

Disability Alliance response R41

SUMMARY of response to the Work and Pensions Committee *'inquiry to examine the extent of child poverty in the UK and the effectiveness of the Government's strategy to eradicate it.'*

- Government research emphasises that *'Ill health and disability are both a cause and a consequence of income poverty and disadvantage.'*
- Government statistics indicate that one in three children living in a household which includes a disabled adult, and over two in five children living in families with both disabled adult(s) and disabled child(ren) are poor.
- We are concerned that some 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.
- Until such costs are included in measurements of poverty, we cannot know how many children live in poverty.
- Targeted and effective strategies designed to reduce poverty among families with one or more disabled child(ren) are currently undermined by a lack of information about the numbers, location and needs of such children.
- The Government's emphasis on employment as the primary (or indeed the only) route out of poverty may not be relevant for families with disabled children and/or disabled parents.
- Although the benefit system recognises that bringing up a severely disabled child costs more than bringing up a child without a disability, benefit income varies because of: low take up; incorrect benefits assessments; inadequacy of benefits to cover extra costs.
- A disability benefit take-up campaign along with a well-funded, welfare advice sector are essential to ensure that families with disabled children, and disabled parents receive their full benefit entitlement.

Work and Pensions Committee ‘inquiry to examine the extent of child poverty in the UK and the effectiveness of the government’s strategy to eradicate it.’

1. Introduction

Disability Alliance is a national registered charity whose principal aim is relieving poverty and improving the living standards of disabled people. Our eventual aim is to break the link between poverty and disability.

1.1 The Alliance is a membership organisation with over 400 members which range from small self-help groups to major national disability charities. We are controlled by disabled people who form a majority of our Board of Trustees.

1.2 We provide information on social security benefits to disabled adults and children, their families, carers and professional advisers; undertake research into the needs of disabled people - with a particular emphasis on income needs - and have an extensive programme of training courses aimed at professionals working in both the statutory and voluntary sectors. We are best known as the authors of the *Disability Rights Handbook*, an annual publication with a print-run of 30,000, but also produce a wide range of guides to benefits. We have recently produced *Don’t Miss Out! A Benefits and services for children with disabilities or special needs*.

1.3 Our policy work is informed by our daily contact with disabled children and adults and those who provide services for them. We are currently gathering evidence on the sort of additional costs families with two or more disabled children and disabled parents incur. This information provides the basis of our response to this inquiry.

2. Background information

2.1 *Disability Alliance warmly welcomes the Government’s strategies to reduce child poverty, and believes that the basis has been laid for an across-the-board strategy that encompasses different services.*

- 2.2 *However, we are concerned that the needs of disabled children, and of children with sick or disabled parents, are not being adequately addressed by the current system. This is partly due to lack of information about the numbers, location and needs of such children and partly because the Government's emphasis on employment as the primary (or indeed the only) route out of poverty may not be relevant for such families.*
- 2.3 According to Government statistics 'the risk of a child living in a low income household is increased by the presence of disabled people.'ⁱ Forty three per cent of children (over two in five) who live in a household with one or more disabled adults live in poverty (taken as below 60 per cent median income) and this figure rises to 46 per cent of children in families with both disabled adult(s) and disabled child(ren).'ⁱⁱ 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'ⁱⁱⁱ we believe this is a serious underestimate of the true rate of poverty among such children because they fail to take into account the extra living costs associated with disability.
- 2.4 Disabled children suffer material, educational and social disadvantages in the short-term which are compounded by inadequate income, high costs and a bleak long-term prospect of unemployment.
- 2.5 Child poverty and adult poverty are inextricably linked. Disabled children will, in time, become disabled adults. Many will become disabled parents. Action is clearly needed now to address the needs of such children and their parents to avoid perpetuating a cycle of poverty and social exclusion.
- 2.6 Disability Alliance believes that unless the Government ensures that all families have an adequate income whether or not they can work, the perennial link between poor health and disability, and poverty, deprivation and social exclusion will not be broken.

3. The measurement of child poverty and the Government's annual poverty report Opportunity for all.

3.1 *Measurement of child poverty*

3.1.1 *Extra costs*

While we accept that relative income has to be central to any approach to measuring poverty, without incorporating extra disability costs it does not illuminate the real situation of disabled children or children living with sick or disabled parents. Indeed until such research has been undertaken we cannot know how many disabled children (and indeed their non-disabled siblings), or children with sick or disabled parents live in poverty. Disability related costs also need to be monitored over time, as it is possible that they may rise faster than ordinary costs.

3.1.2 *Material deprivation*

The DWP has recently acknowledged in its preliminary findings on measuring child poverty that ‘a broader and more tailored approach to necessities might be required for specific groups such as disabled children, as it has been shown that there are differences between disabled and non-disabled people’s views of what items are essential.’ Such discrepancies must inform any measurement of child poverty.

3.1.3 *Social exclusion*

The most common definition of poverty applied to economically advanced societies is exclusion from ordinary living patterns, customs and activities due to lack of resources (Townsend, 1979). Disabled people are often excluded from social and leisure activities and work as a consequence not just of low income but of discrimination and lack of accessibility.

3.1.4 Disabled children may not be able to participate in the sort of ‘free’ social activities available to non-disabled children (such as going to the park, a playground or a friend’s house) and yet their families are often unable to access and/or finance leisure activities (such as the cinema, swimming, theme parks etc.) These children are therefore at particular risk of social exclusion.

3.1.5 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.

3.2 ***Opportunity for all***

3.2.1 While we welcome the Government’s commitment to monitoring different aspects of poverty and social exclusion, we feel that the indicators used in *Opportunity for all* are too narrow in scope, and

we are also concerned that the emphasis is more on the causes (worklessness) than the outcomes of poverty.

- 3.2.2 The DWP's 4th annual report *Opportunity for all* states that '*We believe the opportunity to work, prosper and save is the key to sharing in rising national wealth and to a secure retirement*' three aspirations that are, sadly, often denied to disabled parents and families with disabled children.
- 3.2.3 Although the Government's policy is based on '*work for those who can, security for those who can't*' in the most recent *Opportunity for all*, work as the main route out of poverty remains the primary focus, even in the section entitled 'Support for those unable to work'. Comments like '*the benefit system has long been passive, overlooking people with a disability or long-term illness and ignoring their needs for work and social inclusion*' and '*It is a mistake to think that all people with a disability or long-term illness are unable to work*' hardly engage with or monitor the shortcomings of a benefit system that condemns many families who are unable to work to live in poverty.
- 3.2.4 As we argued in our consultation on measuring child poverty '*the reasons for worklessness are as important as its incidence. Disabled people often cannot work because of their disability. Many disabled people would like to work, but cannot find – or keep – a job because of employer ignorance or discrimination. The majority of parents of disabled children would like to work, but cannot find appropriate and flexible childcare. If 'worklessness' as such is taken as an indicator, all it can do is confirm that lack of work is the cause of poverty.*'

4 The extent of child poverty in the UK and the causes of it.

4.1 Extent of child poverty

- 4.1.1 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.
- 4.1.2 Research emanating from the DWP emphasises that further information about families who experience disability or ill-health and their children is urgently required. For example, although the DWP report on *Characteristics of large families* did not consider

'the health of the family overall' it recommends that *'the health status of partners and of children needs further exploration.'* We strongly agree.

4.1.3 Information about children with sick or disabled parents needs to be improved. In March 2003, *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. 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 ethnic minority groups, families who have accessed employment, families who have fallen out of the labour market.

4.1.4 *Disabled people*

The 2001 Census indicates that there are almost 8.5 million disabled people in England and Wales, or 18% of the population - an increase from 13.3% in the 1991 census. Approximately 2.6 million disabled people of working age are unemployed and on benefits, of whom of whom many would like to work.

4.1.5 *Children with sick or disabled parents*

Recent DWP statistics on children living in families on key benefits reveal that 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.

4.1.6 *Disabled children*

Given the proliferation of statistical studies it is extraordinary that the Government remains reliant upon the 1989 OPCS report which produced a figure of 360,000 disabled children in GB aged under 16, of whom 170,000 have a severe disability. Given that 7,000 severely disabled children are born every year, and the number of children who have 'hidden disabilities' such as autism is increasing, this figure is likely to be significantly higher. Furthermore, disabled children in families who experience problems with diagnosis or misdiagnosis and/or do not claim disability benefits for their children or carer's allowance for themselves may not have been included. We therefore suggest that there may be up to half a million children and young people in the UK with some form of disability or long-term illness who are

susceptible to poverty. Many of these children have non-disabled siblings. Up-to-date statistics are needed to facilitate targeted action for this group of children.

4.1.7 *Families with two or more disabled children*

Statistics on the number of families with two or more disabled children are similarly thin on the ground. There are currently between 17,500 families and 20,000^{iv} families with more than one disabled child, of which about 7,500 plus 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. This is an easily identified group of children who are particularly susceptible to poverty and would benefit from targeted action.

4.2 **Causes of child poverty**

4.2.1 *Disability and ill-health*

Government research constantly highlights the link between poverty and disability. For example the **Family and Children Survey 2001: Living standards and the children** refers to 'the classic link between low income and measures of poor health' and 'the interconnectedness of low income, poor health and restricted work participation.' It concludes that 'Ill health and disability are both a cause and a consequence of income poverty and disadvantage.'

4.3 *Low benefit take-up*

4.3.1 *Recent research^v indicates that access to welfare benefits advice in primary health care settings has a beneficial impact upon an individual's health and facilitates social inclusion. And yet no clear strategies have been put in place to ensure that disabled parents and families with sick or disabled children obtain clear and accessible information about benefit entitlement.*

4.3.2 *In our response to the Department of Health's consultation **Healthy Start: Proposals for reform of the Welfare Food Scheme** we argued that 'the provision of welfare advice is as important to the success of the Healthy Start scheme as are links with health professionals or nutritional experts. We would strongly urge that the Healthy Start scheme be linked to the provision of*

comprehensive welfare advice services within a primary care setting.' *Although this proposal was warmly welcomed by Baroness Massey in a debate in the House of Lords on 3 February 2003, it has not been taken forward.*

- 4.3.3 Recently published statistics indicate that the Government's tax credits take-up campaign has been very successful. The large number of households getting the disabled child element of child tax credit and the increase in the number of families benefiting from the disabled worker premia within working tax credit (WTC) are very welcome. These figures indicate what can be achieved if political will and resources are made available to encourage take-up.
- 4.3.4 We would strongly suggest that the Government launch a similar campaign to encourage the take-up of disability benefits. However, although a generalised campaign is clearly effective, families with disabled children also need personal support and guidance when applying for disability benefits such as Disability Living Allowance (DLA) and Carer's Allowance (CA). A well-funded, welfare advice sector is essential to provide such support. And yet established and reputable advice services are closing due to lack of funding. Such closures can only have a negative impact on child poverty levels.

5. The impact of child poverty on children and families – are specific groups particularly affected?

- 5.1 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.
- 5.2 *Extra costs*
Research reveals that it costs three times more to bring up a child with severe disabilities than a child without a disability. There are no additional costs that are lower for disabled children than for non-disabled children. Unlike families with non-disabled children, who spend approximately 60% of their budget to clothe and feed

their child, parents with disabled children have to spend a substantial proportion of their income on transport costs. Furthermore, additional expenses often occur suddenly and randomly (for example when their child falls ill) pushing families into debt. Families emphasise other costs – such as *'being a disabled family'*.^{vi}

5.3 *Families with disabled children*

Families with disabled children are more likely to be single parents; less likely to work; more likely to be in semi-skilled or unskilled manual jobs; more likely to be dependent on income support; less likely to own their own home than families with non-disabled children. They are therefore particularly susceptible to poverty.

5.4 *Families with two or more disabled children*

Research into the numbers and needs of families with two or more disabled children indicate that, compared with families with one disabled child, they are:^{vii}

- less likely to work;
- experienced 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

5.4.1 Managing *simultaneous* demands is rendered infinitely 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. The lack of recognition of the *particular and cumulative* difficulties faced by families with more than one disabled child meant that services were often inadequate.

5.4.2 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'*.

5.5 **Extra costs**

Disability Alliance is currently gathering evidence of additional expenses from families with two or more disabled children. These include:

- 5.5.1 *Transport.* Families report that because they need a ‘people carrier’ they have to pay a larger deposit 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.
- 5.5.2 *Special equipment/adaptations:* These include: putting locks on all pieces of kitchen equipment, windows, doors and garden gates; high garden fences; ‘stable’ doors on all the bedrooms to prevent the children ‘escaping’ but allow their mother 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. Although one family received a grant from a charity for a computer (which was a ‘*God-send*’), they 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...*’
- 5.5.3 *Hospital appointments:* ‘*Because I have three children with disabilities, they’ve all got different appointment times, so when I take one child in I have to pay someone to look after my other children...they make no allowances for that, none whatsoever. ...With six monthly reviews I sometimes have four or five appointments in a very short space. That does hammer you.*’
- 5.5.4 *Hospital admissions:* ‘*Everything costs more with hospital admissions*’ particularly when the child stays in for a protracted period, and the mother stays with them. Transport back and forwards to see the other children, financing additional caring and domestic support, parking, toiletries, pyjama’s, food for the parent staying with the child – the list is endless and ‘*The hospital provides nothing.*’ One family with five children have recently flown a parent over from India to help out with while the mother stayed with her older son during a four week hospital stay. ‘*I don’t know what I’m going to do...my other son has to go into hospital for the same operation in six months.*’ She recently told us that ‘*We’re falling further and further into debt...*’
- 5.5.5 *Heating and laundry.* 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....*’ Another 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!*'

- 5.5.6 *Replacement of furniture, clothing & household equipment:* 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.' Another reports that her autistic sons are very destructive and things constantly need replacing – including clothes.
- 5.5.7 *Clothing.* Special clothing is usually required, which needs to be of high quality and yet replaced regularly. Two of the families bought special shoes from a firm in Sheffield that cost £142. ('*I need two pairs for both the girls every year.*')
- 5.5.8 *Food:* special diets are sometimes needed, food often gets wasted.
- 5.5.9 *Play, toys, leisure:* 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. The mothers feel that the children are '*harder to occupy as they get older.*' They '*can't go swimming, or clubbing, to the park...*' Sharing seems to 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.
- 5.5.10 *Holidays:* '*Oh forget it, forget it! We don't go on holidays, we go on military manoeuvres.*'^{viii}
- 5.6 ***Inadequate income***
Although the benefit system recognises that bringing up a severely disabled child costs more than bringing up a child without a disability, benefit income varies considerably for three reasons:
- 5.6.1 *Low take up:* Although take up of Disability Living Allowance (DLA) is known to be low (between 40% and 60%) it is not known what percentage of disabled children are failing to receive their DLA

entitlement. However, given the high number of families who have never received benefit advice, it is likely to be high. (*'To begin with we didn't know anything – it's only through friends that I found out about DLA: no-one tells you anything.'*^{ix}) Even when families do find out what support is available, the system may be too complex, the rewards too meagre and the eligibility too limiting to justify the effort. Furthermore families may think *'everybody has to care for their children'* and so do not apply for carer's allowance, or may feel *'my child isn't disabled'* so they don't apply for DLA.

- 5.6.2 *Incorrect benefit assessments:* Many parents of disabled children do not receive the maximum amount of benefit because of lack of information and support. However, they may not have the time, energy or expertise to challenge decisions that may well be incorrect. Families in our survey who do get DLA comment on discrepancies within the system. One family with two autistic boys received 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.'*
- 5.6.3 Families in our survey also tell us that they are often turned down by the Social Fund, but an endless round of hospital admissions and appointments prevents them appealing within the time limit. Many families are therefore 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 from the state.'*^x
- 5.6.4 *Inadequacy of benefits to cover extra costs:* Even when families do receive the maximum benefit income, they often find that it falls well short of the minimum budget needed to care for a disabled child. Although the Institute of Fiscal Studies (IFS) calculates that average spending per child via the social security system has risen by an unprecedented 44% in real terms^{xi}, families in receipt of their full benefit entitlement still tell us that they are barely getting by. Disability Alliance recently addressed a meeting of the All Party Parliamentary Disability Group where a mother with three disabled children who is in receipt of her maximum benefit entitlement commented that she was *'barely getting by financially.'* Despite increases in income support (IS) it is now a lower proportion of average earnings than at any time over the last 20 years.
- 5.7 *Children with sick or disabled parents*

Sixty percent 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.^{xii}

5.7.1 A recent article in the *Financial Times* reported that, in the last year, 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 (IB). Although sick or disabled parents are likely to be experiencing problems with incorrect assessments we fear that their parental responsibilities leave them less time and energy to appeal.

6. The effectiveness of the Government's strategies to reduce child poverty and whether the child poverty targets will be met. Is enough being done across the Government and are further initiatives needed?

6.1 Despite the Labour Government increases to benefit levels and apparently successful 'welfare to work' programme, child poverty remains higher than it was twenty years ago, and remains higher than most industrialized countries.

6.2 *Work for those who can*

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

6.2.2 However, as one mother in our survey comments, is it '*extremely difficult, if not impossible to find a job that fits in with three disabled children. The main difficulty is finding childcare. The second is the number of appointments (psychologists, speech and language therapy, school meetings, doctors etc...) multiplied by three...*' Another comments '*My eldest son was excluded from his mainstream school in January and was out of school for 4 months. What would I have done if in work or on my own?*'

6.2.3. Although we welcome the introduction of the childcare tax credit, we believe that childcare should be provided free as an integral part of the state education system for all families. Meanwhile,

families with disabled children are particularly disadvantaged by expensive and often inaccessible childcare.

6.2.4 We are concerned that take-up of childcare tax credit will mirror problems with low take-up of other benefits such as DLA and Carer's Allowance. Clearly it is not without significance that recent statistics on the take-up of the childcare tax credit indicate that not a single family with two or more disabled children currently receives this credit.

6.2.5 We therefore recommend that families with disabled children should be able to access the childcare tax credit 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. There should also be a 'run-on' childcare tax credit if a parent loses their job to enable them to seek employment. This would also ensure continuity of childcare for the disabled child.

6.3 *Security for those who can't work*

6.3.1 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.

6.3.2 The Government's 'work to welfare' philosophy has resulted in families who cannot work because they care for their disabled children feeling very undervalued. One in our survey 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*'.

6.3.3 Given that families with disabled children would almost certainly be working if they were not caring full time, it is essential that carer's allowance be improved so that it acknowledges their contribution as carers and better reflects the earnings they are unable to access.

6.4 *Inadequate benefits*

- 6.4.1 Disabled people are over seven times as likely as non-disabled people to be out of work. The majority of disabled people rely upon social security benefits as a main source of income. Unfortunately the Social Exclusion Unit's remit explicitly excludes it from looking at the adequacy of benefits. The fact that the Government has driven through policies that have actually reduced benefit income for some groups, including disabled people has not helped matters.
- 6.4.2 *While Government improvements to child benefit and the child premium in income support, and the child tax credit are to be welcomed, recent statistics from the DWP show that between 1995 and 2002 the average weekly payment of incapacity benefit (IB) went down from £83.48 a week to £82.47. IB currently amounts to less than 17% of average earnings. (Given that thousands of children live in such households, this punitive attitude runs directly counter to the Government's commitment to eradicate child poverty.)*
- 6.4.3 Take up of disability living allowance (DLA) is notoriously low - between 40% and 60%. We would therefore suggest a national take-up campaign to encourage hard-to-reach families to apply for DLA for both themselves and/or their children.
- 6.4.4 We are currently gathering evidence on extra costs incurred by disabled parents many of whom believe that DLA should incorporate a 'parenting element'.
- 6.4.5 Families with two or more disabled children are an easily identified group of children who are particularly susceptible to poverty and would benefit from targeted action. We would like to suggest the following adaptations to the benefit system.
- 6.4.6 *Automatic entitlements:* Where a family has two or more disabled children in receipt of DLA it would make their lives so much easier if entitlements to other help could be triggered automatically, for example the provision of a 'Family Blue Badge' or an automatic grant of £500 a year from the Social Fund. Given the relatively small numbers involved, adopting this principle would not be costly.

- 6.4.7 *Winter Fuel Allowance*: we would like to see this extended to families with two or more disabled children, given the extra heating and laundry costs they incur.
- 6.4.8 *Social Fund*: In our survey, we found that families were turned down by the Social Fund and, because of demands on their time, did not appeal. We know also that many families applying to the Family Fund (see below) have been turned down by the Social Fund. We would suggest that an automatic annual grant of £500 be paid to families with two or more disabled children (in receipt of DLA). This would help cover the many ongoing extra costs such families face. Costs such as clothing, where the children's different disabilities mean that handing down clothes is not possible, to the additional costs involved with hospital admissions (which include childcare for the second disabled child and any non-disabled children at home). Many hospitals require a parent to 'live-in' with their disabled child during treatment and recovery but do not recognise the extra costs this creates for parents.
- 6.4.9 *Family Fund* :. The Fund is being regularly asked for help by desperate families for essential items (eg washing machines, clothing) which the Social Fund should have helped with. This is sapping the Family Fund's ability to finance the sort of 'extra' activities originally envisaged - such as holidays and driving lessons. In addition, due to shortage of funds, the Family Fund increasingly finds itself unable to help families where a parent is in work. We would recommend an increase in the funding available so that parents are not disadvantaged for going to work.
- 6.4.10 *Carer's allowance*: (CA) is an earnings replacement benefit and should therefore match other long-term earnings replacement benefits, like incapacity benefit. Another option would be to make the allowance non-taxable (like severe disablement allowance) which would allow for a more generous CTC calculation.
- 6.4.11 Families in our survey feel very strongly that it is unfair that a couple with two or more disabled children can both claim carer's allowance, but a lone parent who may be caring for two or three disabled children can only get one lot of carer's allowance. 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 income support.

- 6.4.12 *Child tax credit:* Within the tax credit calculation there is an enhanced disabled child element worth £18.60 a week, available to families with a child on DLA higher rate care component. We would like this element paid automatically to families with a second (and for each subsequent) disabled child, regardless of the level of DLA received. This would be in addition to the disabled child element and the enhanced disabled child element (where the child qualified due to receipt of DLA higher rate care component).
- 6.4.13 *Childcare Tax Credit:* We feel that the Government should pay 100% of childcare costs for families with disabled children to reflect the extra costs and more limited choices such families face. Meanwhile however, families with two or more disabled children need to access childcare tax credit for the period in which they are jobseeking. It is asking the impossible for a parent to look after two or more severely disabled children and look for work without help with childcare. Families tell us they have enormous difficulties finding suitable childcare and it can take a while for their child to settle (and for childcare staff to feel confident in their role). The most realistic way of helping families is to enable them to get childcare up and running smoothly before seeking employment. Similarly, where a parent is between jobs it would make sense for childcare to continue while the parent looks for a new job. Given the complexities of accessing appropriate childcare, and the need to avoid disruption to such children, allowing a 6 month between jobs buffer would be of most help.
- 6.4.14 *Hospital fares:* The existing scheme should be extended to include visits to a child in hospital, as well as taking a child for treatment.
- 6.4.15 *Hospital downrating:* DLA and carers allowance should be brought in line with new downrating rules for other benefits during hospital stays.
- 6.4.16 *Disability living allowance:* There should be no age limit for access to either the higher or lower mobility component of DLA. This would bring it into line with the care component. Parents would still have to prove that the needs of their child were greater than those of a non-disabled child. Accessing the mobility component would enable families to access Motability and the Blue Badge from an earlier age, which is particularly important for families who have two or more disabled children.

7. **Comparison between child poverty in the UK and other countries.**

7.1 Although Disability Alliance is not equipped to comment on international comparisons, we do feel that the situation in the US, upon which the UK bases so much of its social policy, provides salutary lessons which we can only hope will be heeded by the Government. In the US a shift from on-going cash assistance to one focused on moving parents into permanent jobs is causing severe problems for people who face particular barriers to employment. Foremost amongst this group is disabled people, and the most common barriers are physical or mental health problems or the need to care for a disabled household member^{xiii}. Many are lone parents. Surely this is not a situation we wish to emulate.

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ⁱ *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*

ⁱⁱ Households Below Average Income 2001/02 – Table 4.7

ⁱⁱⁱ See 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*

^{iv} Tozer, R. in *Share an idea: the magazine of contact a family*, Autumn 2002, p.9

^v See, for example, *What is the impact on individual health of services in primary health care settings which offer welfare benefits advice?* (The Health and Community Care Research Unit, University of Liverpool, 2002) and *Tackling pensioner poverty: Encouraging take-up of entitlements* (National Audit Office, November 2002).

^{vi} 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) .

^{vii} 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)

^{viii} Preston, G. 'Families with two or more disabled children – preliminary findings'. (*The Disability Rights Bulletin*, Winter 2002.)

^{ix} Families with two or more disabled children

^x Disability Alliance, *Families with two or more disabled children - case studies*

^{xi} Adam, Stuart, Brewer, Mike, Reed, Howard. *The benefits of parenting: Government financial support for families with children since 1975*, (Joseph Rowntree Foundation and Institute of Fiscal Studies – Commentary 91, 15 November 2002)

^{xii} Burchardt, Tania. *Enduring economic exclusion: Disabled people, income and work* (Joseph Rowntree Foundation, 2000)

^{xiii} Wilkins, Andrea *TANF and Disabled parents* (*Welfare Reform* (National Conference of State Legislature, March 2003)'