

# **Hard-working families**

**Caring for two or more disabled  
children**

By Gabrielle Preston

## **Acknowledgements**

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# Summary

## Background

Disability Alliance has been gathering evidence on the extra costs incurred by families with two or more disabled children, and considering whether income from state benefits is sufficient to cover their needs.

## Statistics

There are estimated to be around 5.7 million carers in the UK, of whom about 14% look after a disabled child or young adult. There are around 770,000 children under the age of 16 '*...with a limiting long-standing illness or disability*'. Families with disabled children are particularly susceptible to poverty because low income is compounded by high costs. Over 98% of disabled children are cared for at home.

There are currently between 17,500 and 20,000 families with more than one disabled child, of which about 7,500 families are caring for two or more severely disabled children. This means that there are well over 15,000 severely disabled children living in a family where there is another severely disabled child. Many have non-disabled siblings.

Government statistics indicate that '*...in households with a disabled child but no disabled adult, the risk of children being in a low income household was similar to that for children as a whole*'. However, we are concerned that a significant number of children who live in poverty are not deemed to do so because disability benefits (theirs or their parents') are counted as income, but the huge extra costs associated with disability are not taken into account.

## Government policy

### Child poverty

In March 1999, Tony Blair delivered his historic Toynbee Hall promise that Labour would '*...eradicate child poverty within a generation*'.

## Work for those who can

A number of strategies have been developed by Government to ease the transition from benefits to paid employment, including the introduction of tax credits and help with the costs of childcare. However, combining working (or studying) and caring for a sick or disabled child remains extremely difficult.

Although the tiny minority of parents with disabled children who do work experience psychological benefits, they encounter a huge number of problems including: working below their skill level in exchange for flexible employment; difficulties accessing information about benefits, services and employment; inadequate childcare provision and the failure of educational, social and health providers to take account of their hours of work.

## Security for those who can't

Although the Government has introduced a number of improvements to financial support for low-income families with disabled children, benefit income varies considerably because of:

- Low take up;
- Inadequacy of benefits to cover extra costs;
- Incorrect assessments and the appeal process.

Furthermore, the failure of the social security system to recognise the cumulative impact of caring for two or more severely disabled children militates against the effective targeting of financial support.

## Poverty

Families with disabled children are particularly susceptible to poverty because high rates of worklessness are compounded by high costs. Families with disabled children are more likely to be single parents, more likely to be dependent on income support and less likely to own their own home than families whose children are not disabled. Families with two or more disabled children are significantly more disadvantaged than families who have only one disabled child.

## Extra costs

Research has shown that it costs three times more to bring up a child with severe disabilities than a child without a disability. There are no costs that are lower for disabled children than for children without disabilities.

Costs soar when families are caring for two or more disabled children. Managing simultaneous demands is rendered more difficult by unsuitable housing, lack of transport, restricted opportunities to access leisure facilities, and the number of different professionals and agencies involved in family life.

It is well known that families with disabled children incur extra costs as a direct result of their child's disability. We wanted to investigate what happened to costs when families have to balance the needs of two or more disabled children, sometimes alongside the needs of their non-disabled siblings. This is what families told us.

## Services

Far from reducing costs, an inadequate and fragmented service, or the provision of inappropriate support, often puts costs up.

**Hospital admissions:** *"...everything costs more with hospital visits"*, particularly when the child stays in for a protracted period, and the mother stays with them.

**Medical appointments:** if one child is visiting the doctor there is no provision for caring for the other child(ren), *"...recently I had to refuse a course of speech therapy for my youngest daughter because the times offered didn't fit with the boys"* – mother with three autistic children.

**Childcare/respice care:** although families agree that the greatest help would be *"specialist childminders for both children or other special needs clubs"*, finding somebody who is able and willing to look after two or more disabled children is virtually impossible.

**Transport:** families with disabled children not only use transport more often because of frequent visits to hospitals and clinics, but they also have to pay more. Families feel that there is a 'postcode lottery' in operation in relation to the blue badge scheme.

**Education:** whilst local authorities will usually transport children to and from the school, parents have to pick their child up if they become ill or have a medical appointment in the middle of the day.

**Housing:** families with disabled children are not only more likely to live in damp, cold and inadequate housing – which is more expensive to heat – but they may have to move in quest of more suitable housing, ending up some distance from shops and facilities, putting costs up further.

**Heating and laundry:** keeping disabled children warm – especially in winter when children are often ill – is a constant struggle.

**Special equipment/adaptations:** families report on the need for a wide range of additional equipment that is needed to keep their children safe.

**Replacement of furniture, clothing & household equipment:** families report extra wear and tear and need for more frequent replacements.

**Clothing:** high quality, high cost special clothing is often required.

**Food:** special diets are sometimes needed and food often gets wasted.

**Play, toys, leisure:** entertaining children – who often have to spend a disproportionate amount of time at home – is difficult and expensive. Toys have to be *"...chunky, safe and usable"*. Families can't make do with cheap options. Popping to the local park may not be possible – families may have to pay to go out. Children are *"...harder to occupy as they get older"*.

**Holidays:** *"...oh forget it, forget it! We don't go on holidays, we go on military manoeuvres..."*

**Giving up work:** the biggest cost to families is having to give up paid employment, or being forced to work reduced hours.

## **Evidence from families**

### **Employment**

Although most mothers would like to be in paid employment, barriers include: caring responsibilities, day-time appointments, ill-health, the paucity of suitable childcare and anxiety about losing benefits.

### **Working and caring**

A small number of parents in our study did manage to work. However, employment seems to generate as many problems as it solves.

### **American families**

A number of American families filled in our on-line questionnaire. Although the Labour Government is heavily influenced by policy emanating from the USA, it does not appear to provide a positive blueprint for lone parents.

### **Social exclusion**

High transport costs, inaccessible and/or expensive leisure facilities, and public hostility means that families with disabled children often become housebound. Keeping in touch with other families in a similar situation is difficult. Other problems include:

### **Family outings**

Families miss out on activities that families with non-disabled children who have a similar income can afford.

### **Family breakdown**

Caring for disabled children without adequate support "...puts a strain on a marriage'.

### **Poor health**

For many parents "...poor health", due to stress, prolonged lack of sleep and a poor diet and "...living on the breadline", is a big issue: "...what if we do get ill, what happens then?".

### **Older disabled children**

Families report that current provision for disabled teenagers is inadequate: "...they're lumped in together", even though they have very different needs and interests. Most of the parents feel that costs rise as their children get older.

### **Non-disabled siblings**

The needs of non-disabled siblings is a constant source of anxiety and guilt.

### **Family support**

Extended families are often not able – or willing – to help out.

### **Public hostility**

"...the reaction of other people!" often has an adverse impact on a family's willingness to go out.

### **Benefits**

#### **Access to information**

Families describe "...constantly fighting" to get the information and support they need. Accessing information about benefits is particularly problematic.

#### **Adequacy**

A lot of families feel angry and let down by a benefit system that "...doesn't come near covering our needs". Even when families receive their full benefit entitlement they worry about the future: "...my husband's constant worry is 'how are we going to cope if they scrap carer's allowance or DLA?'".

Problems within the benefit system include:

**Carer's allowance:** the low level of carer's allowance (£44.35pw 2004-5 figures), is considered particularly insulting by families who may be caring for two, three or sometimes even four people.

**Disability Living Allowance (DLA):** families report on inconsistencies within the system: "...we got high rate DLA for our first child, but the second was turned down completely even though she had more problems than the first ...".

**Motability:** families may need a 'people carrier' and therefore have to pay a larger deposit out of their DLA to Motability.

**Social Fund:** families are constantly being turned down by the Social Fund, but an endless round of hospital admissions and appointments means they often can't appeal within the time limit, even though the chances of success are high.

**Family Fund:** families are often forced to turn to the Family Fund, or voluntary sector organisations for support: *"...I'm sick to death of having to beg voluntary sector organisations for money we should get as a matter of right"*.

**Debt**

Families often fall into debt: *"...I borrowed money from friends, different places, and got loads of debt"*.

# Introduction

## Background to study

Disability Alliance has been gathering information about the extra costs incurred by families with two or more disabled children, and considering whether income from state benefits is sufficient to cover their needs.

We gathered evidence directly from families with two or more disabled children. A small number of voluntary sector and statutory organisations (including the Lady Hoare Trust, Ataxia, the National Autistic Society, National Deaf Children's Society, Barnardo's, Parent Partnership, Shared Care Network and Contact a Family) kindly put us in touch with families who had expressed a willingness to participate in our study. Other families read about the study on our website, on the websites of participating organisations, or in specialist magazines. We undertook ten detailed interviews and received 25 questionnaires filled in by families.

We do not, of course, claim that this is a representative sample of families with disabled children. However, many of the issues raised resonate with wider research findings.

## Statistics

### Disabled children

There are estimated to be around 5.7 million carers in the UK, of whom about 14% look after a disabled child or young adult. Until recently, the Government was reliant upon the 1989 Office of Population, Censuses and Surveys reports which indicated that at that time there were 360,000 disabled children in GB aged under 16, of whom 170,000 had a severe disability. However, the Department for Work and Pensions (DWP) – drawing on the Family Resources Survey 2002/03 – calculates that around 700,000 children are covered by the Disability Discrimination Act. More recently, *Improving the life chances of disabled people*, published by the Prime Minister's Strategy Unit, indicates that there are around 770,000 children under the age of 16 *'...with a limiting long-standing illness or disability'*.<sup>1</sup> It notes a

*'...marked increase in the numbers of children with Autistic Spectrum Disorders (ASD) and other behavioural difficulties'*, (many of which are not deemed to be disabilities) and it is likely that this number is higher and growing rapidly.

Over 98% of disabled children are cared for at home.

### Families with two or more disabled children

There are currently between 17,500 and 20,000 families with more than one disabled child, of which about 7,500 families are caring for two or more severely disabled children. This means that there are well over 15,000 severely disabled children living in a family where there is another severely disabled child. Many have non-disabled siblings.

Families with disabled children are particularly susceptible to poverty because of a combination of high rates of worklessness (the majority of families are out of work and wholly dependent upon benefits) and high costs. The recently published analysis of the Family and Children Survey (FACS) reveals that lone parents are twice as likely to have children whose health they describe as 'not good' as a couple family. Five per cent of lone parents care for two or more disabled children.<sup>2</sup>

### Poverty and disability

Although Government statistics indicate that: *'...in households with a disabled child but no disabled adult, the risk of children being in a low income household was similar to that for children as a whole'*,<sup>3</sup> we believe this is a serious underestimate of the true rate of poverty among such children because no account is taken of the extra living costs associated with disability. We are concerned that a significant number of children who live in poverty are not deemed to do so because disability benefits (theirs or their parents') are counted as income, but the huge extra costs associated with disability are not taken into account. (The Government recently indicated that it accepts estimates that 55% of families with disabled children live in, or on the margins, of poverty.<sup>4</sup>)

Compared to families whose children are not disabled, families with one disabled child are more likely to be single parents, less likely to work and more likely to be in semi-skilled or unskilled manual jobs. They are also more likely to be dependent on income support and less likely to own their own home. They are therefore particularly susceptible to poverty.

Families with two or more disabled children are even more disadvantaged than families who have only one disabled child. Research<sup>5</sup> into the numbers and needs of families with two or more disabled children indicate that, compared with families with one disabled child, they are:

- less likely to work;
- experience a greater dependence on benefits;
- have more difficulties accessing support;
- mothers are more likely to have a disability themselves;
- fathers are more likely not to be working because of illness or disability;
- more likely to be lone parents.

These families are therefore particularly susceptible to poverty.

## Background research

### Extra costs

Research reveals that it costs three times more to bring up a child with severe disabilities than a child without a disability.<sup>6</sup> There are no costs that are lower for disabled children than for children without disabilities, (although one mother we spoke to bitterly observes, "...we save costs in that they don't go to 'clubs' like 'normal' children of their age might..."). Unlike families with non-disabled children – who spend approximately 60% of their budget to clothe and feed their child – parents with disabled children spend a substantial proportion of their income on transport costs. A recent report from the Family Fund reveals that families with severely disabled children need an extra £104.68 per week (£5,443.35 per annum) over and above their current incomes because of the "...significant additional expenditure related to the needs of the disabled/seriously ill child".<sup>7</sup>

Furthermore, additional expenses often occur suddenly and randomly (for example when their child falls ill) pushing families into debt. Contact a Family and the Family Fund report that on all indicators of debt, families with disabled children fare worse than families who do not have disabled children. Many families attribute this situation to the added expense their disabled child generates.<sup>8</sup> Families also emphasise other costs – such as; "...being a disabled family'.

Costs soar tangentially when families are caring for two or more disabled children. Managing simultaneous demands – taxing in itself – is rendered more difficult by unsuitable housing, lack of transport, restricted opportunities to access leisure facilities, and the number of different professionals and agencies involved in family life. Families feel that having two disabled children is "...more than double", having one disabled child, but suspect that support systems try to get "...two for the price of one". Given that two carers are often needed very few parents are in a position to work, although the majority would like to.

### Employment

The Government emphasises that work is the primary route out of poverty. However, despite Government initiatives to draw mothers – specifically lone parents – into paid employment, combining working (or studying) and caring for a sick or disabled child remains extremely difficult. Only 3% of mothers with disabled children are in full-time employment (compared with 22% of mothers with non-disabled children) and only 13% manage part-time work (compared to 39% of mothers with non-disabled children). 85% of mothers with disabled children are not in paid employment.<sup>9</sup> However, according to a survey undertaken by the Council for Disabled Children, 85% would like to work – at least part-time.

Although combining employment with care of disabled children has financial and psychological benefits, research undertaken in 1998<sup>10</sup> indicates that parents with disabled children:

- often work below their skill level in exchange for flexible employment;
- report that benefits do not adequately compensate them for loss of earning and extra costs associated with disability;

- find it difficult to access information about benefits, services and employment;
- experience inadequate childcare provision;
- report that educational, social and health providers do not take account of their hours of work;
- find it stressful filling in assessment forms repeatedly for different public bodies.

The report concludes that there is an urgent need for co-ordination between employers and service providers.

## **Social exclusion**

High transport costs, inaccessible and/or expensive leisure facilities, and public hostility means that families and their children are often housebound. Keeping in touch with other families in a similar situation is difficult. Although extended family can be a valuable source of support, the families who participated in our study report that even when relatives live nearby, they are often daunted by the prospect of dealing with two or more disabled children – particularly if they have behavioural difficulties. Families usually have to cope on their own.

## **The benefit system**

Although the Government has introduced a number of improvements to financial support for families with disabled children, the failure of the social security system to recognise the cumulative impact of caring for two or more severely disabled children militates against the effective targeting of financial support. In her report on families with two or more disabled children, Rosemary Tozer comments that: *“Sometimes it is the combination of the children’s personalities and their differing needs, rather than their individual impairments, which are particularly difficult for them and their families to manage.”*<sup>11</sup> A benefit system that focuses on disparate individuals and fails to take a holistic view of a family’s needs ignores a sea of hidden and unmet financial needs.

Drawing on families’ comments and experiences, this report considers the impact Government strategies and policies to reduce child poverty have had on the lives of families with two or more disabled children.

# Policy context

## Child poverty

In March 1999, Tony Blair delivered his historic Toynbee Hall promise that Labour would “...eradicate child poverty within a generation”. The Treasury subsequently delivered ambitious targets on child poverty: Labour would reduce the number of children living in poverty by at least a quarter by 2004 on the basis of the 60% median income as reported in Households Below Average Income (HBAI). The Government’s commitment to halve child poverty by 2010, and eradicate it by 2020 will be assessed on the basis of three new measurements of child poverty published by the DWP in the wake of an extensive consultation exercise.

## Absolute low income

Children are counted as poor on this measure if they live in a household with a before housing cost (BHC) equivalised<sup>12</sup> income of less than 60% of the 1998/99 median income, uprated for inflation.

## Relative low income

Children are counted as poor if they live in a household with a BHC equivalised income of less than 60% of the contemporary median.

## Material deprivation and low income combined

Children are counted as poor if they live in a household with a BHC equivalised income of less than 70% of the contemporary median and if they lack material necessities and cannot afford them.

The DWP indicate that poverty will only be deemed to be falling if all three measures show a decline in the number of children in poverty.

## Work for those who can

Focusing on work as the primary route out of poverty, New Labour has implemented a number of initiatives designed to draw marginalised groups – such as lone parents and disabled people – into paid employment. A number of strategies have been introduced to ease the transition from benefits to paid employment, including the

introduction of tax credits and help with the costs of childcare. However, high levels of poverty in ‘workless’ families generates concerns about the Government’s commitment to providing ‘security for those who can’t’ work. Recent research indicates that while ‘work for those who can’ has made a real contribution to reducing poverty, there is a limit to how much further employment measures will help. ‘Security for those who can’t’ is essential to maintain the progress that has been made so far.<sup>13</sup>

## Security for those who can’t...?

The Government recognises that families with disabled children incur extra costs, and has introduced a number of significant improvements to disability benefits for low income families with disabled children: financial support for such families has risen by 103% since 1997. Low income families who have a severely disabled child have seen an increase of 184%. (For example, by 2004, the disabled child premium in child tax credit had doubled, from £21.45 to £42.49, and the carer premium had increased from £13.65 to £25.55.)

However, benefit income varies considerably for the following reasons:

### Low take up

Research undertaken by the DWP (previously the Department of Social Security) indicates that take-up of disability living allowance (DLA) is low – estimated at between 40% and 60%. A complex system puts many families off applying. Families may think “...everybody has to care for their children” and so fail to apply for carer’s allowance, or “...my child isn’t disabled”, so fail to apply for DLA. Applications seem to have an infinitely greater chance of success if support is provided by an advice worker.<sup>14</sup>

### Lack of information and incorrect assessments

Parents of disabled children often fail to get their full benefit entitlement because of lack of information and support. (“...nobody tells you

anything"). The Audit Commission reports that families are sometimes given incorrect advice by medical practitioners upon whom they may rely for advice.<sup>15</sup> A disturbing number of families have never received benefit advice.

Furthermore, research indicates that 'socially disadvantaged' families are less likely to apply for DLA and carer's allowance and are more likely to be turned down if they do apply, or to be awarded lower rates than families with similar needs. Families from minority ethnic groups are even more disadvantaged than already disadvantaged white families with a disabled child.<sup>16</sup>

### **Appeals**

A number of families report applications for benefits being refused, downrated, or withdrawn. Balancing appeals and tribunals alongside hospital appointments and assessments is clearly extremely stressful, and has an impact on a family's ability to launch a successful appeal. Although 54% of people are successful at DLA appeals families tell us that the daily demands on their time often prevent them appealing against poor decisions. One family we spoke to had spent 12 months appealing against a decision to withdraw DLA and thus missed the deadline for applying for a Motability car.

Families who do get DLA comment on discrepancies within the system. One mother in our study who has two autistic boys was awarded the middle rate for her older son and the higher rate for her second son, even though he had lesser needs: "...but I'm not going to complain...a review might reduce both their rates".

### **Inadequacy of benefits**

Even when families do receive the maximum benefit entitlement, they often find that it falls well short of the minimum budget needed to care for a disabled child. Families with disabled children who took part in the Barnardo's study '*Still Missing Out*',<sup>17</sup> reported that recent improvements in benefits for disabled children – for example increases in the child premium of income support and extending the higher rate mobility component of DLA to three and four year old children – had made little or no difference to their financial situation. Families are particularly concerned about their children's transition to adulthood.

The Government is rightly proud of its record on child poverty. By 2004-5 financial support for children via tax credits, child benefit and other benefits will have increased by £10.4 billion in real terms from its 1997 level, a rise of 72%.

However, research undertaken by Gabrielle Preston at the Centre for Analysis of Social Exclusion (CASE) reveals that problems with the administration of DLA continue to undermine Government initiatives on child poverty for families with disabled children. Whilst families who participated in the CASE study experience a welcome rise in income when their child is awarded DLA, they report a sudden and sometimes catastrophic drop in income when DLA is downrated or withdrawn. As a result, they were sucked into an endless round of time-consuming and stressful benefit tribunals. Although more often than not DLA was reinstated at appeal, families worry that it will simply be downrated or removed again in the future. This financial roller-coaster undermines feelings of security and generates significant fluctuations in family income. Families who are on income support are particularly vulnerable to dramatic reductions in income.<sup>18</sup>

Families who participated in Disability Alliance's study also report that they are "...barely getting by financially".

# Evidence from families

## Employment

Although mothers with disabled children bitterly resent being told they are not working or are 'inactive', most would like some kind of paid employment outside the home for a few hours a week:

*"I would love to go back to work (for two days a week), to sort of do my own thing, be my own person for a couple of hours a day."*

*"It would give me a chance to breath."*

*"It would help with my depression."*

## Barriers to employment

However, barriers to employment are wide-ranging and seemingly endless. Caring responsibilities, day-time appointments, ill-health, the paucity of suitable childcare and anxiety about losing benefits, prevent many families seeking paid work. Finding the time, energy and money to access childcare, let alone look for a job, is difficult for families who lurch from one crisis to the next. *"Just as you think you've got on top of something, something else happens."*

## Fear of losing benefits

The conviction that the system is *"...out to get us"*, remains an inhibiting factor as far as paid work is concerned: mothers tell us they are worried that they will lose carer's allowance, or their children will lose their DLA. A mother with two deaf children expressed anxiety about undertaking training to help her get a job, because she assumed she would lose her carer's allowance.

## Medical appointments

A mother comments: *"Because I have three children with disabilities, they've all got different appointment times, so when I take one child for an appointment to the hospital, I have to pay someone to look after my other children because my husband (who is severely disabled) can't do it. They make no allowances for that, none whatsoever. I have to pay somebody to get a child into a wheelchair, get them ready for school. Before they*

*get my son (who is hyperactive) ready they have to catch him first...With six monthly reviews I sometimes have four or five appointments in a very short space. That does hammer you."* Another mother comments *"...sometimes I have three or four appointments in a week"*.

## Studies interrupted

One mother reports that although her husband is desperately trying to learn English so that he can get a part-time job: *"...his studies are constantly interrupted by hospital appointments"*. She adds that it would be difficult for him to work, *"...because there's so much physical lifting of the children which only he can do"*.

## Schools

Even when their children start school, families with disabled children have to be available to collect them if they become ill, or the school can't cope with their behaviour. A mother with two autistic sons bitterly observes: *"My eldest son was excluded from his mainstream school in January and was out of school for four months. What would I have done if in work or on my own?"* She adds: *"...they know I'm there, they call me."*

## Childcare

A lone parent writes: *"...I would like to be able to work full-time, if there was affordable and available childcare to look after children with severe autism and learning disabilities"*.

Another mother comments, *"...what would be helpful would be the provision of services that other parents take for granted such as holiday play-schemes and after-school clubs, then I could work"*.

## Disability and ill-health

Given the link between disability and poverty, and poverty and ill-health, it is hardly surprising that parents are often disabled themselves. Sometimes health problems preceded the birth of their disabled children, but sometimes it is a direct result of the stress and strain of caring for their disabled children on an inadequate income with little or no support.

One mother writes: *"...the stress of looking after three disabled children is relentless. My husband has been on anti-depressants for years and has had to be off work on several occasions. Yet he has a very understanding employer"*.

Another mother reports that she developed epilepsy because of high stress levels involved in looking after her two disabled sons without adequate support. Although her partner has continued to work, balancing the demands of his job and his sons' needs has generated high blood-pressure and exhaustion.

A mother who has two severely disabled children and is on incapacity benefit writes: *"...I suffer from depression and regularly attend a psychiatrist who feels my condition is caused by family circumstances"*.

Another mother explains: *"...I am not disabled but due to having to handle my two disabled children, arthritis is setting in in my elbow joints and shoulder joints, as well as back and neck strain. I do get stress-related illnesses as well, and am taking prozac to help"*.

A mother who has a nine year old son with diabetes, and a four year old daughter who is deaf, reports that she did try and return to work after the birth of her daughter but *"...it was a disaster"*, placing additional strain on her partner, her relationship and her health (she has recently developed a stomach ulcer).

### **Caring for disabled adults**

A number of parents who participated in our study care for a disabled adult as well as their disabled children. One family with two severely disabled children and three younger, non-disabled siblings, have recently taken on responsibility for a disabled grandparent.

### **Family breakdown**

Relationships are clearly put under considerable strain. A number of mothers report that their relationships have broken down, *"...because of the children's disabilities"*. For a lone parent, combining caring for two or more disabled children and paid employment is virtually impossible.

### **Working and caring**

Although combining paid employment and caring is clearly challenging for all families, a number of parents in our study did manage to work. However, far from providing the security the Government aspires to, employment seems to generate as many problems as it solves. Partners who combine caring for their disabled children with paid employment report high levels of stress and depression, while the parent with full-time caring responsibilities often feels frustrated about having to cope with daily battles and demands on their own.

One lone parent who is struggling to combine working with caring for her disabled children writes: *"...I would like to be able to work full time hours, if there was affordable and available childcare to look after children with severe autism and learning disabilities... I have not yet found a suitable childminder to deal with my two children so I have to work school hours, term-time only, which restricts me to certain jobs"*. She adds, *"...although my parents are within five miles of our home, they are elderly and do not really understand the difficulties that come with having to raise two children with special needs, alone, on a low income"*.

One mother with two autistic sons comments: *"...my husband would like to reduce his hours to help (with the children) but we can't afford for him to do so"*. Another observes, *"in an ideal world my husband wouldn't have to work, because we need two full-time carers"*.

A couple with two autistic boys are both struggling to remain in employment. The father works full-time, and the mother (who gave up her full-time career to care for her sons) has taken a part-time evening job in Safeways which she can go to as soon as the father returns from work to care for the boys. However she reports that the family is *"...teetering on the edge"* all the time.

A lone parent father writes: *"It would be impossible for me to work at the moment because my youngest autistic son will not stay with anyone else."*

## American families

Although we were gathering information from families with two or more disabled children living in the UK, a number of American families filled in our on-line questionnaire. Although the Labour Government is heavily influenced by policy emanating from the USA, it does not appear to provide a positive blueprint for lone parents. A particular source of distress is the federal Temporary Assistance for Needy Families (TANF) rules which allow welfare recipients to receive cash assistance (a limited sort of income support) for a maximum of five years, although many states have implemented shorter limits.

One mother writes: *"I lost two jobs because of my sons' disabilities, not being able to have a normal life and be dependable because of not being to work on time and having trouble keeping daycare for my son."* She suffers from anxiety and panic attacks, and adds, *"...I am not able to work right now because of all the appointments during the day for myself and the children"*.

Another lone parent writes: *"It would be great to have available support, such as childcare when they are sick, after school programs/activities that someone would assist them to be able to be involved in."* She emphasises that not working *"...is not an option for me. If I don't work, we don't have a roof over our heads, or food in the fridge. It's hard enough to provide that working full-time, as I don't make a lot of money doing what I do, and unable to put in more hours, like in the summers... Was on TANF for a while, until it got close to the two year limit, they were cutting it off, and I had no choice but to go to work, though it's really a struggle to juggle the appointments, the illnesses, etc"*.

## Extra costs

It is well known that families with disabled children incur extra costs as a direct result of their child's disability. We wanted to investigate what happened to costs when families have to balance the needs of two or more disabled children, sometimes alongside the needs of their non-disabled siblings. This is what families told us.

## Services

Far from reducing costs, inadequate and fragmented services, or the provision of inappropriate support, often puts costs up.

### Hospital admissions

Families report that: *"...everything costs more with hospital visits"*, particularly when the child stays in for a protracted period, and the mother stays with them. Transport backwards and forwards to see the children who are at home, financing additional caring and domestic support, parking, toiletries, pyjamas, food for the parent staying with the child – the list is endless. Hospitals often rely upon a parent to help care for their child whilst they are in hospital. Furthermore, although repeated or protracted admissions generate enormous costs, DLA and Carer's Allowance is removed, leading to a drop in weekly income of up to £158.70.

Balancing disabled children's complex needs alongside their non-disabled siblings is a nightmare that has an impact on the whole family. One mother has two teenage daughters who are severely disabled and a six-year-old son who is in and out of hospital *"...sometimes twice a month"*, because he experiences allergic reactions. He also has ADHD (attention deficit and hyperactive disorder). When the girls are admitted to hospital, they tend to go in for three or four weeks, during which time she stays with them. As her husband is seriously disabled, when any of her children are admitted to hospital she has to pay somebody to help out in the mornings and to prepare an evening meal, *"...I have to pay somebody to get a child into a wheelchair, get them ready for school. Before they get my son ready they have to catch him first"*. She adds, *"...there have been instances when we haven't been able to provide both morning and evening support"*, so she has to rush home from the hospital first thing in the morning to help get the children up and ready for school and then return to the hospital. Although the hospital is reliant upon her to help care for her son, it *"...provides nothing!"*. She even has to provide her own food.

Another mother poignantly describes the terrible stress and strain the family were put under when her son was admitted to hospital for a month and she stayed with him. The family do not have a car,

and had to travel backwards and forwards from their home in east London to the hospital in Stanmore (in NW London) on public transport. The mother had to return home every two to three days to sort out clothing, food, uniforms and ironing for her severely disabled daughter and three younger children. Her husband had to balance constant visits to the hospital to bring food, with his caring responsibilities back home. During her son's hospital admission last year, the family flew her husband's mother over from India to help out with the younger children, "...but she cannot carry her 13-year old grand-daughter up and down stairs to get her ready for school in the mornings and up to bed in the evenings" (a process that takes 2 – 3 hours every day).

The family – who have recently been turned down by the Social Fund for a grant to cover additional costs – are desperate, "...I don't know what I'm going to do". The children's mobility will never get any better, but "...hopefully the operation will take the pressure off their lungs and kidneys, improve breathing and help them sit up a bit straighter.". In the wake of the operation her son was desperately ill. He couldn't be hauled up and down the stairs, and therefore had to sleep downstairs, "...he had to use a bath in the kitchen, and a commode". The family – who have now been re-housed – have recently been through the same process with their daughter. Just before the mother went into hospital to be with her daughter, her son caught pneumonia, and his weight went down to four stone "...he caught every little bug". Because she was caring for her daughter in the hospital, her son had to go into respite care for eight days: "...my brother was here for two weeks, he helped out with my mum (who is disabled, and has recently moved in with the family) and the kids – but social services don't give you much help".

### Medical appointments

These also generate additional costs. One mother explains that when her nine-year-old son (who has diabetes) has a hospital appointment, she has to take her five-year-old daughter (who is deaf and has severe behavioural problems) along as well, "...We can't leave her because there's nobody who signs". However, because "...he runs away all the time, her father has to take the day off work to look after my daughter when my son has a short appointment".

Balancing different appointments doesn't just generate extra costs; it can have an impact on a child's treatment. A mother with three autistic children tells us: "...recently I had to refuse a course of speech therapy for my youngest daughter because the times offered did not fit in with the boys. She will have to wait until September at least before being offered another course".

### Childcare/respite care

Childcare is a perennial problem. Although families agree that the greatest help would be "...specialist childminders for both children or other special needs clubs", finding somebody who is able and willing to look after two or more disabled children is virtually impossible.

A mother summarises the problems: "To find suitable childcare is almost impossible. We rely on close friends for emergencies as they know the children and the children know them. We can't, for example, ring an agency and get any babysitter/childminder. We need someone who has knowledge of autism and who would get to know the children and all the strategies we use at home.' Other families agree. A mother comments: "...no babysitter can handle two. One is hard enough.' Another writes: "...childcare is too expensive for two children and is not easily available. Nobody will take them on unless we pay a lot of money". A mother with two severely disabled children writes: that "...as they require a very high level of supervision to keep them safe, if (childcare) was available I would not be able to afford it".

Access to statutory childcare services is more difficult for families with two or more disabled children. One parent writes: "We occasionally use Family Link for (our daughter) but they won't take both and won't take (our son) who is the most difficult." Another comments: "Social services, Family Link etc. have not found anyone to take two or come round to baby sit two."

Families emphasise that they do not just struggle with childcare for their pre-school children, but often need childcare right the way through their children's teens – and beyond. One mother explains: "...my son's 17 and he still needs a lot of caring – but after they're 16 they don't help you any more".

Furthermore, whilst extended family are a welcome source of support, families we spoke to feel that their immediate family are often daunted by the prospect of helping with two or more disabled children, or grandparents are too elderly or infirm to help out.

### Transport

Transport is one of the largest sources of additional cost. Families with disabled children not only use transport more often because of frequent visits to hospitals and clinics, but they also have to pay more.

A mother writes: *"...my husband needs the car for work and I use taxis to transport the children to hospitals and the GP – a round trip of more than 20 miles"*.

A car is often essential. One mother comments *"...the Council provides a free bus pass, but the girls can't get on a bus... I didn't bother to get it this year"*. Another mother observes: *"...ultimately we would love to buy a car so we can do things together as a family, but it would have to be very large to take all the family and the wheelchairs"*. The family would like to be in a position to rent a car for a day for occasional outings. For the moment however they report that: *"...when we go out, we have to pay for two taxis, and they charge for the extra children, which they shouldn't"*.

Another writes: *"...as we have just lost the Motability component we have had to buy an older car which has put a further financial burden on our family. A car is absolutely essential for us to function as a family"*. One mother comments that ideally her family needs two cars: *"...because we have to be in different places at the same time"*.

### Education

Although families usually do not have to pay for education, appropriate schools are often a long way from home and whilst the local authority will usually transport children to and from the school, parents have to pick their child up if they become ill or have a medical appointment in the middle of the day. Parents often have pagers or mobiles so they can be contacted in an emergency. *"I have to keep a mobile phone so that I can be reached at all times, as I'm the only parent..."* (The need to be available during school hours seriously undermines

a parent's ability to access paid employment – the biggest cost of all.)

Although the school will provide special educational equipment for the child, families may have to buy children special drink containers and cutlery. Furthermore, as one parent observes, special equipment is expected to last all year, and she has to pay for replacements when things go missing.

One parent had to buy her daughter a power chair when she transferred to secondary school: *"...because she's able to walk a little bit, she didn't get a grant – the council said it was only available if she sits in it 24 hours a day. It cost £3,366 – I had to take out a loan that I'm still paying off. It got broken because she took it to school – I'm trying to get the school to pay to fix it..."*, she adds: *"...nine times out of ten, I have to spend 20 minutes in the mornings fixing the wheelchair"*.

### Housing

Day-to-day problems are exacerbated by poor housing. Families with disabled children are not only more likely to live in damp, cold and inadequate housing – which is more expensive to heat – but they may have to move in quest of more suitable housing. This could be some distance from shops and facilities, putting costs up further. One mother writes: *"...we are not within walking distance of any facilities so yes, it does have an impact on costs"*. Another writes: *"...live in a tourist area – so very expensive..."*.

### Other costs

#### Heating and laundry

Keeping disabled children warm – especially in winter when children are often ill – is a constant struggle. One mother comments: *"...after (my son's) operation he had to stay downstairs, and it was freezing. The door's always open and we don't have carpets and it's impossible to keep it warm... the fan heaters are on all the time"*. Another explains, *"...the heating is on at night as (my autistic son) will wake up if he's cold"*.

Washing clothes and sheets is an ongoing problem. A mother with three disabled children and disabled husband comments: *"...the washing machine is on at least five times a day and that's on a good day!"*.

A mother writes: *"Laundry is completely out of control as the children are very messy and not fully toilet trained. I need the laundry to be quick which means using the tumble dryer all the time, this is very expensive."*

### Special equipment/adaptations

Families report on the need for a wide range of additional equipment that is needed to keep their children safe. This includes: putting locks on all pieces of kitchen equipment, windows, doors and garden gates; high garden fences; 'stable' doors on all the bedrooms which prevent the children 'escaping' but allow a parent to check on them; the installation of special low pressure taps in the bathroom, *"...to avoid it flooding too quickly"*; CCTV cameras for night-time epilepsy and sleepwalking; waterbeds and 'special chairs' *"...because of perpetual bedwetting and nose bleeds"*, a giant cot-bed (£1,500). *"Two way locks fitted to all internal doors for safety... new double glazed fire escape windows fitted throughout with special locks."*

Although financial help is sometimes available, families can't always wait for this to be processed. One family who had their bathroom renovated to make it safe for their children comments: *'... we paid for this ourselves because the housing executive took so long to process the applications for home improvements that we could not wait any longer...we took out loans to cover the renovations'*.

Another family who received a grant from a charity for a computer (which was a *"...an absolute God-send"*), still had to buy a sloping board, computer table and chair for use at home, £14 a year insurance and £20 a month to get 24 hour BT internet access: *"It's impossible to go to the library..."*.

### Replacement of furniture, clothing & household equipment

Sorting out broken or damaged equipment is an ongoing problem. One mother explains that: *"...with three wheelchairs in the house, things get bashed and broken"*. They *"...crash against doors and furniture and scrape the paintwork"*. One mother reports that her autistic sons are very destructive and things constantly need replacing – including clothes. A mother writes: *"...have had to*

*replace child-2's bed twice as he uses it as a trampoline, but because of his disability he doesn't understand why he shouldn't do it"*. Another comments that her daughter destroys everything: *"...including the curtains"*. One family constantly need to buy extra bedding *"...as older son's nappy leaks overnight"*. Another tells us: *"I go through at least seven sets of sheets a month – they don't take any notice of that!"*

### Clothing

High quality, high cost special clothing is often required. A mother explains: *"...you can't buy off the peg clothes for them – you've got to buy what they can wear and fit in the wheelchair"*. Two of the families buy special shoes from a firm in Sheffield that cost £142 (*"I can't buy them in the high street – they have to be made specially. I need two pairs for both the girls every year"*). One mother reports: *"...I don't buy anything with buttons or fasteners"*.

Families find it difficult to shop around for clothes and shoes – which need to be regularly replaced. *"My son will ruin his (shoes) very quickly due to his crawling on all fours."* Another parent reports the same problem with constant holes in her son's trousers *"due to crawling"*. A lone father writes of his two autistic sons *"...they go through clothes, shoes, bedding much more than their brother. At the moment the cost is increasing and has never gone down"*.

### Food

Special diets are sometimes needed: *"...(my son) has a lot of gluten-free products – pasta, biscuits and pastries... and they cost more"* and food often gets wasted. A lone parent comments: *"I have to buy high quality food to help keep their immune system strong, special supplements that are pretty expensive...and try and keep them from getting sick all the time, so I can work."*

Another reports that she *"...buys a lot of disposable plates, cups and plastic cutlery"* because of breakages and a family who do not have a car explains: *"...we can't shop around"* so they have to buy food from the local shops which they fear may be more expensive.

## Play, toys, leisure

Entertaining children – who often have to spend a disproportionate amount of time at home – is difficult and expensive. Toys have to be “...*chunky, safe and usable*”. Families can’t make do with cheap options. “...*I’ve got about 400 videos because they can’t go the pictures*”. Although computers and televisions are viewed as essential, one mother comments that her perpetually housebound children “...*get bored very easily, but they need more than the television and the computer*”. She and her husband are often too exhausted to entertain them. Another comments: “...*my son has a nintendo and a playstation – because you can’t let him out... All the children have a tv in their room – it took us years get them. People come out and say ‘she’s a spoilt brat’ but they don’t understand*”. A mother with two autistic sons and a daughter with ADHD tells us: “...*you take them out somewhere, you pay the entrance fee and it might be expensive, then the children want to go straight home*”.

Popping around to the local park is sometimes difficult, and families may have to pay to go out. One mother observes that: “...*the costlier leisure activities tend to be more successful, like going to the zoo or to a theme park*”. She would like “...*an inclusive play area in at least one local park...where my son’s needs are understood and where we could meet other parents*”.

Sharing may be more difficult to organise with two disabled children: “...*because they can’t get out, the girls are very jealous of their space and things ... anyway, they like different things*”. One family had to buy an extra television for their eldest, non-disabled child because their two autistic sons repeatedly watch the same video. A father with three sons, two of whom are autistic writes: “...*I have saved for a computer for my boys which both schools agreed would benefit everybody and which no charitable organisation would help with. But caused problems as they all want to use it at the same time*”.

The mothers feel that their children are “...*harder to occupy as they get older*”. They “...*can’t go swimming, or clubbing, to the park*”. One mother with two teenage daughters comments “...*I have to work around what she’s good at and take it from there*”. One of her girls is passionate about

pets “...*so now we’ve got four kittens, a dog somebody threw off the railway lines, two gerbils, two hamsters, two fish and two frogs*”. The vet’s fees are extortionate.

## Holidays

One mother comments: “*Oh forget it, forget it! We don’t go on holidays, we go on military manoeuvres...you have to think of every detail – is there a petrol station with a toilet where they can get in? I have to devise a route...It’s a nightmare – you’ve got to check if the station is accessible, and then you’ve got to check the train – make sure the children aren’t stuck in the guard’s van. And then you have to check if you can get to the buffet, and of course you can’t, so you’ve got take everything you could possibly need...and then you’ve got to check if the beach is accessible...and then they tell you ‘Oh there’s no room for wheelchairs, you can’t use the dining room until it’s empty’ so you have wait to the end of the breakfast session and everything’s cold...’*”

Going on holidays with two or more disabled children is virtually impossible for lone parents – and not just because of the cost: “...*I cannot go away unless I can find another person to go with me – impossible to do alone*”.

A parent writes: “...*holidays used to be cheap camping affairs before my son. Now we have to rent houses and research thoroughly beforehand to make sure he will be safe. Foreign holidays are more successful because the weather is less restrictive and he is calmer outdoors*”.

Leaving a home environment that has been adapted to suit children’s needs can be hazardous. A mother with three children, two of whom are severely disabled writes: “...*when the children are away from their home environment the situation becomes unsafe and supervision has to be increased...*”, she adds: “...*we have given up on (family holidays) as so often we have had to pack up and come home early as we could not cope with the extra supervision that was required when the children were out of their safe environment. We would have to buy alarms for doors and windows in holiday accommodation and even then we would be more or less confined to that accommodation*”.

### **Giving up work**

The biggest cost to families is having to give up paid employment, or being forced to work reduced hours. Sometimes both members of a couple are forced to give up work to help care for their disabled children. A mother reports: *"...my husband and I had to give up work for ten years to look after our three disabled children"*. Another writes: *"...our biggest financial drain has been that I have had to give up work and my husband has to work part-time and take holidays off, mainly unpaid (luckily his employer, the NHS, has been extremely understanding)"*.

### **Social exclusion**

High transport costs, inaccessible and/or expensive leisure facilities, and public hostility means that families with disabled children often become housebound. Keeping in touch with other families in a similar situation is difficult.

### **Family outings**

Families miss out on activities that families with non-disabled children who have a similar income can afford, for example (in the words of one mother): *"...trips to the cinema, swimming pool and other leisure activities. Eating out together is impossible, eating together in our own home is a nightmare, which means there is no way we could have friends round for a meal"*. A father whose wife and daughters are severely disabled writes that his family misses out on: *"...holidays, spontaneity, blending into the crowd, taking quick journeys for this and that"*.

A lone parent lists the things her disabled boys miss out on: *"...joining clubs, going on proper holidays, being able to access play schemes during the holiday, as child 2 is severely disabled he cannot access a vast range of activities without constant supervision, bike rides, days out to theme parks, going out for meals, birthday parties, picnics, staying over at friend's houses, not having to plan each to military precision"*. She adds: *"...we are restricted where we go out, even a trip to Sainsbury's, where we go every week, can result in a screaming fit and leaving the shop without purchasing anything"*.

A lone parent writes: *"...I can't leave my son alone in my house for fear that he is going to hurt my*

*daughter or go outside and do what he wants no matter what the consequences are"*.

### **Family breakdown**

Caring for disabled children without adequate support *'...puts a strain on a marriage'*. A lone parent writes: *"The biggest cost was the breakup of the family. My husband couldn't handle the intensity of this responsibility."*

A couple in which the father works full-time (*"...so we have more money than many others"*), report that high levels of stress *"...put the relationship under constant stress...There's not time to be together as a couple, let alone as a person"*. She demands: *"...why isn't there more prevention – it's only when the child is actually ill that they get support"*.

The inability to go out compounds high levels of stress and takes its toll on relationships: *"...we haven't been out together for three years... even though we can pay (for childcare), we can't find anybody"*.

### **Poor health**

For many parents poor health – due to stress, prolonged lack of sleep and a poor diet and *"...living on the breadline"* – is a big issue. Mothers worry that the impact of stress and strain on their health will undermine their ability to care for their children: *"...what if we do get ill, what happens then?"*.

As one mother comments: *"...we don't go out at all, eat on the run, have a restricted diet (the children have to come first), can't afford the dentist or prescriptions"*. Another mother comments: *"...I had to pay my dentist three times and I haven't got there because of transport problems"*. Another reports that the father takes anti-depressants and needs *"...constant visits to the doctor and counselling"*.

One mother – who has five children, two of whom are severely disabled – reports that: *"...there is a great deal of carrying of the children"*. She and her husband *"...have to get up eight or nine times a night to turn the children"*. The stress has had a huge impact upon their health. She has developed asthma and her husband has a stomach ulcer and back problems. She recently reported that: *"...my*

*chest has got even worse, I have three inhalers and I'm on anti-depressants. Sometimes I can't even get up the stairs".*

A mother with a disabled husband, two seriously disabled daughters, and a hyperactive son with health problems comments: *"...a couple of months ago I had all three down at the same time. My doctor put me on anti-depressants...this is my biggest nightmare. It's only happened the once – I don't know how I would cope if it happened again".*

### **Older disabled children**

All of the mothers whose disabled children are teenagers expressed outrage at the woeful lack of suitable teen-based clubs or leisure activities. One mother complained that current provision for disabled teenagers is inadequate and complained that *"...they're lumped in together"* even though they have very different needs and interests. *"Actually the biggest difference for my 13 and 11 year olds would be if somebody would come and take each individual girl to a club they liked to do the things they like so that I could breath for a bit and they could do what they want."* Her daughter is trying to start up a teenage club *"with computers and discos and things"*. She comments: *"...there's nothing for children with mobility problems who are doing well academically – for their particular needs"*.

Most of the parents feel that costs rise as their children get older. The sort of short-term, additional costs that are triggered by a new baby (nappies, special foods, toys to entertain them at home) may continue throughout childhood – as does the stress of caring for children 24 hours a day. For some families, their caring responsibilities may last into adulthood.

### **Non-disabled siblings**

The needs of non-disabled siblings is a constant source of anxiety and guilt. One mother comments that she feels *"...constantly guilty and worried"* about her younger children, but explains that her two disabled children *"...have to come first"*. Another mother who has two autistic sons, comments of her third child: *"...I am constantly beating myself up about this...he is very emotional, very sensitive. When he wants to be, he's so good with them but there are so many things we can't*

*do, places we can't go"*.

A lone father writes: *"I try to treat all three boys the same but I have to admit my youngest son does receive extra treats to make up for the extra time and energy I have to spend on the other two."* Another comments: *"...the younger ones go without things"*, because *"...the older two (wheelchair users) have to come first"*.

A mother who has two severely disabled children, and a non-disabled child writes: *"...we took out loans to cover the renovations including a fourth bedroom for John as his non-disabled brother Thomas refused to share with him, we also felt that Thomas needed a room where he could escape from the other two children who are very demanding and destructive to Thomas's personal things"*. She adds *"...the main thing (Thomas) goes without is time, as so much has to go on looking after the disabled children. They lose out on holidays as we have no time to do anything but look after the disabled children...Freedom is greatly restricted. Thomas has to carry a mobile phone when out of the house, as I cannot take the children with me to look for him when he is out playing. He must remember always to lock the front door when he comes in and get someone to lock it after himself when he goes out. He locks himself in his bedroom to try and get some peace from the two youngest children. We try to compensate by letting him have his own tv and satellite system in his room. We cannot go out and do the things that other families do together and Thomas resents his brother and sister for this"*. She continues: *"...because Thomas resents the other two so much we spend a lot of our time refereeing and trying to prevent flare ups. The two children with disabilities get on really well with Thomas being very much the outsider. The two disabled children share toys, leisure items, videos and they play together. Thomas also resents not having a brother or sister that he can play with (his own words)"*.

Non-disabled siblings may have to take on caring responsibilities in the long- term. One person wrote to us to explain how, even though she is now a mother herself, she still has to shoulder responsibilities for her grown-up disabled siblings: *"...because I spend a considerable amount of time involved in the care of my disabled siblings, my daughter misses out on 'time'...I feel under*

*pressure to the burden of responsibility falling on me all the time, as there is no one else in the family to share this with. I seem to be responsible for all communication between my siblings – it is always me who phones”. She adds: “...I am trying to become the recognised respite carer for my older brother...but as things appear to stand I would not be able to receive any financial support for this”.*

### **Family support**

Although research indicates that families with disabled children prefer to access informal support from family and friends, the mothers we spoke to feel that extended families are an unreliable source of support. One mother writes: *“...the family do not get involved at all even though they all live within ten minutes of us”*. Another comments that although her family lives in the area they have limited knowledge about, or understanding of, autism, and don't seem inclined to acquire any: *“...they don't seem to understand disability, they don't realise how hard it is”*. Another comments: *“...I don't have any family in this country, just me – and I can't rely on the neighbours”*. The age of grandparents impacts on their ability – if not their willingness – to help out. One father writes: *“...both my parents are in their 70's and I'm an only child”*. A mother who receives a lot of support from her own parents was concerned about relying upon her elderly father for support. She explained that her teenage sons have severe mobility problems, but they have become too heavy for her father to lift: *“...he's no spring chicken”*.

An Asian mother comments: *“...my family doesn't talk to us”*, because she re-married after the departure of her first husband (who left *“because of the children's disabilities”*).

### **Public hostility**

It's not just financial constraints that keep families at home. A number of families (particularly those whose children have autistic spectrum or behavioural problems) comment that: *“...the reaction of other people!”* often has an adverse impact on their willingness to go out.

A mother with two profoundly deaf children and a daughter with *“...severe behavioural problems”* is desperate for a firm diagnosis *“because the general public might be a bit more understanding”*.

# Families and the benefits system

## The battle for information and support

Families are “constantly fighting” to get the information and support they need. The questionnaires are littered with comments like: “...you have to fight for the basics”; “...we have just started our fight to get our bathroom changed to suit children’s needs. Yes a fight. Everything seems to come down to this”; “...If you cope, the local social services say – fine, you’re coping – but if you don’t cope, you’re worried they’ll come and take your children – it’s a vicious circle”. One mother comments: “...everything’s an argument – some families employ solicitors to argue their case, some people just give up and a lot of people don’t even know they can argue”. Another states: “...if we make a lot of noise – they won’t want to mess with us”.

Accessing information about benefits is clearly difficult. A mother comments: “...you wouldn’t believe how many parents don’t realise they can get DLA...or the blue badge”. Another observes: “...you’re given a bounty baby pack when your child is diagnosed with a disability – why don’t hospitals have a pack with information about benefits?”.

Another mother who has a nine year old son with diabetes, and a deaf daughter aged five explains: “...there is no centralised system for information so I spend hours and hours on the phone, hours and hours writing letters... I’m looking at how I can get back to work”. She tells us that their application for DLA “...was repeatedly turned down”, until they received help from National Deaf Children’s Society. “Filling out forms is incredibly time-consuming...”

Like other families she makes sure that she “...tells other people I know who live near us about the information I’ve found...”. Another mother comments “...I’m starting an information group at the school...you wouldn’t believe how many parents don’t know about the orange [now blue] badge scheme or don’t realise they can get DLA”. She also makes sure that her neighbours know about DLA: “...one little girl lives four doors down,

*her daughter has the same disability as my girls, but she’d didn’t apply for DLA until I moved in – nobody told her before”. She adds: “...families from ethnic minorities don’t ask for anything”.*

However, even when families do get the benefits to which they are entitled, anxiety about losing them is constantly on the families’ minds. One mother tells us: “My husband’s constant worry is “how are we going to cope if they scrap carer’s allowance or DLA?” – my husband worries about it more than me, because I’d fight if they tried to take anything away from my kids that they’re entitled to”.

## Adequacy of benefits

As revealed above, families with two or more disabled children incur enormous additional costs, and suffer from a significantly reduced opportunity to work. It is therefore hardly surprising that families feel angry and let down by a benefit system that – in the words of one family who receive their full benefit entitlement: “...doesn’t come near covering our needs”. One mother bitterly observes: “...you need to get a person with two non-disabled children and see what the glaring differences are. You need to see it in black and white – how big these differences are”.

## Carer’s allowance

At a mere £44.35 a week (2004 –5 figures), carer’s allowance is considered particularly insulting for families who may be caring for two, three or sometimes even four people. One mother who gave up her full time job as a nurse to care for three disabled children and a disabled husband receives only one lot of carer’s allowance for the eldest child. “Why should she be considered more important than her sister who is also disabled? It’s a joke!”, she adds bitterly, “...if I was nursing these three children in hospital it would cost them £2,000 a week”.

She’s not the only one to feel enraged. One mother writes: “...one thing that makes me furious is when people say caring isn’t working...I get 52p an hour. A friend who works in an old peoples’ home gets

*£6.00 an hour... she says 'you shouldn't do it' to me, but they're my kids". Another mother writes: "...as carers of two children with disabilities we feel undervalued, underpaid, stressed. The Government don't care, as far as they are concerned carers are a form of cheap labour. We are sick of being labelled 'unemployed' and continually told there is no such job as a 'carer'". Another bitterly observes: "...we look after them 24 hours a day – they're not toys that you can turn on in the morning, and switch off at night and put in a cupboard".*

### **Disability Living Allowance (DLA)**

Families report on inconsistencies within the system. A mother who has three children, two of whom have Down's Syndrome and are severely disabled, and is disabled herself writes: *"...we got high rate DLA for our first child, but the second was turned down completely even though she had more problems than the first ...we fought this on the grounds that one child was being discriminated against and the decision was overturned to high rate".*

One mother who receives DLA for her two autistic sons comments: *"...there's a certain way of filling (the forms) in...you have to write things in a certain way".* However, although the family has received support and advice from Parent Partnership and Contact a Family they have encountered major discrepancies within the system: *"...DLA is still one of those things that doesn't make sense".*

### **Motability**

Families report that because they need a 'people carrier' they have to pay a larger deposit out of their DLA to Motability. One mother explains she has to *"...put so much away every month to have ready when it's renewed every three years".* This saps the family's day-to-day income.

### **Blue badge**

Families feel that a 'postcode lottery' is in operation where access to a blue badge often seems to depend on the person making the decision. One mother who applied for a blue badge for her deaf child and her autistic daughter was told by her local authority that: *"...no deaf or autistic child has a blue badge" and that "...furthermore if they heard of anyone who did, he would take the badge away. His attitude got to me – he was very rude and very*

*un-understanding".* She points out *"...because it's often safer to carry him on my hip, I've got a bad back myself...I could do with a family badge".* Another mother comments: *"...although we were lucky to get a blue badge in the last two years, I feel that families with one or more disabled child should be given a 'family blue badge' automatically".* She adds: *"...we often have to drive to places where others would be able to walk and the cost of parking is a big issue".* Another explains that although she was turned down for a blue badge (because her daughter *"...can walk"*) her GP supported their case *"...because I kept having injuries from having to drag my daughter screaming, kicking and biting into the clinic".*

### **Social fund**

Decision making is notoriously poor when turning down applications for community care grants.<sup>19</sup> Families in our study also tell us that although they are frequently turned down by the Social Fund, they often don't have time to appeal – even though the chances of success are high. Families are constantly being turned down by the Social Fund, but an endless round of hospital admissions and appointments means they often can't appeal within the time limits: *"The Social Fund turned us down for specialist mattress, they told me '...the Family Fund Trust will help you', but I said: "...the Family Fund will only help you once a year, and they helped us last year (with some clothes) and will absolutely not help us again. So I'm going to have to appeal this, and they must have known they were out of order because she rang back half an hour later and said I could have it! Why don't they live and learn about how the Family Fund works".* She adds: *"...it makes you feel a fool, it's demeaning".*

One mother, who was turned down by the Social Fund when her son went into hospital for a four week admission following surgery, was successful when she applied for assistance when her daughter went into hospital for the same operation a year later: *"...it was only because I spoke to somebody nice who was prepared to listen".*

### **Family Fund**

Because of these sorts of problems, families report that they are often forced to turn to the Family Fund, or voluntary sector organisations for support.

However, even when families are able to access one-off grants (and these are very welcome), they don't take account of the unending wear and tear on furniture, and constant need to replace and fix things. A mother comments "...I'm sick to death of having to beg voluntary sector organisations for money we should get as a matter of right".

### Debt

Given the problems families experience accessing financial support they often fall into debt. One mother tells us: "...I borrowed money from friends, different places, and got loads of debt...I just left it, I was near breaking point, so I just left it and kept on borrowing money. Six years ago I borrowed £6,000, borrowed from different cousins, I'm still paying that off".

### What changes do families suggest?

When asked 'What would be of greatest financial help to your family?' the following responses were provided:

*"The family needs more financial support and better services, better transport.";*

*"Improved benefits, a social fund/grants available for people like myself who are coping without much help – and to have someone in Support Services who understands every case is different!";*

*"Better childcare";*

*"We missed the deadline for the Motability car because the appeal (for DLA) took 12 months to be heard.";*

*"Access to grants would enable us to afford things like a new cooker which would be safer, more substantial safety things and also give us the money to employ a nanny or some other help so that we could have some respite.";*

*"Help! financial and respite. Problems with clubs, activities, supervision (no carer) wills, trust, insurance, child bond savings.";*

*"We'd like to take the kids out somewhere as a family – we can't even do that...My children should be enjoying themselves. In an ideal world my husband shouldn't have to work, because we need two full-time carers.";*

*"The biggest difference would be accessibility to childcare 'We're living on the edge and are constantly stressed by money shortages.'";*

*"People just see the wheelchair and that's all they see – they don't see that she's got a brain and that she's coming home with 'A's";*

*"If you cope, the local services say – you're fine, you're coping – but if you don't cope you're worried they'll come and take your children away – it's a vicious circle.";*

*"Better support from social services in respite and more flexibility with this service. More family support generally in the home especially when the children are sick and housework is not done ...";*

*"Help to allow us to take a family holiday while having breaks in the caring to allow us to do things with (our non-disabled son) and to enjoy the holiday ourselves.".*

A lone parent writes: "...enough with the surveys – I am not the only single parent out there raising two or more disabled children, and struggling every day to make ends meet. We could use some real help and not just talk about help that is needed. Too much talk, surveys, research, studies, discussion forums etc., it should follow with tangible results".

# Conclusion and recommendations

## Statistics

Disability Alliance believes that current official statistics seriously underestimate the true extent of poverty among disabled adults and disabled children because they fail to take into account the extra living costs associated with disability. Extra costs disability benefits, such as disability living allowance (DLA) are included as income although they are meant to cover some of the additional costs incurred by disabled people. Furthermore, whilst Government statistics on income are adjusted to take account of variations in the size and composition of the household (a process called equivalisation) no adjustment is made for disability. We believe there needs to be an adjustment (equivalisation) for disability incorporated into current statistics. As a first step DLA needs to be ignored as income.

Disability Alliance believes that statistical information about the number, location, and household composition of families with disabled children needs to be radically improved and their situation monitored in *'Opportunity for all'*. Statistical information should include: the number of disabled and non-disabled children per household; whether the household is lone parent or couple; the number of adults per household; whether any of the adults are disabled; the family's ethnic status; and the family's main source of income.

## Information about benefit take-up

Although Disability Alliance welcomes additional financial support for low income families with disabled children, little is known about the number of disabled children who are accessing additional support (which is triggered by an award of DLA, with specific levels of DLA also triggering an award of Carers Allowance for the parent). We believe that poor statistics on the number of children awarded DLA, and at which level, severely undermine a coherent analysis of the efficacy of Government initiatives to reduce poverty among disabled children. Are hard-to-reach families, particularly from black and minority ethnic groups, accessing the support to which their disabled child is

entitled? Information is also needed about what associated benefits (such as carer's allowance, or disabled child premium or severe disabled child premium in Child Tax Credit, or carer premium within income support) the family receives.

## Employment

Although ensuring that people are 'better-off in work' is important, Disability Alliance believes that condemning families in 'workless' households to live in poverty is both unacceptable and counterproductive. Keeping families on the 'breadline' has an adverse impact on parent/carer's health, which in turn undermines their ability to work. As one father in our study put it: *"...I would like to (work) but I can't physically"*. It goes against the Government's commitments on child poverty.

Furthermore, the Government's 'welfare to work' campaign has been accompanied by a high level media assault on benefit 'skyvers and fraudsters'. This has done little to reassure families with disabled children that they are entitled to claim benefits, resulting in low take up and high levels of poverty. Families who are unable to work do not feel that they are inadequately supported by the government and yet remain anxious about the impact paid employment may have on their benefit income. They express both anger and suspicion about what they perceive as a judgmental and punitive social security system that is: *"...out to get them"*.

## Childcare

Families with disabled children and disabled parents confront barriers to childcare over and above those faced by other families. Both groups of parents are disproportionately reliant upon local authority support services, and are particularly vulnerable to gaps in provision. Information on the numbers, geographical locations and needs of families with disabled children should be compiled so that childcare can be provided in a targeted rather than a generalised manner. Local authority support services for families with disabled children need to be improved and extended.

The focus of childcare provision should not be confined to the 'early years', but should consider the needs of disabled teenagers and young people who may experience widely varying care needs but would benefit from social contact with their peer group. Parents and their children should be able to choose whether they need integrated youth clubs, or more specialised provision (for example for young people with learning disabilities or challenging behaviour.)

Disability Alliance believes that the provision of universal and free childcare for all, irrespective of work status, is the only way to resolve discrepancies and inadequacies of current provision. However, until such time as this can be achieved we would like to submit the following recommendations:

### Childcare Tax Credit

- Families with disabled children should be able to access help with the costs of childcare for a 'transitional' period prior to taking up employment to ensure that their childcare arrangements are suitable and unlikely to break down, and enable them to regain the confidence, skills and training they need to access employment;
- childcare tax credit should be allowed to run on for at least eight weeks for parent/carers following the loss of a job. This would enable the parent to job-seek without the need to be caring at the same time and provide continuity of care for the child;
- the upper limit of eligible costs for families with a disabled child should be increased and/or the rates should be changed so that all children are treated as a first child where there is a disabled child in the family.
- childcare tax credit should be made available to families where one partner is in work of 16 hours or more a week and the other is caring for a disabled child and other sibling(s);
- families who choose to care for their disabled children themselves should be adequately supported both in financial terms – for example, by a significant increase in CA – and by the provision of appropriate and affordable support services.

## Benefits

### Take-up of DLA

Disability Alliance believes that the Government should finance a targeted DLA take-up campaign on a national basis. In practice, this would need to involve partnerships between local and central government and the voluntary sector and would target health and education professionals as well as Sure Start. The involvement of the independent advice sector will be crucial in providing ongoing support and advice to disabled parents and families with disabled children.

### DLA – mobility component

The higher rate DLA mobility component is currently restricted to children aged three or over. The lower rate mobility component is restricted to children aged five or over. Disability Alliance believes that there should be no lower age limits for disabled children to access a mobility component. The current criteria – that the lower rate mobility component can only be awarded to a child who requires '*substantially more guidance or supervision from another person than persons of (their) age in normal physical and mental health would require*' – removes the need for an age limit.

### Carer's Allowance (CA)

Inadequate support for parents who are unable to work because they are full-time carers consolidates the underlying conviction that their valuable contribution to society is neither acknowledged nor appreciated. Disability Alliance believes that, because CA is an earnings replacement benefit, it should, as a minimum, match other long-term earnings replacement benefits, like incapacity benefit. In addition it should be non-taxable (like severe disablement allowance) which would allow for a more generous child tax credit calculation. Furthermore, families feel very strongly that it is unfair that a couple with two or more disabled children can both claim CA, but a lone parent who may be caring for two or three disabled children can only get one lot of CA. There is therefore a strong argument for an additional payment within CA for carers looking after more than one disabled child. This additional payment could be reflected in a double carers' premium for those families on means-tested benefits.

**Winter Fuel Allowance**

Disability Alliance believes that the winter fuel payment (currently worth £200) should be extended to families with disabled children. If the winter fuel payment was extended to families with a severely disabled child (i.e. higher DLA care or mobility, or middle rate care) 237,100 families would benefit – at the relatively low cost of £47.42 million. This would be a major help in offsetting some of their additional disability-related expenditure.

**Social Fund**

Disability Alliance would suggest that the Government consider an automatic annual grant of £500 for families on Income Support whose child is in receipt of DLA. This would reduce bureaucratic costs and ensure that low income families with disabled children are receiving the additional support they need. The current rules on the repayment of the Social Fund for people moving into work act as a major disincentive to do so. We suggest that where a parent comes off IS and moves into work, payment of a loan should be suspended for a six month period. If they remain in work after that time, the loan should be written off.

**Hospital downrating**

Disability Alliance recommends that the Government reconsider the current rationale for hospital downrating and that meanwhile, DLA and CA are brought in line with new downrating rules for other benefits during hospital stays.

# Appendix

## Glossary of terms

### **Disability living allowance (DLA)**

DLA is a non means-tested benefit intended as a contribution towards the extra costs of disability. It has two components. The care component is paid at three rates according to assessed need for supervision and help with personal care (highest - £58.80, middle - £39.80 and low - £15.55 a week 2004-5 figures). A mobility component payable at two rates, £55.55 and £41.05 is also available. DLA can be claimed by anyone under 65. Eligibility for the higher rate mobility component was recently reduced from age five to age three.

### **Carer's Allowance (CA)**

CA is a benefit for people who regularly spend at least 35 hours a week caring for a severely disabled adult or child. Severely disabled is defined as someone who gets the middle or highest rate of the care component of DLA or any rate of Attendance Allowance (AA). The carer does not have to be related to or live with the disabled person. CA is available whether or not someone has ever worked and it is possible for someone who is themselves getting DLA or AA to get CA. Carer's Allowance is £44.35 a week (2004-5 rate). For those who qualify for CA, a carer premium of £25.55 will be included in their applicable amount for income support (IS), income-based job seeker's allowance (JSA), housing benefit and/or council tax benefit.

### **Social Fund**

The discretionary social fund provides grants and interest-free loans for needs that are difficult to meet from weekly benefits. There are three types of payment:

**Community care grants** – intended to promote community care by assisting people on IS, JSA or pension credit (PC) to live independently in the community.

**Budgeting loans** – interest-free, repayable loans for people who have been on IS, income-based JSA or PC for at least 26 weeks, to help meet

intermittent expenses for specified items for which it may be difficult to budget, to enable the costs to be spread over time.

**Crisis loans** – interest-free, repayable loans for people (whether on benefit or not) unable to meet their immediate short-term needs in a crisis.

### **Family Fund**

The Family Fund provides grants to families caring for a severely disabled or seriously ill child aged 15 years or under. It is an independent charity funded by the four governments of England, Northern Ireland, Scotland and Wales. Grants provided by the fund are discretionary and applicants must meet the following criteria: families gross earned income is under £23,000 or the household income is made up entirely of benefits and savings under £18,000; the child should not be in the care, or treated as in the care of a Local Authority; the family must be living permanently in the UK or satisfy the restrictions on the help the Fund can give to 'families from abroad' and the help requested should relate to the needs arising from the child's condition and not be the responsibility of any statutory agency. The Fund can consider helping with any item relating to the child's condition and regularly helps families with holidays, recreation grants, white goods, driving lessons for main carer and clothing/bedding. To apply contact the Family Fund at Family Fund Unit 4, Alpha Court, Monks Cross Drive, Huntingdon, York, YO32 9WN.

### **Direct Payments**

Direct payments allow a person who has been assessed as needing services by their local authority to receive cash to arrange and pay for them. It is possible to have a combination of some services provided directly by social services and others arranged by the disabled person with direct payments. Direct payments are available to someone who is: a disabled person; a carer; aged 16 and over; assessed as needing community care services or services as a carer; willing to have payments; and able to manage payments. Parents in England, Wales and Scotland can receive direct payments to purchase services for disabled children.

**Motability**

A charity, set up by Government, and designed to help disabled people buy or hire a car, wheelchair or scooter. The applicant has to be in receipt of high rate DLA mobility component as this is used as payment.

**'Opportunity for All'**

Is the Department for Work and Pension's (DWP) annual report on poverty and social exclusion. It was first published by the DWP in September 1999. In the first report the DWP set out their strategy for tackling poverty and social exclusion, and established indicators of progress to monitor the effectiveness of this strategy. The 6th report has just been published.

## Footnotes

- 1 *'Improving the Life Chances of Disabled People'* (Prime Minister's Strategy Unit, January 2005)
- 2 Barnes, Matt and Willitts, Maxine et al., *'Families and children in Britain: Findings from the 2002 Families and Children Study'* (FACS) (DWP, 2004) Analysis of 2002 Family and Children Survey
- 3 HBAI 2001/2 – which reveals that 35% of children in families with a disabled children live in poverty, and *'Proportion of children living in low income households: by presence of disabled people in the family', 1999-00: Social Trends 32*, Office for National Statistics
- 4 Gordon, David. *'Disabled children in Britain: A re-analysis of the OPCS disability survey'* (The Stationery Office, 2000). *'Almost 55% of the families with children with disabilities were living in or on the margins of poverty in 1985 – according to a definition of poverty that would be accepted by a large majority of people.'* This figure is accepted by the Government, see *'Improving the life chances of disabled people'*.
- 5 Lawson, Dot. *'Complex numbers: Families with more than one disabled child'* (SPRU, Social Policy Report, February 1998) and Tozer, Rosemary. At the double: supporting families with two or more severely disabled children (JRF & National Children's Bureau November 1999).
- 6 Dobson, Barbara. Middleton, Sue. *'Paying to care: The cost of childhood disability'* (YPS for JRF, July 1998) and Dobson, Barbara, Middleton, Sue, and Braithwaite, Ian. *'The impact of childhood disability on family life'*, (YPS for JRF, June 2001) .
- 7 Woolley, M. *'Income and Expenditure of Families with a Severely Disabled Child'* (Family Fund, 2004)
- 8 Harrison, J and Woolley, M. *Debt and Disability: 'The impact of debt on families with disabled children'* (Contact a Family and Family Fund, 2004)
- 9 See ECP – disabled children, op cit
- 10 Kagan Carolyn, Leis Suzan, Heaton, Patricia. *'Caring to Work: Accounts of working parents of disabled children'* (Family Policy Studies Centre, May 1998)
- 11 Tozer (op cit)
- 12 Equivalised income is the process whereby income data is adjusted to take into account variations in both the size and composition of the household. Although the Government acknowledges that needs also differ by disability status, no adjustment is made to take account of extra costs.
- 13 See, for example, Russell, Philippa. *'Disabled children, their families and poverty'* (End Child Poverty Campaign Briefing); Adelman, Laura., Middleton, Sue., Ashwroth, Karlk., *'Britain's poorest children: Severe and persistent poverty and social exclusion'* (Save the Children, 2003), and Sunderland, Holly., Sefton, Tom., and Piachaud, David., *'Poverty in Britain: the impact of government policy since 1997'* (Policy Press for the Joseph Rowntree Foundation, 2003)
- 14 In the *'Child Poverty Review'* which was published as part of the 2004 Spending Review, the Chancellor reports that financial support for disabled children (triggered by an award of middle or highest rate disability living allowance) has increased by 70% since 1997. The numbers of children receiving DLA has increased by 30% since 1997, and by nearly 5% in the 12 months to February 2004. 256,000 severely disabled children currently receive DLA. On the subject of take-up he notes that *'The DWP is working toward improving the claim process for disability benefits and developing a new DLA form appropriate for those looking after disabled children. It will be much shorter and responsive to customer needs. A more personal and responsive service will remove barriers and encourage people to claim.'*
- 15 Louise Gitter, *'Services for disabled children'* in The Disability Rights Bulletin, Winter 2003, p. 6.
- 16 Roberts, Keri, Lawton, Dot. *Reaching its target? 'Disability living allowance for children'* (Social Policy Report No. 9, Social Policy Research Unit, University of York, 1999) and Chamba, Rampaul, Adham, Waqar, Hirst, Michael, Lawton, Dot, Beresford, Bryony. *'On the edge: Minority ethnic families caring for a severely disabled child'* (Policy Press, May 1999)
- 17 Sharma, Neera. *'Still Missing Out? Ending poverty and social exclusion: messages to government from families with disabled children'* (Barnado's, 2002)
- 18 Preston, Gabrielle. *'Helter Skelter; Families, disabled children and the benefit system'* (CASEreport, CASE and Disability Alliance, London School of Economics, 2005).
- 19 The Independent Review Service for the Social Fund recently reported important errors in 69% of the Reviewing Officer's decisions they overturned indicating that: *'...budgetary pressures are improperly influencing decisions about qualifications and priority'*.