About Families:

exploring the evidence on disability

about families
gathering evidence • informing action

crfr
centre for research on families and relationships

parenting
across scotland

capability
scotland

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The *About Families* partnership sought to ensure that the changing needs of parents - including families affected by disability - are met by providing accessible and relevant evidence to inform services. Over three years (2010 – 2013), About Families identified and investigated four key parenting topics, produced clear language topic reports, and supported a range of organisations and services to use evidence, and consult with service users, to inform service development. The project also piloted an Evidence Bank, which produced concise evidence reviews in direct response to family and disability service related research questions.

The topics were:

1. Parenting Teenagers: relationships and behaviour (October 2010)
2. Together and Apart: supporting families through change (June 2011)
3. Parenting on a Low Income (March 2012)
4. Parenting and Support (October 2012)

Supporting families affected by disability: *About Families* considered how these parenting issues relate to families affected by disability as well as those not affected. It aimed to enable parenting professionals to provide services appropriate for all families, and to help those working in the disability field have a deeper understanding of parenting and family issues.

This report brings together evidence across the four About Families topic reports relating to disability, and the gaps in evidence.

About Families was a partnership between the Centre for Research on Families and Relationships (CRFR), Capability Scotland and Parenting across Scotland (a consortium of parenting and relationship organisations: Aberlour Childcare Trust, Capability Scotland, CHILDREN 1st, One Parent Families Scotland, Relationships Scotland, SMC, and Scottish Adoption).

It was funded by the National Lottery through the Big Lottery Fund.

Full topic reports can be downloaded at http://aboutfamilies.org.uk/publications/

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1. Disability and gaps in family research

- research with and about families generally does not include (or identify) families affected by disability
- research that does include families affected by disability tends to be about disability rather than other family circumstances, or how such circumstances combine with existing pressures associated with disability
- there is little research which views disabled parents as parents, rather than service users
- research tends to focus on children, rather than parents, with disabilities
- research tends to emphasise the difficulties associated with living with disabilities or long term conditions. While it is important to acknowledge and address these challenges, the prevalence of this view can give the impression that having a disability or a disabled child will inevitably lead to difficulties and family strain
- families affected by disability can be portrayed as an homogenous group
- there is very little research about the role or needs of extended family members who are supporting disabled parents.
- across the UK, there is incomplete statistical information about the numbers of disabled parents, and some that is available is unclear. However, Capability Scotland requests further analysis of national data, such as the Scottish Health Survey.

Increasing the evidence on disability

In response to this research gap, *About Families* commissioned a survey and interviews with disabled parents and/or parents of disabled children for each topic report. This was done on a small scale using Capability Scotland's 1 in 4 Poll* and other services to ask families about their experiences. Whilst not representative of the views of families affected by disability across Scotland, it does present some reflections to inform discussions and service development. These responses are included in 'Families affected by disabilities say' boxes throughout.

**Capability Scotland's 1 in 4 Poll was established in 2000 and so-called because one in four households in Scotland lives with disability. 1 in 4 Poll panel members have personal experience of disability and respond to 3-4 surveys each year on issues that relate to disability equality.*

> *"We have learned that there is less evidence out there than we originally thought – especially about disabled parents and their families. It's been really helpful in identifying what is there, and where the gaps are."*
>
> *"Disability has been made more visible though the About Families research, which has shown how little research has been done on disabled parents and their families."*
> Comments from project partners

2. *About Families* topics – evidence on disability

Topic 1 - Parenting Teenagers: relationships and behaviour

We know from calls to helplines that parents of teenagers often struggle and feel isolated, particularly around behaviour and relationship issues. *About Families* asked what research could tell us about these issues.

Disabled parents and/or teenagers were not explicitly included in the research found during the review. Through our small-scale research with Capability Scotland's 1 in 4 Poll and other services, we asked parents to reflect on the findings and offer their own views and experiences.

Families affected by disability say: Parents in our research reported much similarity between the research findings and their experiences, and felt that parents' personalities and their role within the family were the key factors in behaviour and relationship issues, regardless of any disability. However, parents felt there was some difference in some areas:

Parenting together: While both disabled parents and parents of disabled teenagers generally agreed that mothers take more responsibility than fathers for their teens' activities, parents of disabled teenagers felt both parents have to be involved in all areas of their teenagers' life as they need to work more as a team.

Parental satisfaction: Parents of disabled teenagers reported that seeing their teen develop socially, rather than in relation to their age, was a key factor in their parental satisfaction. They also highlighted that teenagers' development could be limited by available resources and societal attitudes towards disability.

Communication: Some parents of disabled teenagers rely much more on other people, such as practitioners, to gain information as direct communication with their teen can be limited by their disability.

Although some parents of disabled teenagers reported feeling that more detailed communication is necessary due to the nature of the disability, generally the issues over how parents communicate with their teens were felt to be the same regardless of disability.

Parents of disabled teenagers who were able to use mobile phones reported a particularly heavy reliance on mobiles where the teen was felt to be more vulnerable due to their disability. However, some teenagers did not have mobiles if they were unable to use them, or would misuse them.

Impact on teenagers: disabled parents participating in our research highlighted the impact that having a disabled parent can have on teenagers (for example, being bullied at school); and the potential for teenagers becoming carers, or even be assumed to be carers by some agencies.

Topic 2 – Together and Apart: supporting families through change

Since good relationships between parents are important for the well-being of both adults and children, *About Families* asked what research could tell us about sustaining healthy relationships and coping with relationship breakdown.

Sustaining relationships and managing change

- ***Communication and conflict***

Families affected by disabilities say: Two thirds of parents in our poll felt that communication is a key factor in relationship difficulties. Problems stem from a range of issues: parents disagreeing over what the child's impairment is and how best to manage it; partners receiving a lack of support leading to a lack of time/energy to communicate effectively; disagreements about the disabled child's treatment and/or ways of tackling behavioural problems; all of which may result in parents feeling withdrawn or depressed.

- ***What puts pressure on relationships?***

Parents of disabled children can experience grief as they mourn for the 'imagined' baby (Green, 2007 cited in Glenn, 2007). Mothers' grief may be less severe if she feels supported by her partner (Statham, 2002 cited in Glenn, 2007). The impact of grief on the marital relationship is largely neglected by the literature (Glenn, 2007).

The multiple pressures associated with parenting children with chronic illnesses or disabilities can have a detrimental impact on parents' health, relationship and ability to parent. In a UK survey of parents, around three quarters experienced stress/depression and/or tiredness/lack of sleep which most linked with the challenges and lack of support associated with having their disabled child. Almost one quarter felt that the additional challenges caused major problems in their relationship or led to their separation (Shapiro, 2003). These challenges include managing more traditionally gendered parenting roles; a lack of time for each other; managing different coping styles; coming to terms with loss and grief; adjusting to changes over time; the care demands specific to their child's disability; and acute financial pressures (Glenn, 2007).

Families affected by disabilities say: Two thirds of parents told us that they felt the additional challenges associated with having a disabled child had had a negative impact on their relationship with their partner, with a quarter saying they had caused major problems or led to separation. Those who had separated said that coping with childcare, changing roles, juggling work and childcare, and resentment about changes to routine contributed to tensions the most.

Other factors that put pressure on relationships include dealing with health professionals/ other organisations (including time taken to attend appointments); dealing with family and friends who find it difficult to come to terms with disability; lack of time with their partner; and concerns about their child's future.

New pressures and concerns can arise as a child with a disability grows up (Todd et al, 2005 cited in Glenn, 2007). These can include: realising that communication and mobility problems will not improve; their child may not be able to live independently in adulthood or have a family; how the community and society will integrate with their child; education (Heiman, 2002, cited in Glenn, 2007); employment; and planning long-term care. Coping with increasingly challenging behaviour and growing physical care demands can all coincide with the usual challenges of puberty and adolescence. Transition to adulthood often coincides with a massive reduction in state support, and a move from specialised paediatric care to adult teams, whose case-load is largely made up of the elderly (Glenn, 2007). When older siblings leave home, the important emotional and practical support that they frequently provide is lost (Todd et al, 2005 cited in Glenn, 2007; Hartley, 2010).

Where children with disabilities continue to live in the family home into early adulthood, pressures for families can be on-going. This means that parents of children with a long term condition can experience continued marital strain (Hartley et al, 2010).

- *What helps parents to manage better?*

Parents say they manage better when they:

- talk about problems and don't let them escalate
- make time to be together as a couple (not put the relationship on the back burner)
- develop trust and respect and reflect these in their behaviour
- share a positive outlook
- share responsibilities (this does not mean evenly dividing tasks, but that each partner is happy with their roles and is confident that the other one is doing their bit)
- learn to give and take
- use humour to relieve tension (Walker et al, 2010)

Families affected by disabilities say: Most respondents agreed that the list of factors above helps parents in disabled families to manage better. Parents also identified support from family and friends, support from external organisations and access to short term breaks.

A supportive relationship can help with parenting stress (Kersh, 2006). Partners with good relationships can provide each other with useful emotional and practical support, and are also more likely to get support from other sources (Quinton, 2004 cited in Glenn, 2007). However, the multiple pressures of caring for a child with a disability leave parents with little time for themselves, other siblings or their relationship. 90% of parents of a child with a learning disability say they do not have enough time together (Bauman, 2004 cited in Glenn, 2007).

- *How relationships end*

A range of pressures and problems usually contribute to relationship breakdown. These include childcare, household duties, financial difficulties and work demands, alongside a lack of time to talk and poor communication (Walker et al, 2010). Parents of a child with a disability experience the 'normal' stresses and strains that all parents face, and the additional pressures can exacerbate any relationship problems that already existed (Glenn, 2007; Shapiro, 2003).

Although many couples parenting a child with a disability stay together, they are more likely to divorce or separate than parents caring for a non-disabled child (Glenn, 2007). In the UK, 53% of parents caring for a child with a disability believe the challenges they faced had caused either 'some' or 'major' difficulties or the breakdown of the relationship (Shapiro, 2003).

Families affected by disabilities say: The respondents who had separated or divorced identified two main causes for the breakdown in the relationship: partners disagreeing over what the child's impairment is and how best to manage it; and the impact of the general pressures and challenges faced in caring for a child with a disability.

Separated parents with disabled children are less likely to form new relationships (Corman et al, 1992 cited in Glenn, 2007). In the UK, around three in ten lone parents have a sick or disabled child, equating to over 40,000 lone parents with a disabled or sick child in Scotland (One Parent Families Scotland, 2008). Where they do re-partner, they are likely to experience added pressures as partners negotiate care roles and responsibilities (Turnbull et al, 2006 cited in Glenn, 2007).

Couples may stay together because they feel uncertain about parenting a child with a disability alone. Parents may feel that finding another home which is suitably equipped for their child's needs would be difficult. Moving may mean reorganising healthcare and education packages. In cases of domestic violence, separation is especially problematic if this means moving to a new area and non-adapted accommodation (Glenn, 2007).

Families affected by disabilities say: Some parents said they had stayed in a relationship despite it having broken down because they felt responsible for caring for their child. Nearly half of respondents felt they would not be able to find suitable accommodation following relationship breakdown because they thought it would not be available, did not know how to find out about it or felt they would not be able to afford it. Separated parents were more likely to think they would find accommodation, suggesting they had experience of doing so.

Contact with children after separation

In Scotland, most disputes happen because the non-resident father is not satisfied with contact arrangements. In most cases, they had not approached other services, suggesting that parents need more knowledge and understanding about available services (Laing et al, 2010). Parents affected by disability sometimes feel discriminated against in court decisions regarding child residence and contact (Wates, 2003).

Families affected by disabilities say: Three quarters of parents who were divorced/separated said they felt that disagreements about approaches to parenting and difficulties in making decisions for the parent not living with the child can make it difficult to co-parent after relationship breakdown.

Financial issues

In families affected by disability, reduced earnings and increased expenditure can put strain on relationships. 55% of families caring for a child with a disability are living in or at the margins of poverty (Harrison and Woolley, 2004). If the father is affected by disability, household finances are more likely to be affected which can contribute to family breakdown (Clarke et al, 2008). Although there is disagreement over the size of extra costs incurred by disability and how best to measure them, estimates range from £7.24 to £1,513 per week (Tibble, 2005).

It costs three times more to bring up a child with a disability than a non-disabled child (Glenn, 2007). Families often meet costs of equipment or care that are not provided by the NHS or Social Services due to tight budgets and waiting lists (Shapiro, 2003). Alongside the usual financial pressures of separation, some parents must rely on benefits as their main source of income (Glenn, 2007).

Appropriate and affordable childcare for disabled children can be hard to find. Caring responsibilities can therefore affect parents' ability to work (Glenn, 2007). Of mothers with disabled children, 3% of are employed full-time and 13% part-time, compared to 22% and 39% of mothers with non-disabled children respectively (One Parent Families Scotland, 2008).

For families affected by disability, financial pressures may continue into old age. Parents who could not work, or whose work was constrained by caring responsibilities, may not have met minimum contributions for state pension entitlement and generally make lower contributions into pension schemes than families of non-disabled children (Wooley, 2004; Glenn, 2007).

Families affected by disabilities say: Practical issues (mostly about housing and finance) would be the main concern immediately following separation, as well as concerns about managing alone.

Supporting parents

Literature about families including children with disabilities tends to focus around preventing, rather than supporting, relationship breakdown. Family support is often seen as being delivered through short term breaks, and supporting the parents by providing support for the child.

Parenting programmes need to address issues specific to parenting a child with a disability or behavioural problems (Glenn, 2007).

Families affected by disabilities say: Short term breaks can support families by providing parents with time on their own, with their partners or with their other children. However, some parents feel that availability is limited.

Families affected by disabilities say: As with all types of families, parents told us that key barriers to seeking help with relationship difficulties are: lack of awareness of services available; covering up issues to protect the children; and not wanting to admit to having problems. Some parents felt that health professionals are not aware of what help is available. Others were concerned that parents would be perceived as having 'failed' if they asked for help.

Parents felt that relationship services were unlikely to help them deal with a breakdown in a relationship because they felt such services would not have the necessary knowledge over disability, the support offered would not help, or their partner would refuse to take part.

A quarter of parents felt that lack of suitable childcare for their disabled child would make it difficult to access relationship services.

Existing contact with professionals about their disabled child meant that parents were less likely to seek outside help, either because they had poor experience of professionals or because they did not want anyone else involved professionally in their lives.

Topic 3 – Parenting on a Low Income

Given the negative effects of financial hardship, and the current economic climate, *About Families* asked what research could tell us about parenting on a low income.

Who is most at risk of living in poverty?

Alongside children, those at particular risk of poverty include lone parents (who are mostly women), people who are not working, people affected by disability and people from ethnic minorities (McKendrick et al, 2011).

Why do some families experience poverty?

A combination of social, political and economic factors drive the nature and extent of poverty, including inequality, low pay, inadequate benefits, poor-quality work opportunities and lack of support for those with caring responsibilities, ill health or affected by disability (McKendrick et al, 2011).

Disability, income, and employment

1 in 5 of the Scottish population (1 million people) is disabled, and 1 in 4 people will experience a mental health problem. Half (49%) of Scottish households including someone

with a disability have net annual incomes below £15,000. More than half (52%) of disabled people are unemployed. Those materially affected by the economic climate are up to 8 times more likely to have sought help for depression and anxiety. Nearly 1 in 5 (19%) disabled people who require an adapted home live in one that is 'not at all' or 'not very' suitable (Disability Agenda Scotland, 2011).

Social barriers such as people's attitudes to disability, and physical and organisational barriers, mean that disabled people generally have fewer opportunities and a lower quality of life than non-disabled people (Disability Wales, 2011). In terms of employment, a focus on 'inability or ability to work' can emphasise the supply side and downplay the inherent problems in labour market conditions. This fails to recognise socially determined opportunities and exclusions (Kenway, 2008).

Trends and statistics

- Around a third of all disabled adults aged 25 to retirement are living in low-income households, twice the rate of that for non-disabled adults (The Poverty Site).
- At every level of qualification, the proportion of people aged 25 to 49 with a work-limiting disability who lack, but want, paid work is much greater than for those without a disability (The Poverty Site).
- 30% of disabled lone mothers are in employment compared with 65% of non-disabled lone mothers. While lone parenthood reduces the female employment rate by 15 percentage points (from 80% to 65%), disability reduces employment for both lone mothers and non-lone mothers by around 40 percentage points (from 65% to 30% and 80% to 40% respectively) (The Poverty Site).
- In Scotland in 2009/10 19% of people in households affected by disability were in relative poverty, compared to 16% for households not affected by disability (Scottish Government 2011).

The additional costs of disability

Living with a disability or ill-health generates extra costs. Although there is disagreement over the extent of extra costs incurred by disability and how best to measure them, estimates range from £7.24 to £1,513 per week (Tibble, 2005). It can cost three times more to bring up a child with a disability than a non-disabled child (Glenn, 2007) and families often have to meet costs of equipment or care that are not provided by the NHS or Social Services because of tight budgets and waiting lists (Shapiro, 2003). Parents of disabled children can spend almost twice as much on comparable items as parents of non-disabled children (Dobson et al, 2001, cited in Cunningham-Burley et al, 2005).

Extra costs can include specialist equipment, toys and clothes; care services; adaptations; higher utility bills (such as heating and laundry); specialist food and medication. Official poverty statistics are based on standard income measurements that do not take into account this higher cost of living of many people affected by disability or recognise their different needs. They rank a disabled and non-disabled person equally if they have equal income (Kenway, 2008).

These additional costs, alongside other factors associated with disability (such as lack of suitable education and employment opportunities) heighten families' vulnerability to poverty. Financial pressures increase for families caring for more than one person with a disability (Preston 2005, cited in Ridge 2009). One estimate is that 55% of families with a disabled child are living in or on the margins of poverty (Gordon 2000, cited in Cunningham-Burley et al 2005).

Families affected by disability say: We asked parents and carers in our poll about disability related expenditure. This refers to money spent on things that would not be necessary if the parent or child were not disabled. Over half the respondents (52%) thought that 20% or more of their income was spent on costs relating to their child's disability and one in ten put the proportion at 40% or more.

In terms of housing costs, the main additional cost was utility bills, mentioned by 77% of respondents. Heating bills were a particular issue as keeping a constant temperature was important for many disabled children's welfare. Adaptations to housing were an expense mentioned by 43% of respondents and some often felt unable to implement the adaptations that their disabled children needed.

Non-housing costs mentioned were transport (66% of respondents), clothing (64%), specialist equipment (53%) and care services (43%). Additional costs for transport included taking disabled children to school and to medical and other appointments. One parent also mentioned the need for overnight accommodation for the whole family when their child has specialist treatment.

Living in a rural area was thought to increase costs relating to disability, mainly because of the increased need for transport.

Other key areas mentioned were holidays and childcare. Holidays can be prohibitively expensive due to high costs of suitable accommodation. The need for, and therefore cost of, appropriate childcare can continue into the disabled child's teenage years.

Impacts of additional costs on family life

Families affected by disability say: Two thirds (64%) of parents and carers felt that the additional costs relating to disability had an impact on family life and parenting in terms of cutting back expenditure (including the effect of this on siblings) and increased stress. Over half (54%) said they had reduced spending on family life in order to meet the additional costs relating to disability. The main impact was the inability to afford holidays. Other areas affected including food, heating and other essentials. One of the specific areas of stress mentioned was concern for the future, particularly in the light of changes to the benefits system as children grow up.

Managing resources

Parents use a range of creative and skilful strategies to manage resources and protect children from the impacts of low income (McKendrick et al 2003a; Seaman et al 2005, Ghate et al 2002). Spending is strictly prioritised, with leisure and recreation activities cut first, followed in turn by heating, equipment, clothing and food. Payments are timed carefully and made in small installments. Other strategies include children taking turns in having mobile phone credit; bargain hunting; letting young people know how much the family budget can sustain; re-using clothing by siblings; long-term planning and using mail order catalogues (Seaman et al 2005; McKendrick et al 2003a). Similar strategies are reported by families affected by disability, along with 'staying in', going without food and transport and using savings (Woolley 2004 cited in Cunningham-Burley et al 2005). Informal support (benefits in kind, handed on clothing) is common (McKendrick et al 2003a).

Attempts to budget can be undermined by the sudden appearance of additional needs, benefit changes and employment conditions (Ridge 2009; McKendrick et al 2003a). For lone parents on low incomes (Ridge and Millar, 2008; Millar and Ridge, 2009 cited in Ridge 2009) and families affected by disability (Preston 2005 cited in Ridge 2009), changes in family circumstances such as bereavement, unemployment, divorce and the onset of illness and disability can have a profound effect on ability to pay.

Families affected by disability say: Nearly half of respondents (47%), including all those with disabled children, said that their ability to meet the additional costs relating to disability was worse than a year ago. Only 1% of respondents felt they were in a better position, and 40% said their position was about the same.

Access to benefits

The benefits system is often a significant source of stress for families, including those affected by disability (Hooper et al, 2007 cited in Ridge 2009; Mitchell and Sloper 2002 cited in Cunningham- Burley et al, 2005). It is seen as complex, difficult to understand and negotiate, and confusing. Late or missed payments can result in families going into debt, while changes in payment can exacerbate stress and financial strain. With few resources to fall back on, interruptions, delays or deductions in payments can be extremely destabilising (Ridge 2009; Mitchell and Sloper, 2002 cited in Cunningham- Burley et al, 2005).

For families with disabled children, making successful claims can be difficult even with information (Cunningham-Burley et al, 2005) and parents sometimes need professional help from a social worker or advice worker (Preston 2005 cited in Ridge, 2009). This was reflected in the *About Families* research with families affected by disability. Families affected by disability on the lowest incomes and those from minority ethnic groups are least likely to apply for support (Preston 2004 cited in Cunningham- Burley et al, 2005). Less than half of children affected by disability receive Disability Living Allowance (Preston et al, 2006).

Parents of disabled children can feel anxious about the stigma attached to benefit claimants. However, claiming Disability Living Allowance (DLA) is an essential step in obtaining extra funds to meet the additional costs of disability. DLA can make a significant impact for the whole family, not just the disabled child (Preston, 2005 cited in Ridge, 2009). Receipt of disability benefits can decrease the risk of a child living in poverty by 14% (Department for Work and Pensions, 2011).

Families affected by disability say: 27% of respondents felt they did not have access to information on benefits which could help them with the additional costs relating to disability, either because they were not aware of sources of information or they felt it was difficult to find information. Comments showed mixed experience of obtaining information through health professionals. 30% of respondents said they didn't know if they had access to information on benefits, which suggests a general lack of certainty over availability and eligibility.

Work and care

Parents of disabled children face particular barriers to employment. Employers can be reluctant to allow mothers of disabled children to take time off for daytime appointments or unanticipated ill-health (Dowling and Dolan, 2001 cited in Cunningham-Burley et al, 2005). The need to take unpaid compassionate leave can result in financial uncertainty (Preston, 2005 cited in Ridge, 2009). Since parents of disabled children tend to spend longer periods of time caring for their children, they may take work below their skill level when they re-enter the job market, and experience fewer opportunities for study or voluntary work (Preston, 2005 cited in Cunningham-Burley et al, 2005).

Lack of affordable and appropriate childcare for disabled children is a significant employment barrier (Cunningham-Burley et al, 2005; Capability Scotland, 2003). In Scotland nearly 70% of working parents with a disabled child relied on family members for childcare and half of them did so because of a lack of other suitable childcare (Capability Scotland, 2003). The Scottish Out of School Care Network (Boyd, 2002) reports that very few childminders, out of school care groups and private nurseries have appropriate training and expertise in special needs childcare (cited in Cunningham-Burley et al, 2005). A survey of Scottish rural out of school clubs found that few disabled children were accessing places, even though, in principle, the clubs were willing to accept children with additional needs (cited in Cunningham- Burley et al, 2005).

Disabled adults affected by disability can face particular barriers to employment (Cunningham- Burley et al, 2005; Ridge, 2009; Green, 2007; Capability Scotland, 2003). These include lack of opportunity for education and training (Capability Scotland, 2003), lack of support, inflexible employers, fear of losing benefits and the low-paid nature of much employment (Cunningham-Burley et al, 2005). The need for flexible work patterns to accommodate health-related needs (such as pain, fatigue, unpredictable symptoms and health appointments) can conflict with employers' needs (Salway et al, 2007 cited in Ridge, 2009). Other major barriers include discrimination and prejudice from others, and low confidence (Capability Scotland 2003, cited in Cunningham-Burley et al, 2005).

Families affected by disability say: 90% of parents or carers felt that the circumstances arising from their or their child's disability had an impact on the number of working hours or type of work they could access. The main impacts were either that one parent could not work at all or they could only work part time. 82% of families also felt that the additional challenges associated with having a disabled child made it more difficult to juggle work and family life. Reasons included the need to attend frequent appointments, problems with accessing suitable childcare and the increased likelihood of having to take time off work to care for a sick child.

Families with more than one disabled child say they would prefer:

- better childcare and accessibility to childcare;
- better services and short term breaks; and
- co-ordinated support that is flexible, designed around routines and crises, and meets whole families' needs (Cunningham-Burley et al, 2005).

Impact of the current economic climate

Families affected by disability say: Over 80% of respondents said that their disability related expenditure had increased in the past year. The main areas that had increased were basic commodities such as petrol, electricity, gas, food, and clothing.

What would help families affected by disability?

74% of respondents suggested what would be of greatest help to them in reducing financial pressure and managing family life. The key areas are:

- reducing fuel and utility costs (one parent suggested a 'disability discount' on fuel bills);
- increase in, and certainty around, benefits and entitlements;
- availability of affordable and suitable childcare and short term breaks (including out of 9-5 office hours);
- improved support such as with therapies and equipment; and
- access to work, including flexible hours.

Changes to disability related benefits: The replacement of Disability Living Allowance (DLA) with Personal Independence Payments (PIP) is also likely to result in increased poverty amongst disabled people. The UK Government has announced a 20% reduction in spending on this benefit (HM Treasury, 2010) which is intended to meet the added costs that can arise from having a disability. In addition, the Welfare Reform Bill proposes the reduction of Disability Premiums that families with disabled children receive by up to 50%. The scale of the proposed welfare changes, combined with the on-going cut-backs in existing welfare advice and other local services, are likely to increase anxiety and uncertainty amongst families.

Topic 4 – Parenting and Support

Given the importance of support for parenting, *About Families* asked what research could tell us about how families seek, experience, and manage support from friends, family and formal services.

Gaps in research about parenting and support: Much of the existing research on engaging parents in formal services is from the perspective of service providers rather than those using services. Evaluations of services tend to assess attendance and completion rates rather than outcomes for parents and families. There is little research which explores the characteristics or perspectives of non-service users. It is not clear how social support can be best enhanced for those parents who need it.

There are very few rigorous evaluations of service interventions involving disabled parents. There is very little research about the role or needs of extended family members who are supporting disabled parents.

Disabled parents and support

Although equality legislation requires service providers to make reasonable and permanent adjustments to enable disabled people to physically access services, the number of disabled parents accessing support groups is very low, especially deaf parents and parents with learning difficulties and visual impairments. A mapping of family support services in England and Wales reported that only a fifth of parental support groups made special attempts to include disabled parents (Henricson et al, 2001, cited in Katz, 2007).

Not seeing disability in terms of social disadvantage and restriction of activity effectively means that disability is seen as an impairment, and equates disability with dependency and a need for 'care'. Disabled parents commonly face the assumption that impairment or illness in itself (inevitably) leads to child deprivation, potential harm or abuse. These risks are created and/or exacerbated by the lack of appropriate support, unequal access to mainstream services, negative attitudes, and the poverty and poor housing which can be associated with physical/sensory impairments, learning difficulties, and mental health difficulties.

The parenting responsibilities of disabled parents can be overlooked by services, and only considered where children are viewed as 'at risk' or as young carers. Building in this 'risk' as a starting point can mean parents are anxious about seeking support, and can prevent services from being accessible and responsive to parents' needs.

Social support from family and friends

Families affected by disability can experience negative attitudes from informal support networks. Intolerance and ignorance from extended family members, friends, and people in the wider community can lead to disabled parents and parents of disabled children feeling further isolated and cut off from people they might have previously relied on, which heightens stress for the whole family (Clavering, 2007).

Families affected by disability say: Two thirds of respondents in our survey said they received support from friends and/or family, mainly emotional or social support (someone to talk to/listen). Practical support received was usually childcare, respite or help with siblings. However, 27% of parents said they did not receive any support.

Some parents who received support from family/friends felt their or their child's impairment had a positive impact, such as strengthening relationships by bringing people closer together. However, the majority felt that friends/family had negative attitudes towards disability or difficulties in dealing with disability, which in turn caused stress in relationships. Practical issues arising in receiving support from family and friends included problems with handling specialist equipment or dealing with specific impairments or conditions.

Support from formal services

- *Programmes and interventions*

Families affected by disability say: Nearly two thirds of parents responding to our survey felt they knew how to find services to help them in their role as a parent. Services were mainly found through social services, the internet or other parents.

Respite care was the most requested support service, followed by health/social care and adaptation services. However, parents reported mixed experiences in requesting services, with some saying they find it difficult to get the services they need and feel kept 'in the dark' about their request. Only one in five parents felt they got the parenting support that they needed from services. Respite care and advice were the two key areas that parents felt they were not receiving effective support.

Generally, parents felt dissatisfied with the timescales for services, particularly for respite care. Comments from parents suggested that many had reached crisis point before help became available and many felt that social work departments had created unacceptable delays in providing services.

- *Information and advice for parents*

Families affected by disability say: Just over a third of parents responding to our survey felt they had access to the information they needed about parenting a disabled child, which ranged from general information about impairments and conditions and services/ support to specific information about transitions and benefits.

Many parents said they find it difficult to know where to start to look for information and tend to explore a range of sources before they find the information they require. Professionals were felt to be unhelpful or unforthcoming in providing information.

Generally, parents said they preferred accessing information in print, in person or via the internet. Many parents preferred a mix of formats, with face to face contact offering the opportunity to ask questions and print/internet providing reference material.

- ***Practical barriers***

A range of practical barriers can hinder engagement with services. These include lack of transport; inconvenient timing of classes; pressures on parents' time (particularly for lone parents and working parents); parents' lack of knowledge of services and how they could help; and geographical location (particularly for families in rural areas) (Katz et al, 2007; MacQueen et al, 2007).

Disabled parents can face additional physical barriers to accessing services, including inaccessible transport. Also, lighting and colour contrasts can affect visually impaired parents (Katz et al, 2007).

Families affected by disability say: A quarter of parents responding to our survey felt that the circumstances associated with being a disabled parent or having a disabled child made it more difficult to access services intended to support parents. Suggestions for improving support to parents focussed on increased flexibility, particularly for working parents; effective communication; improved responsiveness to phone calls; more effective information provision; and better understanding of the needs of families affected by disability.

Parents in urban areas generally felt that living in a city meant better access to services. Other factors considered to have an impact on accessing support were: access to information; staff availability; financial resources (both reduced resources for services and financial difficulties experienced by families); and negative attitudes towards disability.

Particular issues for families affected by disability

The additional costs of parenting with a disability are not acknowledged by the benefits system. Additional costs can include increased reliance on convenience foods; increased use of more expensive social activities (because cheaper options are inaccessible); paying for assistance to support parenting tasks; paying a support worker's costs when going out; costs of specialist or adapted equipment; increased transport costs; and increased reliance on childcare (Joseph Rowntree Foundation, 2003).

The 'gap' that exists between children and families' services and adults' services is not helpful in supporting disabled parents in their parenting role (Goodinge, 2000, cited in Clarke, 2010). Disabled parents say they would prefer assistance with parenting tasks to be available from adult community care services. Parents do not want their children to be labelled as 'in need' and feel their own entitlements to support should be recognised (Joseph Rowntree Foundation, 2003).

Practitioners often report a lack of confidence and experience in supporting disabled parents. This is partly due to lack of clarity over whether such support comes under an adult or child social work remit (Olsen and Tyers, 2004). Those working in adults' services report particular difficulties when parents' needs cross specialist service boundaries (Morris and Wates, 2006), and those providing most effective support tend to be comfortable in recognising where they lack knowledge and are able to approach others for advice (Olsen and Tyers, 2004).

Parenting responsibilities of disabled parents can be overlooked by services, and only considered where children are viewed as 'at risk' or as young carers (Clarke, 2010; Joseph Rowntree Foundation, 2003). Some disabled parents report that assessments tend to focus on parental 'incapacity' instead of the support that would enhance their ability to look after their children (Joseph Rowntree Foundation, 2003). A focus on the risk of young people becoming 'carers' presents disabled people as being 'cared for' rather than having active parenting roles, and overlooks the complexity of caring roles within the family (Clarke 2010; Joseph Rowntree Foundation, 2003). The whole family, and how to support and help disabled parents in their parenting role, is rarely considered (Goodinge, 2000, cited in Clarke, 2010). Fear that services might view a child of a disabled parent as 'in need' or 'at risk' can be a barrier to seeking support and may result in anxiety for parents, even where individual workers are experienced positively (Clarke, 2010).

The needs of disabled adults who previously required little support can change when they become parents. They can be seen as unable to meet their child's needs and referred to childcare teams where their own disability may go unrecognised, meaning they do not receive support as parents (Olsen and Tyers, 2004).

Support offered to disabled parents is not always appropriate to their needs, which can increase pressure and stress. For example, paid carers may not be suitably trained, or the time allocation may be inflexible. In addition, refusing one form of support can mean families are not eligible to receive an alternative. This can influence decisions over use of services in the future (Clavering, 2007). In some situations, children are identified as 'young carers' and the only help the family is offered concerns enabling the child to carry on being a 'young carer' (Joseph Rowntree Foundation, 2003)

Seemingly affluent families may still need support. Families with visible signs of relatively high earnings, such as a house, car, or expensive clothes, can experience escalating financial costs and reduced earning capacity after having a disabled child but be denied support on the basis of their previous financial status (Clavering, 2007).

Parents of disabled children develop strategies for communicating with professionals, and some are more able to communicate more effectively than others. For example, some parents report being 'business-like' and behaving assertively in order to be taken seriously. Bureaucratic forms and processes require skills that not all parents possess in equal measure, meaning that some families are more disadvantaged than others (Clavering, 2007). This was reflected in our survey of families affected by disability – parents who felt they were confident and prepared to be assertive felt they were more likely than those who were unconfident to get the support they needed.

For disabled parents, other disabled parents are key sources of information and advice (Joseph Rowntree Foundation, 2003; Clavering, 2007). Health and social services professionals often do not have relevant knowledge or expertise, and neither do voluntary sector parent support organisations. Information and support aimed at parents are often not accessible to disabled parents and do not deal with their particular concerns – including fears about seeking help from statutory services (Joseph Rowntree Foundation, 2003).

- ***What could help?***

Parents of disabled children prefer:

- Above all, parents of disabled children want people to see the child first and the condition after (Clavering, 2007).

Disabled parents prefer:

- Timely, accurate and accessible information in a range of formats and available on an equal basis to that received by non-disabled parents
- Timely and responsive support (e.g. providing home adaptations for a baby before it becomes a toddler)
- To be seen as individuals
- Support which fits in with, rather than takes over, family life and helps parents to retain parental control and choice (to 'do the parenting')
- Professionals with good communication skills who can put them at their ease and allay fears of asking for support. These personal qualities can overcome a lack of specialist training
- Someone fighting your corner: seen as important in reducing barriers to fair treatment, and in supporting parents to access services and other entitlements, such as benefits, a fair hearing in court, and information about assessments
- Flexible support: e.g. support which can be used at short notice and flexibly as their needs and their children's needs change.
- Culturally appropriate support (e.g. assistance in preparing traditional Asian food)
- Imaginative support: e.g. 'walking bus' to school

(Olsen and Tyers, 2004)

Other factors which can help disabled parents and parents with additional support needs:

- **Direct payments** can enable parents to have more choice and control over the way support is provided (Morris and Wates, 2006).
- **Voluntary sector services** which provide support tailored to each family's circumstances are particularly helpful for parents with mental health issues (Morris and Wates, 2006).

- **Services which meet a range of support needs.** This includes information, advice and advocacy, and counselling. Parents particularly appreciate services which enable them to gain support from other parents in similar situations. This range of services is more often found within the voluntary sector than the statutory sector (Morris and Wates, 2006).
- **Services that enable them to have a break from caring for their children.** Such services are particularly likely to be valued by parents who are ill, in pain and/or who experience high levels of stress, and by those who have few informal sources of support to draw on (Morris and Wates, 2006).

Qualities of professional approach found to be most supportive are:
With parents

- Awareness and interest in the wider family context
- Having time to 'sit and listen', take parents seriously and follow up any concerns
- Willingness and knowledge to talk with parents about alternative sources of support and information
- Engaging in a dialogue with parents, to offer information and support appropriate to the family's needs, even if that means acknowledging uncertainty and limits of knowledge, and to proactively seek to develop new skills and/or services when an unmet need is recognised

With children

- Seeing the child as an individual and 'looking beyond the disability'
- Conveying confidence and calm around the child
- Valuing children's achievements outside of established developmental criteria that may at times emphasise all that a child cannot do
- Enough time to build up a relationship with a child

Professional attitudes to disability are important:

- Knowledge about specific conditions, while supporting and celebrating achievements
- An open mind and willingness to challenge existing debilitating norms and stereotypes
- The ability to work with uncertainties and be open to alternatives

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