarding my education I am interested in some of the courses at my local college, but the courses are too expensive and there are no discounts for parent carers. If I could access these courses I would be more equipped for the work force."

The carer concluded that the chance for a 2 week holiday is really what she needed as this would give her a chance to unwind which a mini-break could not provide. The carer felt too embarrassed to ask for more help.

“You are a carer, but you are also a parent, you try to stay well in the meantime”

Case study 7

This carer had her assessment about three or four years ago.. Her son is now 14 years old and he had autism. The outcome that the carer wanted to achieve was increased short term breaks. At the time of the carer’s assessment, her son had access to breaks via Crossroads and this was for 6 hours on a Saturday. The carer found the assessment to be intrusive and the social worker was critical of her parenting skills. The carer did succeed in getting additional breaks but this was not through the input of social care. This had resulted from her campaigning work and funding from a “Friends” fund raising group at her son’s school. The breaks comprised of overnight stays (residential component) at the school where formerly her son had been a day pupil. This was for once a week for a term. The carer explained that the pressing need for breaks was eventually resolved. Her son was accepted as a full time boarded at an Independent school.

“I did not feel that there was any value in the carer’s assessment, I had to fight for everything that I got. There was a lot of personal questions involved, they criticised your parenting skills and then you are told that there is nothing at the end of it. There is no continuity in terms of access to social workers either. You are constantly having to start all over again and repeat information.”

Analysis of the case studies provided here focusing in the main at this stage on the carer’s desired requirement for short term breaks has revealed other more widespread issues. In terms of the carer breaks, this is an aspect of support that all carers in this small scale consultation exercise have stated that they desired as the most important outcome of their carer’s assessment. It is fair that whilst some carers were able to access some breaks, all of those particular carers stated that it was not sufficient to meet their needs. The majority of the carers stated that the child’s ineligibility for services acted as a major bar to getting support and or an increase in that support as well as access to a carer’s assessment. The issue for the need for clarity in this area has already been dealt with earlier in the report. On the one hand there is a widespread recognition of carers’ needs with respect to short term breaks in research and indeed in “Next Steps for the Carers Strategy this is a point overtly made. On the other hand evidence points to an apparent paucity of support in this regard.

Nef Consulting⁶ produced a report in 2009 on the social and economic value of short breaks. This report has been commissioned by Action for Children and Every Disabled Child Matters. To ascertain the findings, telephone interviews were conducted with AHDC lead staff from five Pathfinder authorities.

The report highlights that short breaks provides families with a mechanism by which to cope with the pressures of caring for a disabled child. *“This has an indirect impact on the family environment in terms of less stress for the parents and more time for other siblings, which can be translated into a higher sense of well being for the family as a whole.”*

This report provides an impact map which illustrates outcomes for the stakeholder groups involved in the interviews. For the parent/families/carers of disabled children, the following outcomes were noted:

⁶ Nef Consulting – The social and economic value of short breaks – December 2009.

- The child is less dependent on the parent
- Creation of a less chaotic and more sustainable family environment
- Less anxiety about the child's welfare when using short term break placements
- Being able to cope better
- More free time to do own things (time with other children, training, rest)

Other outcomes noted are:

- Disabled children are less likely to be placed in long term residential care
- Disabled children have higher levels of health and well being
- Parents have higher health and well being
- Parents/carers take less time off sick due to stress
- Family members and siblings have higher levels of well being

A further examination of the case studies will reveal the impacts as the carers themselves describe, of the effect of a lack of regular breaks. Stress is commonly referred to by the carers as a consequence of a lack of time out from caring as well as noting the effect this had on their emotional well being. There are also consequences in some cases on their employment that are also cited. It is worth noting that carers are twice as likely to be in poor health themselves in comparison to parents who do not have a disabled child. The Nef report comments: *"A meta-analysis conducted in 2003 showed that carers had 23% higher levels of stress hormones than non carers"*⁷

The Nef report stated that it can be assumed therefore that carers are at least 25% more likely to visit their GP in any given year which translated into one extra visit per year.

The Nef report also makes some interesting calculations about caring and employment. The report calculates that there are 462,000 families with a disabled child. The report assumes that each of the household contact 1.64 adults, there could be 757,680 adults potentially at work. However 34% of such households have no one in paid work. An assumption is made that of the other 66% of households, at least one person is in work, approximately 500,000 people are working. Not all of them will work full time, so assuming that 75% work full time, this equates to 375,000 full time employees taking additional sick days. Given that average person takes 8 days of sick a year, this translates as a parent of a disabled child in full time work taking 2 extra sick days per year.

That the carers have made the link between the impact of caring and lack of breaks and risks to employment is quite evident. The Government has recognised in the refresh of the Carers Strategy that lack of access to reliable replacement care will have an effect on carers' health and their ability to work and carry out their caring role. In recognition of the importance to carers of short term breaks the Government has now committed £800

⁷ Vitaliano PP, Jianping Z and Scanlan JM (2003) Is Caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin* 129(6): 946-972

million for this form of provision. This funding announcement follows on from the Government recently asking Parliament to approve Regulations on Breaks for Carers of Disabled Children from April 2011 referred to earlier in the report. A new evaluation of the short term breaks programme⁸ which has been recently published also shows the positive impacts that short breaks can have on families on disabled children, with 88% of families surveyed currently using some form of short term breaks services. The Government, however, clearly has recognised that there is more work to be done to better target services and make sure all families have access to a wide range of support. The funding announcement coupled with the introduction of the short term breaks duty does send a powerful signal to local authorities about the importance of continuing and developing the level and quality of provision.

This small scale qualitative study does reveal that the carers involved in this consultation do place access to short term breaks as a high priority. It also shows a high level of dissatisfaction amongst this cohort of the frequency of short term breaks. It does show some of the barriers that currently exist in accessing this support as well as difficulties that parent carers have in accessing a carer's assessment. The report has touched on the impacts this has had on carers' health and well being as well as their employment. The provision of short term breaks however is also valued for giving time to other family members and more time for themselves, a chance to recharge ones batteries and sustain the caring role. The carers on the whole are largely telling us by the feedback provided that the carers' assessment outcomes are not delivering what they seek in terms of access to regular and reliable short term breaks. The case studies also provide insightful information on a whole range of other topic areas. The HM Government "Recognised, valued and supported: Next steps for the Carers Strategy comments:

"Access to relevant and timely information and advice is also vital throughout the caring role, particularly at times of significant change, for example, to help parent carers negotiate the transition from children's services to adult health and social care services, and at the end of life".

The carer in case study 3 noted:

"When you are going through transition with your family, you have a need for information and advice, how would my role change as a carer over time? Also my daughter is getting older, she has a need for leisure, this also needs exploring. My children's independence is important".

The carer in case study 6 also commented on the strains inherent in the Transition process.

"My son is now in supported living. It was quite a challenge during the Transition process to determine whether supported living was the right option or whether my son should have a residential option. During this transition process, I had to make several changes to the reports and my carer's assessment at that time, remarks were taken out of context. With regards to the social worker during Transition, I was disappointed that he did not do his homework. The social worker said that this was because he wanted an open mind but this was very draining for me. His knowledge was about learning disabilities but it was poor on autism and Aspergers in particular. I did not have confidence in this man. I asked my

⁸ Short Breaks Pathfinder Evaluation Research Report PFE-RR062 Department for Education Nov 2010

husband to take over. When the social worker met my son, I felt really judged, as if I was a poor mother. The parent is at a very vulnerable stage at Transition. A social worker who is unprepared is the last thing you want. Afterwards the social worker told my husband that I was an amazing person. I wish he had told me that at the time”.

For these two carers at least, the support during the Transition process was less than ideal. Their primary need appeared to be for useful information and advice to assist decision making and for the second carer in particular not to feel judged and made to feel inadequate about her parenting skills which is an oft repeated theme by parent carers throughout the whole of the consultation. These points are worthy of further consideration. The Government has stressed that access to relevant information at the right time is crucially important for all carers as well as focused support at key stages along the care pathway. In the call for views on setting priorities, in next steps for the Carers Strategy, it is made clear that over a third of respondents felt that there is still a lack of information, advice and advocacy available to carers.

“Health and social care professionals do not proactively provide carers with information on their rights or the services available to them – carers have to seek out information themselves.”

It is useful to recall here that the Childcare Act 2006 extends local authorities existing duty to provide information to the public on childcare and related services. From April 2008, in addition to information on childcare, local authorities are required to provide a range of information which parents may need to support their children through to their 20th birthday. Local authorities are also required to ensure that information is made accessible to all parents who benefit from it. In the report *“Duty to provide information, advice and guidance (Guidance for local authorities childcare act 2006”*⁹ it is made clear that Section 332A of the Education Act 1996 requires local authorities to arrange for the parent of any child in their area with special educational needs to be provided with advice and information relating to those needs. LAs must also take whatever steps they consider appropriate to make Parent Partnership Services (PPS) known to parents, head teachers, schools and others they consider appropriate. The report makes clear:

“Parents, particularly where a child has special educational needs....should be treated as partners. They should be supported so as to be able and empowered to recognise and fulfil their responsibilities as parents and play an active and valued role in their children’s education.

Parents should be able to make their views known about how their child is educated and have access to information, advice and support during assessment and any related decision making processes about special education provision”.

This legislation and the recent introduction of the Carers Breaks Regulations 2010 and the stipulation to publish information to parent about the service available in their area and for accessing it must further assist parent carers.

In the scenarios quoted by the carers overleaf support was not sufficiently forthcoming so that they could feel able and empowered to contribute to the decision making process.

⁹ Duty to provide information advice and assistance: guidance for local authorities childcare act 2006 – depts. For children, schools and families Every Child Matters Change for Children

With respect to the carers refrain that they were made to feel tested and their parenting skills brought into question, this could be a consequence of the Children in Need framework that prioritises “parenting capacity” rather than the extra help parents with disabled children may need with specific tasks, over and above “parenting”. By contrast, Guidance to the 2000 Act (previously referred to in the report) clearly emphasises the important of recognising carers’ expertise and that the assessment should not be regarded as a test. In the recent Department of Health document: *“Carers and personalisation: improving outcomes (social care)”*¹⁰ it is stated:

“To recognise carers as expert care partners is to value both their role in providing support and the wider knowledge and skills they possess as individuals. Doing so greatly increases the likelihood of more personalised, responsive and high quality outcomes for those being supported and makes carers’ valuable and informed contribution available to other carers, service providers and commissioners.”

That carers’ parenting skills are often felt by parent carers to be brought into question and they are made to feel inadequate is regrettable. On a person level for the parent carer it undermines their sense of self worth and satisfaction from caring. That parents parenting skills are often brought into question is also a point made several times by young carers in the report on Young Carers in Surrey¹¹ early in 2010. Examples of the comments made were as follows:

“They tell parents about parenting skills and pass judgements, but some of them (social workers) haven’t even had children themselves.”

“My Mum is a single parent, the social workers are very judgemental, they think that she does not do a good enough job. I have had to go to CAMHS. I was told that my Mum is an unfit parent. They should be looking at the wider family issues, our social worker is a stranger to everyone, she should look at the broader issues. It really is a barrier”

The young carer quoted makes a very useful comment about the “wider family” issues. Central to the theme of personalisation is the need wherever possible, to establish whole family approaches that ensure that there is integrated support planning that benefits everyone involved. This theme has resonance for carers in the 1-1 interviews and is worth exploring more fully.

In Case study 3 in particular the carer explained about the complexity of the caring roles for her and her wider family. She explained that she is a disabled carer, caring for two disabled children and cares for her father from a distance. The carer also explained that there is evidence of co-caring in the family arising from her own disability. For the Government in Carers and Personalisation: Improving Outcomes

“Whole family approaches are the starting point – recognising the interdependence that most of us have with those closest/most important to us.”

We are informed that whole family approaches are appropriate in many circumstances. The Princess Royal Trust for Carers in *“Putting people first without putting carers second”* makes clear:

¹⁰ DOH Carers and Personalisation: improving outcomes (Social care) November 2010

¹¹ Young Carers in Surrey - Geraldine Bolam Independent Consultant 2010

“Where families wish to, they should have the option of being assessed for eligibility as a whole family, rather than having to negotiate separate assessments and eligibility for each individual... For most it would be to achieve a package that tackled all of their needs in a coherent way.”¹²

The carer commented in her interview that the social worker despite protestations to the contrary that *“I am there for the children”* did not ask about her son during her assessment. The young carers’ issues were also insufficiently addressed and because of delays in support, her adult son has missed out on opportunities for support via Surrey Young Carers. The advice from government is that assessors should be identifying who in the family has caring responsibilities, or if they have a carer, and to provide information, advice and signposting or assessment. If a person has a carer, they should be consulted as appropriate and processes should be in place to identify children and young people who are taking on caring responsibilities. There was no robust evidence that this was done sufficiently well when the carer had her own assessment as a disabled person. Staff we are informed need to be carer aware and there needs to be systems and processes in place which ensure that appropriate questions are asked and that staff are knowledgeable about responding to enquiries for information or further help. The previous Labour Government in its own *“think family”* approach had emphasised the importance of *“shifting the mindset to focus on the strengths and difficulties of the whole family rather than those of the parent or child in isolation.”¹³*

The difficulties were compounded as this carer commented that she was tending to think only of the caring issues and perhaps needed further support and time to think about the wider complexities that the family’s relationships roles and circumstances posed. Access to meaningful information and advice is crucial for carers particularly at times of Transition. Another carer spoke about her dismay and anger when a social worker did not appropriately support the non disabled siblings in the family. It was thought that the most useful help was to refer the young people to courses so that they could become care workers. No information was forthcoming about Surrey Young Carers and or Connexions and or Action for Carers and Employment.

The Government maintains that the provision of advice and information is a universal service and therefore something that all carers can have a reasonable expectation of. The 1-1 interviews have provided some small scale evidence where information and advice has been lacking to families.

“I did not find that the assessment provided me with any useful information or leaflets, referrals for other support.”

“I feel very much on my own with no support.”

Difficulties are also compounded for the parent carers when social workers move on. The quick turn round of social workers is an issue that is frequently raised by the parent carers:

¹² The Princess Royal Trust for Carers and Crossroads – Caring for Carers (2009) Putting People first without putting carers second

¹³ “Reaching Out: Think Family – Analysis and themes from the Families at Risk Review Cabinet Office (Social Exclusion Task Force) 2007

“They just don’t stay. It’s difficult to build up trust when there are so many inconsistencies.”

“There is no continuity in terms of access to social workers either, I was having to constantly start all over again and repeat information.”

“The social worker did not inform the family when he left, he just moved on without notification.”

It is certainly regrettable that carers are not kept in the information loop when social workers leave or on extended leave. Arrangements should be put in place for a hand over review to be undertaken and carers are not left in a vacuum. It is very important that carers have a named contact who is sufficiently informed of their circumstances and needs.

By and large the carers have been quite negative about the support and services that they have received and are generally dismissive of the value of carers’ assessments and the outcomes that have been achieved for them. Their focus overall has been on the need to acquire regular short term breaks for them and their family and the feedback from parent carers is that they are largely frustrated because it is difficult to access these because they are told their child is not eligible for services and this hampers their ability to get a carers assessment and to fully explore their needs. Where those carers have been able to access short term breaks, the parent carers by and large did not feel that the breaks allocated were sufficient for their needs. On the whole the parent carers have been dissatisfied by what has been achieved for them when they have attained a carer’s assessment. Parent carers have also provided comments about best practice in relation to carers’ assessments and whether this was applied in their own assessments. In particular there is a focus on whether the assessments looked at the holistic needs of the carer taking into account the need to sustain their caring role and their life outside of caring. These comments will be addressed in concluding remarks at the end of this report as well as how well carers have understood the purpose and value of carers’ assessments.

Professionals’ feedback – parent carers’ assessments and their outcomes

Feedback from a range of professionals was sought from Surrey Young Carers, Action for Carers and Employment and Action for Carers Moving and Handling professionals. All the professionals thought that the parent carers were encountering difficulties accessing carers’ assessments. This difficulty was made worse for the carers as it was thought that they find it difficult to self identify and generally see themselves as parent first and foremost. It was felt that in some cases carers were dismissed and that they needed to be

supported through advocacy, information and advice to get the most out of their assessment process. That carers largely feel “invisible” is also a point made in “*Next Steps for the Carers Strategy*”

“Parents of children with long term conditions or a disability often feel “invisible” and that they are just seen as parents.”

The consequences of this difficulty in self identifying and not being encouraged to do so by professionals is perhaps as the Next Steps document makes clear, that many carers do not seek early access to information and advice.

The feedback from the professionals consulted is that the parent carers are having to fight to get a service.

“It may take quite a few years for a parent carer to think about themselves and their own needs. Their immediate focus is on the child, they are dedicated to the caring role and it might be difficult for them to take up a carer’s assessment.”

It was thought that outcomes, aside from recognition, where social workers have addressed this, it may just be as little as referrals to support from the third sector e.g. carers support organisations.

“I feel that some parent carers are shocked if they get anything at all. It may be a struggle for parent carers to get an assessment of their own needs. I also think that Transition can be fraught with difficulties, navigating through is not easy for them. Parent carers often experience anger and disappointment in some cases.”

When asked for case examples, the examples quoted were mixed in terms of outcomes for the parent carers. On the one hand an instance was quoted where a family asked Surrey Young Carers for assistance in getting breaks provision as the son’s behaviour was taking a toll on the family. SYC made a referral to the Children’s services only for the response to be made that the son did not meet the complex needs criteria. A request was also made to Adults services for a carer’s assessment but each service in turn argued over whose responsibility it was.

On a more positive note, an example was quoted where a parent carer was in receipt of a direct payment. The Mum had MS and got access to a care worker and the parent carer was freed up to get quality time with his disabled son. The carer’s direct payment gave the carer gym subscription and a holiday for the family.

Conclusion

The consultation with the parent carers in late November and December 2010 has yielded some very useful feedback about how well Surrey Children’s services have been supporting them. Given the small scale nature of the consultation however it cannot be said to be representative of all parent carers in Surrey. Analysis of a questionnaire about parent carers will shortly be forthcoming and should provide further useful information

about this cohort and the analysis will later be attached as an appendix to this report. The report author is most grateful to the input of the parent carers without whom this research would not have been made possible. The insight and experience of some professionals supporting parent carers has also been useful and enriched this study. A great deal of information already exists about parent carers and their needs and some of this research has also been included in the report. The focus of this report is to consider what outcomes have been achieved for parent carers following their carer's assessment. Of necessity, the report author has had to give some consideration to the barriers that exist for carers in getting a carer's assessment as this theme has loomed large in the parent carers' feedback.

A great deal of material is also available about parent carers' desired outcomes. A study from the University of York¹⁴ (Social Policy Resource Unit) provides some useful data on this subject. Desired outcomes for parent carers in this study include:

- Having a life/identity of one's own over above being a parent of a disabled child
- Having control over one's life
- Spending quality time with the disabled child
- Achieving a balance between the time spent caring with the time spent parenting/enjoying quality time with the child
- Maintaining one's own physical and emotional well being
- Having adequate financial resources
- Having other material practical resources
- Feeling skilled and informed (about the child's condition, about services etc)

Outcomes for families include:

- Maintaining family life
- Helping siblings adjust to having a disabled brother/sister
- Undertaking activities with all family members

The SPRU report also comments on the importance parent carers attach to having positive relationships with professionals and having confidence in services. Some of these themes are echoed by the parent carers in this report. Parent carers did discuss for example, the importance of spending quality time with the disabled child and achieving a better balance with time spent with the family. Having access to a break was prioritised by the parent carers in this study as being the most important outcome to them and as a means to achieving the aforementioned objectives. The parent carers have commented on the need to have more control over their lives and this was expressed with a particular focus on their health and employment needs. Carers spoke about the intolerable stresses in their lives

¹⁴ The University of York (Social Policy Research Unit) "Outcomes for parents with disabled children and carers of disabled or adults: Similarities, differences and the implications for assessment practice" - 2007

and in some cases the consequences for their employment as a result of their caring role. One carer spoke with great fluency about her regret that her assessment did not pick up on her employment aspirations. She spoke with some frustration at not being able to access courses which would help her to engage with the world of work now that her son had a residential placement. It was surely an omission of the assessor not to address these issues and contrary to the carers' legislation.

Some of the feedback of the parent carers is suggestive that the carer's assessment did not sufficiently take a holistic picture of the carer's needs with respect to their life outside of caring. The reference to the carer's frustrated plans for employment provides some testimony to this and there are other examples with the parent carers where this was not fully discussed. An example is quoted where in the carer's view he was made redundant because of the impact of his caring role and another where the carer stated that her relationship with her employer is currently under strain. Carers also talked about some of their health concerns and there were examples where carers had serious health issues to deal with such as cancer and intolerable stress levels. The carers did not recall that their health issues were sufficiently addressed or referrals made for useful support and or information. The report conducted by SPRU makes the point that the framework for assessing the needs of parents with disabled children fails to acknowledge the extra help they may require in order to enjoy the same levels of opportunity as parents whose children do not have disabilities – a right explicitly conferred on carers through the 2004 Carers (Equal Opportunities) Act. That these needs should be fully addressed in the Children Act Assessment is a point addressed earlier in the report and is made clear by Luke Clements book on "Carers and their Rights"¹⁵. His comments are quoted in detail.

The point that is repeatedly stressed by the parent carers in this study is that their inability to access short term breaks is related in part because they are told their child does not meet eligibility criteria and because of funding constraints. This in turn they feel denies them access to a carer's assessment, an important point to highlight in a study on carers' views about assessment outcomes. The report author does make clear that it is very important that the criteria for access to services by disabled children shows without any room for doubt how it will take into account carers' legislation and the right of parent carers to request an assessment. That parent carers need access to breaks has been long highlighted in research. Parents of disabled children are at increased risk of stress compared to other parents and stress levels are strongly linked to child behaviour and sleeping problems.

The Quality Protects Research Briefings ¹⁶ comments:

"A break from caring is one of parents' most frequently reported needs, but families also require support that enables them to do activities together as a whole family. Short term breaks, domiciliary services and accessible and appropriate play and leisure services are all part of this service."

¹⁵ Luke Clements Carers and their Rights -4th Edition

¹⁶ Quality Protects Research Briefings Chapter 6 – Meeting the needs of disabled children – 2002 (Dept of Health, Research in Practice, Making Research Count)

The report notes that factors effecting take up include a lack of information, of culturally appropriate services and services supporting children with challenging behaviour or complex health needs.

The report also advises that:

“Research indicates that few carers feel that they have had an assessment of their own needs or are aware of their right to ask for one. It is important that assessments are clearly offered to carers”.

These points are borne out by the research by the parent carers in Surrey. One carer when asked if she'd had an assessment stated in the negative only to comment later that she had received a direct payment. The majority of carers in this study stated that they did not think that the social workers clarified the purpose of the assessment or that they fully appreciated the value of one. One of the carers in the focus groups made clear that she did not know about her rights till fairly recently and that the most important source of information was other parent carers. It is therefore hugely important that parent carers are proactively informed about their rights to request a carer's assessment.

The feedback from the parent carers has been rich in detail covering a wide range of issues including the difficulties that are experienced at the time of Transition, the failure of professionals at this stage to provide useful information and advice to inform decision making. There was also a perception that services would be reduced when the child was in receipt of adult care services. The majority of parent carers have also commented on the stressful nature of the assessment and in particular the questioning of their parenting skills. This may in part be because of the Child in Need assessment framework with its emphasis on parenting capacity but runs counter to Guidance to carers' legislation and recent Government statements about the need to recognise carers expertise such as that quoted in HM Governments' "Recognised, valued and supported – Next Steps for the Carers Strategy" and the inherent philosophy of personalisation which has been quoted elsewhere in the report.

From the feedback taken as a whole it is perhaps fair but troubling to conclude that in terms of the parent carers in this study, they were largely disappointed in their aspirations for short term breaks. Likewise other hoped for outcomes such as assistance with a life outside of caring, useful information and advice especially around assessment and assistance with contingency planning were not immediately forthcoming. In terms of short terms breaks the carers often found those difficult to access and insufficient in quantity and flexibility (in some cases). Difficulties have been compounded by some carers in what they described as the quick turn over of staff and in some cases they had been distressed to find that social workers had moved on and they had not been informed.

This is not acceptable to the parent carers and they should not be kept out of the information loop. Parent carers should be informed about or involved in arrangements about the hand - over of cases. With respect to planning for emergencies, the clear outcome of parent carers was to be reassured about what should happen in emergencies and what support might kick in such instances. There wasn't any evidence where this was spoken about that there had been contingency planning. As mentioned in earlier research on adult carers by the report author, where positive intervention is achieved by social care this is highly valued by carers. When negative scenarios are present carers stress levels

are significantly higher and if unaddressed long term there are likely to be health impacts for the carer.

In addition, there has been some worrying feedback by the parent carers about the interpretation of law and what this has meant for some parent carers. Luke Clements makes the point that:

“Neither the 1995 nor the 2000 Acts includes a stipulation (found in social security law) that the care provided to the disabled child must (for instance) be “substantially in excess of the normal requirements of persons of his age”

This point is made in relation to an earlier case study.

By and large carers talk about being “embattled”, having to fight for their rights, fight for support. Services play such a vital role in meeting the needs of disabled children and their families and in ensuring that they are not excluded from opportunities that most disabled children take for granted. In turn carers wish to be supported in their caring role and have a life outside of caring. A common theme quoted in research is the need for parents and children to have an ordinary and reasonable quality of life. This research in Surrey suggests that there is some way to go before the achievement of their desire outcomes is realised and limited access to short term breaks in particular is constraining the lives of carers and their families. It is envisaged that better clarity about parent carers’ rights in legislation is made possible and that the introduction of the Short Term Breaks Regulations makes a significant difference. With the accent on the wider family approach and recent Ombudsman decisions highlighting the importance of assessing carers’ needs within the wider family context perhaps greater progress can be made possible.

RECOMMENDATIONS

Eligibility. Carers Assessments and Outcomes.

- The refreshed Eligibility Criteria for Children's services will demonstrably take into account carers' legislation and provide improved clarity about the right of parent carers to a carer's assessment
- The eligibility policy should be fully explained to parent carers with reference to the decision making process in individual cases and rationale for outcomes
- When eligibility decision making is formulated, it takes into account that neither the 1995 nor the 2000 Carers Acts includes a stipulation (found in social security law) that the care provided to the disabled child must (for instance) be "substantially in excess of the normal requirements of persons of his age"
- Explanation is given to parent carers about the meaning, purpose and value of a carer's needs assessment. The explanation should provide a full account of the range of outcomes of carer's needs assessments and the anticipated time frames for the receipt of paper work, the delivery of any services, an explanation of the arrangement for future reviews and a conclusion to the process.
- Parent carers are pro-actively informed of their rights and entitlements to carers needs assessments
- Parent carers should have clear expectations in relation to time frames and performance targets for responses to correspondence and telephone calls in general
- Parent carers are routinely told when social workers leave and they are informed and or involved as appropriate in the hand over process.
- Anticipated time frames for the repair and delivery of equipment should be made clear

Information and advice

- There needs to be an increased understanding that access to relevant and timely information and advice is vital throughout the caring role but particularly at times of significant change for example at times of Transition from Children's services to Adult health and social care services. Information and advice/referral from Children's Services about Parent Partnership services needs to be reviewed and better targeted.

Training, knowledge and skills set required:

- The training, knowledge and skills set required can be demonstrably shown to be up to date and conversant with the carers' and other relevant legislation and guidance, and is appropriate to the needs of parent carers whom social workers are supporting.
- Specifically assessment practice and procedures support parent carers wish to pursue education, training or work, or leisure activities if that is their desire. That their aspirations should be taken into account when assessing a carer's need for support is a requirement of the Equal Opportunities Act 2004

- The clear relationship between poor health and caring that increases with the duration and intensity of caring is better understood by social workers. Training, support and supervision of social workers needs to take into account that young working adults, for example caring for a child with either physical or mental health problems, are more likely to suffer ill health than non carers of the same age.
- Social work practitioners can sufficiently encourage carers during the carer's needs assessment process to fully explore the impact of caring, recognise their expertise in caring and examine their feelings about caring. This process should support the parent carer's self esteem, satisfaction in caring and identify what support is available to sustain both the caring role and a life outside of caring.
- Assessment practice, procedure and review addresses the need to take into account contingency planning and recognises the importance parent carers attach to this as a desired outcome of assessments.
- Social workers are enabled to assist parent carers in looking at their situations, to identify solutions and to link up with other support networks
- Social workers are able to demonstrably show skills of empathy, understanding and listening and can understand the context of a parent carer's life within wider family circumstances
- Social workers are further encouraged to think about the wider family approach and understand that care and support can be tailored to support the family as a whole rather than parent carers being expected to provide care and then being offered carers' services which do not tackle the underlying needs of the family
- Parent carers should be regarded as "rights holders" and not just co-producers of care

Short Term Breaks

- Published information about short term breaks in line with the Short Term Breaks Regulations provides clarity about the range of short breaks services in Surrey and the local authority's criteria for accessing them
- Commissioning strategies have been informed by the need to develop comprehensive and coordinated short breaks services that provide positive and inclusive experiences to disabled children and offer flexibility and choice to families
- There is a more enhanced understanding of the importance and desirability of short term breaks for parent carers and the high priority that is attached to them by parent carers in sustaining their caring role and providing access to a life outside of caring. Training programmes, support and supervision programmes for social workers should address this.

BME Carers

- Provide evidence that the recommendations in the report “Review of the views of Black and Minority Ethnic Carers in Woking on Surrey County Council services, in relation to the Care Quality Commission – Outcomes and performance characteristics for carers services” have been fully considered and their appropriateness for parent carers fully taken into account. Information needs to be produced about what recommendations can be taken forward and applied in the care and support of BME parent carers
- Commissioning strategies, support and services recognise that:
 - National research has indicated that BME carers want more information about their child’s disability and in particular, services for their child and themselves. However, poor interpreting support and limited availability of translated materials could make access to appropriate information difficult, particularly for Bangladeshi families
 - Indian and Black African/Caribbean families reported least support from their extended family, with levels of support lower than that found among the survey of white families. Mothers from all ethnic groups represented reported lower levels of support from their partners than white mothers had reported.
 - Overall families from minority ethnic groups caring for a severely disabled child were more disadvantaged than white families in similar situations. Families’ experiences, needs and circumstances varied across ethnic groups.