

Family values

**Disabled parents, extra costs and the
benefit system**

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Foreword

Over the past two years Disability Alliance – in discussion with the Disabled Parents Network – has been collecting evidence on the extra costs incurred by disabled parents. This report looks at some of the issues raised directly by disabled parents and considers whether the current benefit system adequately reflects the specific needs of disabled people with parental responsibilities. Given that this is a very small-scale study, it clearly highlights the need for further research.

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We would also like to thank all the families who provided evidence for this report for giving up their time to share their experiences and views with us.

Summary

Stigma

The ongoing and divisive media preoccupation with 'young carers' had clouded the fact that disabled people often don't receive the support they need to fulfil their parenting role.

Statistics

Disabled parents are not a homogenous group, and their needs vary significantly according to their impairment, their age and the number and ages of their children. There is, however, a dearth of information on the numbers, needs and circumstances of disabled parents and their children.

Poverty and disability

The link between poverty and disability is well established. However, some groups are especially at risk.

Black and minority ethnic families (BME)

Research into poverty, disabled children, and HIV and Aids amongst BME communities strongly suggests high levels of unmet need among such groups. There is evidence of the low take-up of both benefits and of services by BME families.

Lone parents

The stress and strain of coping with disability without adequate support not only takes its toll on a parent or carer's health but on relationships too. Poor nutrition, inadequate housing, a greater dependency on benefits and vulnerability to poor educational and health service provision are just some of the things that render lone parent families susceptible to poverty and ill-health. Disabled lone parents are at particular risk of poverty and social exclusion.

Child poverty

The connection between disability and child poverty is clear. Research into young carers indicates that poverty and social exclusion in households with sick or disabled parents is common. And yet the

financial needs of disabled parents have not been adequately addressed by government initiatives on child poverty.

In March 2004, 'Households Below Average Income' (HBAI) revealed that: '*...children in families containing one or more disabled person are more likely to live in low-income households than those with no disabled persons*'. However, details about their situation are thin in the ground.

Information about children with sick or disabled parents needs to be improved. It would be helpful if HBAI indicated the number of disabled adults and/or children in each household and cross-referenced findings with other groups – such as lone parents, families from minority ethnic groups, families who have accessed employment, families who have fallen out of the labour market.

Adequacy of benefits

Disability Alliance believes that the provision of reliable and appropriate levels of financial support via the benefit system would reduce stress levels, improve health, lessen demands on support services and enhance disabled parents' long term chance of employment.

Employment

Although all disabled people are disadvantaged in the employment field disabled parents fare significantly worse than disabled people without children, and than non-disabled people with children.

Extra costs

Disabled parents incur substantial additional costs as a consequence of being both disabled, and having parental responsibilities. Unfortunately the current system does not recognise the extra costs incurred by disabled parents, which are different from – and often greater than – those incurred by disabled people who do not have children, and by non-disabled parents, for example:

Services

Disabled parents are particularly disadvantaged by poor service provision. This increases stress levels and generates extra costs they are ill-equipped to meet.

Transport

Parents who are disabled incur transport costs over and above those experienced by disabled people who do not have children. Sadly, disabled people may try to keep transport costs down by staying at home. As a disabled parent, such a strategy may not be possible.

Childcare

Disabled parents may have to use more childcare, pre-school facilities, nurseries, after-school clubs and holiday clubs than non-disabled parents. They are often reliant on additional services that enable them to rest during the day and keep their energy levels up for the evenings. The costs of childcare may be increased by their transport needs.

Telephone

Disabled parents are often disproportionately reliant upon the telephone or (if they can afford a PC) using the internet.

Educational costs

Disabled parents may have to pay for educational support for their children if they are unable to provide this themselves.

Safety

Children's safety is a huge issue for a parent who has mobility problems, or a sensory impairment.

Food

Disabled parents incur additional food costs because they may not be able to shop around, or they may be reliant on ready-made meals or take-aways on days they are unable to cook.

Heating and laundry

As with many disabled people, additional heating and laundry costs are a huge issue. However, being a disabled parent can put those costs up considerably.

Leisure and entertainment

Keeping your children entertained when you are

too tired or unwell to play with them can be expensive. Furthermore, parents like to monitor the toys their child is playing with and be able to participate in activities.

Going out

Getting out and about generates expenses that non-disabled parents do not incur: *"I was very reliant on friends to go on outings with me, and of course I had to buy them lunch, and treats for their children."*

Holidays

Going on holiday is a major expense: *"There was always the safety issue with the children when they were young. I could never go camping, or stay in a caravan for example. To ensure that the children were in a safe and contained environment we usually ended up choosing more expensive holidays."*

Black and minority ethnic families

Although families from black and minority ethnic communities have higher levels of unmet need than white families, they may incur additional costs – such as purchasing particular types of food, paying someone to come home to cook this food for them and their children, and of financing someone to help them and their children prepare for activities related to their culture (such as buying and putting on special clothing, attending events, etc).

Fragmented services compound costs

It is difficult to separate out extra costs from inadequate services. A number of parents comment on how the latter exacerbates the former.

Young carers

Often services appear to be more preoccupied with the plight of 'young carers' than in supporting their disabled parents in their parenting role.

Cleaning

One of the biggest additional sources of expense is keeping the house clean – particularly for a parent who is visually impaired or blind. However, inflexible services generate extra costs.

Adaptations

Like all disabled people, disabled parents often have to fight to get adaptations made to their home. However, their parenting responsibilities are often ignored when an assessment is made.

It is not just disabled parents who may suffer from social isolation, but their children as well.

The benefits system

Clearly compensating disabled parents for the huge extra costs they incur as a result of being both disabled *and* a parent is a crucial issue. However, *"...benefits and assessments don't think in terms of disabled parents – you feel invisible"*.

Information

Although the provision of accessible information in a variety of different languages and formats is essential if disabled parents are to get the support they need, lack of information remains a major problem.

Disability Living Allowance (DLA)

Although DLA is supposed to compensate disabled people for the extra costs they incur, the system is not geared to the needs of disabled parents.

Motability

There are difficulties with the current system, which assesses the 'personal use' of the disabled person but ignores that person's additional transport needs if they happen to be a parent.

Social isolation and exclusion

Becoming a parent generates additional stresses and strains that can compound feelings of isolation.

Anxiety

Disabled parents worry about the impact their impairment or ill health will have on their children.

Relationship breakdown

The stress and strain of coping with a disability and young children can take its toll on relationships.

Ill-health

Given the link between poverty and disability, it is hardly surprising that a number of disabled parents live in households in which more than one member is disabled.

Background research

Disabled parents – the long road to recognition

Although the ongoing and divisive media preoccupation with ‘young carers’ continues to cloud the fact disabled people often don’t receive the support they need to fulfil their roles as parents, the situation is beginning to change. The recognition that disabled people can be, and often are, parents, the child poverty debate, and the development of social policies that emphasise the importance of support for parents generally have placed disabled parents – albeit somewhat tenuously – on the social and political agenda.

A jigsaw of services?

At a meeting with Department of Health Inspectors in 1997 the consortium Parents Too! identified a range of concerns about the difficulties disabled parents experienced in accessing appropriate services and support. In the wake of this meeting, the Social Services Inspectorate (SSI) instigated an inspection, the findings of which were published in April 2000.¹

The SSI report begins with the following statement:

‘Providing support for parents to help them bring up their children better is at the core of the Government’s family policy. However, many disabled parents feel that this is still only a pipe dream for them....’

The Inspectors highlighted a number of specific problems:

‘Disabled parents were not identified as a relatively discrete group of service users and in only one authority was service provision for them promoted and backed by a specific policy about their rights.’

‘There were services to meet (disabled parents) personal needs and services for their children but there was lack of flexibility to bring these all together to support them in undertaking their parenting role.’ For example, childcare teams do not necessarily record that parents had a disability

and adult services teams do not routinely record whether there were children in the family.

Task force on supporting disabled adults in their parenting role

In December 2000, the Joseph Rowntree Foundation set up a Task Force on Supporting Disabled Adults in their Parenting Role. The Task Force met over a period of two years and heard evidence from parents, professionals and researchers on a wide range of issues affecting disabled parents and their children. In the first instance, the Task Force assessed how many social services departments had policies and protocols that addressed disabled parents needs and the extent to which these were likely to meet the concerns raised by the SSI and by disabled parents. A report written by Michele Wates established that whilst there was a growing commitment to meeting the needs of disabled parents as a distinct group of service users, issues about how best to develop work across adults’ and children’s divisions remained unresolved.²

In September 2003 the Joseph Rowntree Foundation produced *‘The right to support. Report of the Task Force on Supporting Disabled Adults in their Parenting Role’*. Written by Jenny Morris, it concludes that disabled parents continue to be undermined by poor support and negative attitudes. It highlights a number of concerns, including:

- the failure to consult or involve disabled parents in the development of policies and services concerning adults and/or children;
- the difficulties disabled parents experience accessing information and advice, advocacy and peer support;
- ongoing problems with the relationship between children’s services and adults’ community care services;
- the additional costs disabled parents incur and the inadequacies of the current benefit system to meet these. (See article in Disability Rights Bulletin, Winter 2003.)³

In 1998 the Home Office *'Supporting Families'* document set out the Government's aim of ensuring that: *'...all parents have access to the services and advice and support they need, including parents who have some type of disability. However, there is a paucity of information regarding disabled parents' needs for advice and information services and the types of services available to them'*.

A recent survey by the Home Office found that disabled parents had similar rates of receipt of both information, and formal advice and information, to those of non-disabled parents. However, disabled parents were less likely than non-disabled parents to report being satisfied with the amount and quality of parenting information and advice, and were more likely than non-disabled parents to mention an aspect of bringing up children on which they wanted more advice. The findings from this survey *'...indicate that there may be issues surrounding need for advice and information amongst parents from this group. Further research is needed to explore disabled parents' requirements for advice and information'*.⁴

Black and minority ethnic families

Research into poverty, disabled children, and HIV and Aids amongst BME communities strongly suggests high levels of unmet need among such groups. There is evidence of the low take-up of both benefits and of services by BME families. Barriers to take-up include lack of awareness, communication difficulties and the cultural appropriateness of services. Parents with mental illness often receive uncoordinated support which does not take account of their childcare responsibilities as well as their childcare needs.⁵

There is *'...a high level of unmet social, personal and – in some cases – medical needs among black parents who were disabled or experiencing ill health. None of the families or young people receive regular, adequate or appropriate support services. Experiences of social services, health services and schools showed a lack of understanding of the problems faced and there were examples of discrimination by race and/or disability'*.⁶

Lone parents

There has been a welter of research on lone parents, ill-health, and employment patterns.⁷

The stress and strain of coping with disability without adequate support not only takes its toll on a parent or carer's health but on relationships too. As the 2002 Family and Children Study shows, longstanding illnesses or disabilities are higher among mothers living in lone parent families than among couple families (16% as opposed to 9%).

Longstanding illnesses or disabilities are also more common among mothers who are not in paid work and living on the lowest income quintile. Poor nutrition, inadequate housing, a greater reliance on benefits and vulnerability to poor educational and health service provision are just some of the things that render lone parent families susceptible to poverty and ill-health.

Policy context

Child poverty

Although the Government recognises the link between disability and poverty, and – as its drive on child poverty illustrates – is keen to help parents provide social and financial security for their children – the role of disabled people as parents has been sadly neglected. And yet the connection between disability and child poverty is clear. Research into young carers indicates that poverty and social exclusion in households with sick or disabled parents is common.⁸

There are 14.4 million parents in Britain with a dependent child under the age of 16, of whom about 15% are classified as being disabled. Department for Work and Pensions (DWP) statistics on children living in families on key benefits reveal that some 649,000 children live in households where a parent is in receipt of incapacity benefit, severe disablement allowance or income support with a disability premium. These children are at a significant risk of experiencing poverty and social exclusion.

Disability and poverty

Disabled people are at particular risk of poverty because they experience the double jeopardy of high living expenses and low or zero earnings capacity. While income in disabled households is 20-30% lower than for non-disabled adults, day-to-day living brings extra costs that are directly related to impairment: for example extra heating, laundry and clothing, or special equipment. Furthermore, disabled people have to pay for personal support, goods and services, and help with tasks that non-disabled people can do for themselves.

The DWP's fifth annual report on poverty – *'Opportunity for all'*, notes that: *'...compared with a household with no disabled members, a household with at least one disabled adult is 50 per cent more likely to have a low income, and one with a disabled child is 20 per cent more likely. A household with a disabled child and a disabled adult is twice as likely to have a low income'*.

Government research constantly highlights the link between poverty and disability. In the most recent *'Opportunity for all'* the DWP emphasises, *'...there is a clear link between poverty and ill-health. Poverty and social exclusion are associated with worse health outcomes. Poverty is both a cause and a consequence of ill health. Despite overall improvements, the gap in health outcomes between those at the top and bottom ends of the social scale remains large and in some areas continues to widen'*.

The DWP also accepts *'...the interconnectedness of low income, poor health and restricted work participation'*.⁹ The majority of workless couple households with children have the additional barrier of at least one parent being disabled. In total, 60% of couple workless households with children are in receipt of a disability benefit. Forty two per cent of families in receipt of disability living allowance (DLA) who have children have incomes below 60% median contemporary income after housing costs (AHC). Forty eight per cent of single households in receipt of DLA who also have children have incomes below 60% median (AHC).

However, these stark statistics seriously underestimate the real picture. The DWP accepts that: *'...(poverty) figures cover income only, so the total will include disability benefits but there is no deduction for any extra disability-related costs... (for example equipment such as screen readers for computers, or higher costs for such things as heating, diet or laundry as a result of a disability.) These disadvantages can lead to a high risk of poverty and social exclusion'*.¹⁰ When such costs are incorporated, it is calculated that 60% of disabled adults in families with children have an income below half the general population mean, after adjusting for costs. Although this includes families where the disabled parent is in work, in the majority of cases the disabled parent is in receipt of earnings replacement benefits.¹¹

In *'Opportunity for all'* the DWP concludes that: *'The increased risk of low income is related to the higher rate of worklessness among households with*

a disabled member. This in turn is related to the need of some disabled people for extra care, as well as the lower employment rate among disabled people.’ The DWP highlights the fact that: ‘...disabled people of working age are around seven times as likely as non-disabled people to be out of work and claiming benefit’.

their parental responsibilities alongside managing their disability. The majority of parents however become disabled when their children become older. These parents will benefit from the Government initiatives to reduce the barriers to employment, and strategies to help them retain their jobs.’¹²

Worklessness

Given the strong link between child poverty and children living in workless households, the Government has focused on paid employment as the primary route out of poverty.

The difference the presence of children make to employment patterns in disabled households is revealed by statistics. Disabled parents have an employment rate of a little over 50% (slightly higher than the overall employment rate for disabled people as a whole) compared with an employment rate of 77% amongst non-disabled parents.

Barriers to employment

In the recent Work and Pensions Select Committee Inquiry into child poverty, Disability Alliance provided evidence of some of the barriers disabled parents face:

‘Disabled parents experience the same kind of disadvantages that disabled people generally experience with barriers to employment and discrimination. However, they have the additional problems that they have parental responsibilities and that has an impact on a disabled parent’s health and ability to seek out employment. There is also the childcare issue for them. They may have problems transporting their children and with transport in general. In some ways disabled parents face the same issues as families with disabled children. They need an adequate income to ensure that their health is not adversely affected by the additional caring and responsibilities of becoming a parent. Disabled parents report that becoming a parent tends to compound underlying health problems or a disability, and has an impact on their ability to access employment and their energy levels. Parents who are disabled when they have children need additional support to help them fulfil

Findings

Disability Alliance, with the support of RADAR and the Disabled Parents Network, has been gathering evidence of the additional costs incurred by disabled parents. We have looked at the sorts of costs they incur that are different from those faced by non-disabled parents and by disabled people who are not parents, and considered whether the current system recognises and addresses these costs. Our findings are outlined below.

It is clear that, over and above the huge financial shock involved in becoming a parent, disabled parents incur a vast array of additional expenses that are – unsurprisingly – not recognised by a system that finds it difficult to accept that disabled people are and wish to be parents.

Extra costs Services

As discussed above, disabled parents are particularly disadvantaged by poor service provision. This increases stress levels and generates extra costs which many disabled parents are ill-equipped to cope with.

Transport

Parents who are disabled incur transport costs over and above those experienced by disabled people who do not have children. A mother who has been blind from birth explains how becoming a parent changed her transport needs. Although she had used public transport with confidence before having children, and continued to do so after her daughter was born, the situation changed when her second child was born, when travelling by bus or tube became too hazardous. Unable to hold her daughter's hand, and sort out a buggy and a baby, she was forced to travel everywhere by taxi.

Sadly, disabled people may try to keep transport costs down by staying at home. As a disabled parent, such a strategy may not be possible. A mother who is blind comments that she uses a lot of taxis taking her daughter on outings and trips to ensure that she "...leads as normal a life as possible".

Transport to school – a disabled mother explains: *"The problem was he was not disabled and so he was not entitled to help, and as an adult disabled person there was no budget for me to go to infant school, so they couldn't help."* Sometimes parents have to pay somebody else to take their children to school for them. Others pay for taxis. Unreliable services often renders this not only a costly, but a stressful business. Furthermore, disabled parents also have to pay to take their children to parents' evenings. *"I used to try and go to parents' evenings and be involved, but the costs was too great so in the end I just left it... It would cost £6 there, £6 back – and that's after £20 to take him to school during the day ..."*

A mother who uses an electric scooter to take her children to and from school reports that regular breakdowns mean that she had to buy a back-up scooter.

A lone parent reports that although she finally got a wheelchair after waiting 12 months to be assessed, she still has to pay a wheelchair pusher so she can take her daughter to and from school.

Transport to hospitals and clinics – disabled parents also incur additional costs when their child has to attend hospitals or clinics. As it's the child – not the parent – attending a medical appointment, they do not qualify for community or hospital cars.

Childcare

Disabled parents may have to use more childcare, pre-school facilities, nurseries, after-school clubs and holiday clubs than non-disabled parents. They are often reliant on additional services that enable them to rest during the day and keep their energy levels up for the evenings. The costs of childcare may be increased by their transport needs.

A lone parent reports that although her daughter goes to nursery, she has to pay somebody between £10 and £15 to look after her between 5.00 pm and bedtime. During holidays and half-terms, she has to pay somebody all day.

Although problems with childcare are often associated with children who are under five, disabled parents may experience problems when their child starts school, and no longer qualifies for support that is focused on the early years. There is often no childcare or support during holidays and half-terms.

Telephone

Disabled parents are often disproportionately reliant upon the telephone or (if they can afford a PC) using the internet. A lone parent who is virtually housebound reports that her phone bills are extremely high because *"...I spend my life on the phone talking to agencies"*.

Another parent comments: *"...I have to have a phone upstairs, and another one downstairs – and I need speaker phones. I had to pay for those..."*

Educational

Disabled parents may have to pay for educational support for their children if they are unable to provide this themselves. A blind mother comments: *"I had to pay a tutor to help my son with his reading, which I would otherwise have been able to do myself."* As a lone parent, she also had to pay somebody to come in for at least two hours a week to read bills.

Safety in the home

Children's safety is a huge issue for a parent who has mobility problems, or a sensory impairment. A mother who is blind recalls the difficulties she had with a new born baby: *"I kept on falling and was afraid to carry the baby in case I had an accident."* She records that problems increased when her baby began to move around: *"...that was one of the difficult times for me, I had to think of stairs and stairs gates. I had to prevent him going down the stairs without me – I was always worried about him falling off stairs"*. She bought safety gates and tied a bell to her baby's leg with string so she could hear where he was.

Food

Disabled parents incur additional food costs because they may not be able to shop around, or they may be reliant on ready-made meals or take-aways on days they are unable to cook. A lone parent reports that on days she is too ill to go

shopping or to cook she has to order food to be delivered. A father whose wife is severely disabled comments on *"...the cost of ready made food and take-aways (this amounts to a quite a lot!)..."*

A mother who has chronic ME comments that she cooks double the amount she needs and freezes it for those days when she's not well enough to cook. She therefore needs a larger freezer. Mid week she can only shop at places that she can reach on her scooter: *"...there are no cheap clothing shops, no cheap food shops, so I tend to top up with more expensive foods between big shops"*.

Clothing

Clothing is often more expensive because of the difficulties of shopping around. A mother whose eyesight has recently deteriorated comments, *"...with the other children one of the ways in which I managed financially was by buying stuff in sales and markets – but with being blind I can't do that. People help me buy stuff for him ... but they're not going to shop around and hunt for bargains so people tend to buy much more expensive things"*.

Another mother who is a wheelchair user comments, *"...I have to buy warmer clothing for myself during the time when I had take him to school ..."*. She also has to buy extra clothes for the children *"because I'm too tired to do washing every day"*. This is more of an issue now she has three school uniforms to buy: *"...most people make do with two lots, but I need four of everything because I'm too tired to wash every day"*.

A mother who has severe mobility problems explains that caring for a young child has taken its toll on her shoes and clothing: *"...because I'm up and down all day I have to wear a splint all the time, and this has an impact on my footwear. I have to wear special boots that provide foot support, but with the splint I need to buy extra pairs..."*.

Heating and laundry

As with many disabled people, additional heating and laundry costs are a huge issue. However, being a disabled parent can put those costs up considerably. Parents who are visually impaired and feel that their parental skills are under permanent

scrutiny are often very anxious about cleaning and washing. A blind mother observes, “...if a mother’s shoulder is covered in baby sick, nobody minds, but if the mother’s is disabled then it triggers all sort of alarm bells about ‘neglect’, and not coping...”.

She recalls: “...I used to change the children’s clothes two or three times a day in case they were dirty, when I’m sure other parents would just have left them on. You spend your life anticipating and trying to pre-empt criticism...”.

Another blind mother agrees: “...even now I have the policy of wear once and wash for both of us because I can’t see whether the clothes are dirty or not”.

A mother who has chronic ME reports that she’s often too tired to hang the clothes out to dry, so she uses the tumble drier more – even on sunny days.

Leisure and entertainment

Disabled parents may not be able to take their children on outings or have their friends over, yet lack of adequate support and low income often render it difficult to pay somebody to do so on their behalf. Yet keeping children entertained at home also generates additional costs. Keeping your children entertained when you are too tired or unwell to play with them can be expensive.

Furthermore, parents like to monitor the toys their child is playing with and be able to participate in activities. This brings extra costs for parents who are partially sighted. One parent explains that she always bought videos from RNIB when her child was younger because “...the background story over the normal sound of the video enables parents to know what their child is watching”.

Another mother who is registered blind reports that because she wants to be involved in her two-year-old’s reading, games and puzzles she has to buy a great deal of adhesive labelling materials so that she can put Braille on his puzzles and books. She also has to pay somebody to read or describe the book or puzzle, so that they can make and stick the right Braille labels in the right places.

Going out

Getting out and about generates expenses that non-disabled parents do not incur. “I was very reliant on friends to go on outings with me, and of course I had to buy them lunch, and treats for their children.”

Holidays

Going on holiday is a major expense. “There was always the safety issue with the children when they were young. I could never go camping, or stay in a caravan for example. To ensure that the children were in a safe and contained environment I usually ended up choosing more expensive holidays.”

Black and minority ethnic families

Although families from black and minority ethnic families have higher levels of unmet need than white families, they may also incur additional costs. A father who combines working with caring for his severely disabled young wife and two children, aged seven and nine, comments on the additional costs he incurs because the family is of Asian (Indian) origin. Costs such as purchasing particular types of food, paying someone to come home to cook this food for them and their children, and of financing someone to help his wife and their children prepare for activities related to their culture, such as buying and putting on special clothing, attending events etc.

Fragmented services compound costs

It is difficult to separate out extra costs from inadequate services. A number of parents comment on how the latter exacerbates the former.

A disabled mother who has three children, two of whom have disabilities explains: *"...social services are geared for single disabled or elderly disabled, they can't seem to get their mind around the idea of a young person who also happens to be a mother. They view a disabled person as dependent, but in fact it's the children who are dependent"*.

Another mother comments: *"...as a disabled parent you get the feeling that you have to be perfect – in fact you feel that you have to be better than other mothers or your children will be taken into care"*. She adds, *"...people simply had no faith in my ability to be a parent, and whenever anything went wrong — which it does in every family – they blamed my disability"*.

Another mother reports that she doesn't feel that she's a priority because she has a variable condition. Sometimes she can do things, other times she can't. *"They don't consider how tired a family makes you."*

Another mother comments: *"...the biggest difference would be not to split a child and parent for services... it's a different set of people who look after the baby... because everything that affects one affects the other (they should have) a family service whether you are disabled or not"*.

Young carers

Often services appear to be more preoccupied with the plight of 'young carers' than in supporting their disabled parents in their parenting role. A disabled mother reports her irritation with *"...all this nonsense about young carers"*, pointing out that this wouldn't be an issue if disabled parents were adequately supported. Even so, she adds vehemently that: *"...my children were not young carers – as their mother, I cared for them!"*.

Cleaning

One of the biggest sources of additional expense is keeping the house clean – particularly for a parent who is visually impaired or blind. However, inflexible services generate extra costs. One mother observes: *"...the local authority did provide a home help, but stipulated that they had to do the shopping. In fact I liked to do the shopping myself. What I really needed was somebody to clean the house, but of course they knew better than me what I needed. On the one hand they all tell you that your child is at risk because you won't notice if you washed up the dishes and kept the fridge clean, on the other they insist that your home help does the shopping!"*.

Another mother agrees: *"...they tell you what the home help should do, and when they should do it, even if it doesn't fit in with what you want"*. Because home helps were on offer at times that didn't fit in with the children's needs (for example when she was taking them to, or picking them up from school) she had to pay for a cleaner.

A lone parent who tends to drop glasses and plates has to pay for additional cleaning: *"...with my three and half year old daughter coming downstairs in bare feet..."*.

Adaptations

Like all disabled people, disabled parents often have to fight get adaptations made to their home. However, their parenting responsibilities are often ignored when an assessment is made. One mother was refused a stair lift on the grounds that she could sleep downstairs, *"...but this requires me to sleep separately from my husband and children"*.

Another mother has asked for a stair lift, but she doesn't think she will qualify for one for at least four years – at which point the local authority may accept that her condition is 'permanent.' By then her child will be more independent and it may not be such a priority for her.

The benefits system

Clearly compensating disabled parents for the huge extra costs they incur as a result of being both disabled and a parent is a crucial issue. However, as a lone parent points out: *"...benefits and assessments don't think in terms of disabled parents – you feel invisible"*.

Last year the Department for Work and Pensions reported that 47% of all appeals (69,595) in nine different benefits were successful. There were 40,000 successful appeals for disability living allowance (DLA) and 18,000 successful appeals for incapacity benefit. Although sick or disabled parents are likely to be amongst those experiencing problems with incorrect assessments, we fear that their parental responsibilities leave them less time and energy to appeal. *"Lots of disabled parents don't bother complaining – it takes up too much time and energy."*

Information

Accessing information is a perennial problem. A mother who lost her sight reports that the first year was *"...a nightmare time...I was running around like a headless chicken trying to adjust to my situation, and trying to find out information. Initially I didn't know how to find things out – I couldn't see pamphlets and leaflets and posters. It makes it really difficult"*.

Disability Living Allowance

Although DLA is supposed to compensate disabled people for the extra costs they incur, the system is not sensitive to the needs of disabled parents. As one mother comments, the system is *"...only considering you as an individual, and not considering the pressure the family put on me."* ¹³

Although it is possible to claim DLA if parenting impacts upon the bodily functions of the parent (for example, if you need help to pick up a baby to breastfeed) additional costs that arise as a direct consequence of being a disabled parent – for example the need for additional cleaning, transport, convenience foods, social excursions –

are not taken into consideration. There is now a view amongst welfare rights experts that: *"...if there is an impaired bodily function, and because of that the parent requires help with childcare, including outdoor activities, then that may well count as help with a bodily function that is reasonably required and is of sufficiently close and intimate nature"*. ¹⁴

However, Disability Alliance believes that disabled parents should be able to access DLA, or receive a higher rate of DLA, because parental responsibilities increase costs in ways which are different from, and greater than, the costs incurred by non-disabled parents.

Motability

The Motability scheme is a charity, set up by Government, which is designed to help disabled people buy or hire a car, wheelchair or scooter. The applicant has to be getting the higher rate mobility component of DLA, as this is used as payment. There are difficulties with the current system, which assesses the 'personal use' of the disabled person but ignores that person's additional transport needs if they happen to be a parent. One mother reports on the difficulties she experienced getting a bigger Motability car *"...because the system doesn't view the whole family's needs."* She adds *"It's all right if my husband's doing shopping for me, but it's not okay to take children to scouts..."*. Another mother who has two scooters points out that her DLA mobility component isn't sufficient to cover the back-up scooter and a car that suits the whole family.

Furthermore, disabled parents do not view DLA as a reliable, long-term source of income. A lone parent comments: *"...supposing after three years they decide I can't get DLA – what will I do then. If they take my DLA away I won't be able to take my daughter to school"*.

Social isolation and exclusion

Becoming a parent generates additional stresses and strains that can compound feelings of isolation. However, it's not just the disabled parent who may suffer from social isolation, but their children as well *"...it's terrible for the baby – with the others when I could see I would take them out at least to the park and see things, play with other children, but the child is almost as isolated as me really – I dare not bring other people's children over, I can't see what they're doing I'm scared of anything happening to them ..."*

A father writes: *"...my wife suffered a serious stroke over six years ago (at the age of 32) and we have two young children (aged 7 and 9 now). I have cared for my wife, cared for my children, looked after our home and worked full time. I have no family or friends support"*.

Anxiety

Disabled parents worry about the impact their impairment or ill health will have on their children. A lone parent comments: *"...my main concern was about my daughter – when my daughter came home, I had to pretend to be okay"*.

Relationship breakdown

The stress and strain of coping with a disability and young children can take its toll on relationships. A mother who was diagnosed with ME when her baby was six months feels that if she had received adequate support, things might have been different: *"...as it is my marriage broke up so we all have to be on benefits"*. The additional costs of being a disabled parent were exacerbated by the costs of the divorce.

Ill-health

Given the link between poverty and disability, it is hardly surprising that a number of disabled parents live in households in which more than one member is disabled. A mother who has three disabled children reports that the *"...strain and stress of fighting for everything that the children need"*, has

taken its toll on her health. She ended up in hospital and is now disabled herself. She adds, *"...my mum has Alzheimers – her carers are always calling me, so there's additional strain trying to get this sorted out ..."*. Her husband's health has also been adversely affected.

A mother who is a wheelchair user and has four children, two of whom are disabled, has been forced to use her own carer to help her cope with her children's additional needs. *"I'm having to rely on a carer to help me fill in (DLA) forms (for the children) ..."*

A disabled mother reports that her husband ended up in hospital for two nights due to high levels of stress. She comments: *"...the situation exposed the fact that there is no help for parental emergencies – there's no way the system seems to allow for that..."*. She adds, *"...I rely on my husband so heavily – more than an ordinary wife would – and I'm affected more if anything happens to him"*.

Conclusion and recommendations

Child poverty

We believe that if child poverty is to be reduced, security must be provided for disabled parents who cannot, or choose not to work because of their parenting responsibilities.

Disability Alliance believes that current statistics seriously underestimate the true rate 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) and attendance allowance (AA) 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.

Disability Alliance believes that there needs to be an 'adjustment' for disability incorporated into current statistics. As a first step DLA and AA need to be ignored as income.

Benefits

The demands of being a parent may exacerbate an existing impairment or illness, thereby increasing the need (and costs) for support services (including childcare) and decreasing the ability to seek out employment. Disability Alliance believes that the provision of reliable and appropriate levels of financial support via the benefit system would reduce stress levels, improve health, lessen demands on support services and enhance disabled parents' long term chance of employment.

Take up

Take-up of DLA is notoriously low. Although statistics do not reveal what percentage of disabled parents who are entitled to DLA fail to claim, it seems likely that the numbers will be high – particularly amongst black and minority ethnic groups. A take-up campaign targeting disabled

parents would allay fears that the system is out to 'get them' (and/or take their children away) and would ensure that they received the additional financial support they need to care for themselves and their children.

Lack of information

Although the provision of accessible information in a variety of different languages and formats is essential if disabled parents are to get the support they need, lack of information remains a major problem.

Stigma

Research indicates that disabled parents may be reluctant to apply for support, services and benefits because they fear that a request for help might be construed as an admission of failure and confirm the systemic conviction that they are unfit to parent. This perception is not helped by a virulent press campaign that denigrates disabled people as 'scroungers' and highlights the plight of 'young carers' without reference to lack of support for their parents.

Given the link between poverty and ill-health, it is clearly essential that action is taken to ensure that disabled parents receive their full benefit entitlement and the support services they need to manage their disability and to enable them to fulfil their parental responsibilities.

Adequacy of benefits

We believe that the direct link between worklessness and poverty is a clear indication that the Government is failing in its commitment to provide security for those who – for whatever reason – are unable to work.

Disabled parents incur substantial additional costs as a consequence of being both disabled, and having parental responsibilities. Unfortunately the current system does not recognise the extra costs incurred by disabled parents, which are different from – and often greater than – those incurred by disabled people who do not have children, and by

non-disabled parents. For example, disabled parents may have to pay somebody to take their child to school, or hospital, or incur additional transport costs if they take them themselves.

Disability Alliance believes that parenting responsibilities need to be taken into account when assessing somebody's needs for DLA. This would, for example, help disabled parents finance their additional childcare needs. We also believe that disabled parents should be able to access DLA, or receive a higher rate of DLA, because parental responsibilities increase costs in ways which are different from and greater than the costs incurred by non-disabled parents.

We recommend that research is commissioned which investigates the real extent of the extra costs faced by disabled parents – as has recently been done for working age single disabled people¹⁵ through the use of consensual budget standards.

Employment

The needs of disabled parents are currently slotted into the Government's overall strategy of reducing child poverty by helping parents access employment, and equalising the rates of employment between disabled and non-disabled people. Disability Alliance welcomes initiatives that help disabled parents who want to access employment to do so. However, we would argue that it is necessary to identify and address the specific needs of disabled parents within Government initiatives on flexible working and childcare.

Disability Alliance believes that childcare should be made available to sick or disabled parents, irrespective of their employment status. This would not only be of benefit to the parents themselves in the short-term, but the provision of respite might give them the energy they need to access employment in the long-term. The children of sick or disabled parents could benefit enormously from the provision of appropriate childcare.

Statistics

Disabled parents are not a homogenous group, and their needs vary significantly according to their impairment, their age and the number and ages of their children. There is, however, a dearth of information on the numbers, needs and circumstances of disabled parents and their children. For example, whilst research indicates higher levels of disability and ill-health in groups that are susceptible to poverty – such as lone parent families, workless couples, and families in black and minority ethnic communities – statistics about the numbers of disabled parents in these groups are sparse. (In the 2003 *'Opportunity for All'*, although there was a section on the needs of 'young carers' no mention was made of disabled parents.)

Information about children with sick or disabled parents needs to be improved. It would be helpful if HBAI indicated the number of disabled adults and/or children in each household and cross-referenced findings with other groups – such as lone parents, families from minority ethnic groups, families who have accessed employment and families who have fallen out of the labour market.

Footnotes

- 1 Goodinge, Sara. *'A Jigsaw of Services: Inspection of services to support disabled adults in their parenting role'* (Social Services Inspectorate, Department of Health, 2000).
- 2 Wates, Michele. *'Supporting Disabled Adults in their Parenting Role'* (published for the Joseph Rowntree Foundation by YPS, 2000).
- 3 The Task Force was established by the Joseph Rowntree Foundation with support from the Department of Health). Morris, Jenny. *'Right Support: Report of the Task Force on Supporting Disabled Adults in their Parenting Role'* (Joseph Rowntree Foundation, 2003).
- 4 Creasey, Rebecca, and Trikha, Sara. *'Meeting parents' needs for information: evidence from the 2001 Home Office Citizenship Survey'* (Home Office Online Report 48/04).
- 5 Bignall, T., Box, L., Otoo, S. Black and Ethnic Minority Families Policy Forum (Discussion paper 7) *'Family support for parents with additional needs'* (REU 2001).
- 6 Jones, Adele, Jeyasingham, Dharman and Rajasooriya, Sita – *'Invisible families: The strengths and needs of Black families in which young people have caring responsibilities'* (published by the Policy Press, Joseph Rowntree Foundation, 2002).
- 7 See, for example, Casebourne, Jo., and Britton, Liz., *Lone parents, health and work* (DWP, Research Report 214, August 2004).
- 8 See Emma Stone, *'Poverty, parenting and disability'* in Disability Rights Bulletin, Winter 2003.
- 9 Family and Children Survey 2001: *'Living standards and the children'* (DWP, 2003).
- 10 *Opportunity for all*, 5th edition (DWP 2003).
- 11 Burchardt, Tania. *'Enduring economic exclusion: Disabled people, income and work'* (Joseph Rowntree Foundation, 2000).
- 12 House of Commons Work and Pensions Committee *'Child Poverty in the UK Second Report of Session 2003-04'*, Volume 1 (p. 54).
- 13 DLA is a non means-tested benefit which 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 is also available, payable at two rates, a higher rate of £55.55 and a lower rate of £41.05. DLA can be claimed by anyone under 65. In 2001 eligibility for the high rate mobility component was reduced from age five to age three.
- 14 See Osborne, Simon. *'Bringing up baby: DLA and childcare'* Welfare Rights Bulletin 161 (CPAG).
- 15 Smith, N, Middleton S, Ashton-Brooks K, Cox L and Dobson B with Lorna Reith, *'Disabled people's costs of living: more than you would think'* Joseph Rowntree Foundation, October 2004).