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Equality for disabled people: How will we know if we are making progress?

We are pleased to respond to the Office for Disability Issues (ODI) enquiry into equality for disabled people. This letter summarises the issues we believe are essential to improve equality for disabled people and reduce the economic and social exclusion with which disability is so closely associated. In particular, we focus on issues that are directly linked with child poverty. In this letter we draw on comments from parents with disabled children and officials who attended a roundtable discussion set up by the ODI in the wake of the publication of CPAG's and Contact a Family's policy report *Out of Reach: benefits for disabled children*, along with some comments made by Anne McGuire the Minister for Disabled People at this event.

We also append for your information, copies of CPAG's two reports *A route out of poverty? Disabled people, work and welfare reform* and *Out of Reach: benefits for disabled children* which raise concerns about the accessibility of disability benefits which we believe help to safeguard families from poverty. We enclose a letter from Lord Ashley to Jenny Morris discussing the concerns raised by CPAG at a meeting of the All Party Disability Group on 23 April. We also include an unpublished analysis by Tania Burchardt of the London School of Economics on the possible effect on child poverty of increasing take up of DLA, as this is an unpublished analysis so we would be grateful if you would ask us before this is quoted in the public domain.

We welcome the ODI's determination to ensure that disabled people 'are able to make the same choices as non-disabled people and can participate in work, education, training, leisure, family life, making decisions about housing, travel and getting care or support in the ways they want.' We agree that it is important to monitor progress

The ODI emphasises that there are different ways of measuring equality. It particularly focuses on:

- Disabled children – being able to benefit from access to all forms of education
- Disabled people having same degree of access to employment as non-disabled people
- Disabled people having housing provision, care support and equipment

CPAG would like to emphasise that access to financial support that helps to meet some of the additional costs associated with disability is fundamental to all three issues outlined above. Before considering these measurements in more detail, we outline more general issues that we feel must be addressed.

Child poverty and disability

Over a quarter of children living in poverty have a disabled parent. Around 500,000 children live in households with a disabled parent and a disabled child. Families with disabled children are more likely to live in poverty. We calculate that around one million children living in poverty are affected by poverty which blights their childhood experiences and damages their life chances. The disadvantages associated with living in poverty are greatly compounded for children who are affected by disability. Equality for disabled people will not be achieved until children affected by disability are lifted out of poverty. **We urge the ODI to undertake research to establish the extent to which disability benefits – particularly disability living allowance (DLA) protect children from poverty, and whether they are reaching families who are most at risk of poverty.**

Understanding poverty

Although much has been written about the additional costs associated with disability – including extra care needs, heating and laundry, and more costly childcare and travel - there is little real understanding of how these costs impact upon family income, what living in poverty actually means for families, or what sort of life ‘disabled families’ are entitled to expect.

At the roundtable discussion Bruce Calderwood responded to parents’ comments by stating: ‘I was struck by what you were saying which almost implied an attitude by social workers, by people engaged with families with disabled children. It almost implied that families with disabled children should be poor and that there was something wrong if they worked. Because who do they think they were ... trying to have the same income and aspirations as families without disabled kids? And it has never really dawned on me; there are lots of negative attitudes towards disability, towards disabled children...’

The Minister agreed with these comments, and highlighted the need for policy makers to draw upon the personal experiences of families and children when implementing policies on child poverty: ‘What we do want to gather up as we develop the policy in terms of child poverty etc. is to, yes, to have analysis statistics but also to pick up on the individual experiences of people because that will allow us, yes, to frame the big policy agenda...’ **We urge the ODI to**

ensure that there is a real understanding of the different ways in which poverty impacts upon families affected by disability, and to ensure that this is reflected in policies and ministerial statements about disability. Changing attitudes to disability, and challenging an underlying lack of a sense of entitlement among parents and children affected by disability, is essential to achieve greater equality.

Improving benefit take-up

Research indicates that access to disability living allowance (DLA) and associated benefits reduces poverty, and increases choice and social inclusion. However, take up is low particularly among disadvantaged groups, and the system actively prevents many families receiving the benefits to which they are entitled. Although further research is needed to establish the extent to which DLA safeguards families from poverty, policy makers should bear the following issues in mind when considering the adequacy and accessibility of disability benefits, and the appropriateness of employment as a route out of poverty.

The need for extra cost disability benefits:

People who are affected by disability are more likely to be poor because they have lower income and incur higher costs than non-disabled people. The onset of ill health or disability is often associated with an immediate drop in income because parents often have to reduce the hours they work or move out of paid employment at the same time as costs go up.

A lone parent at the roundtable discussion explains: 'Basically I worked all my life. I was never on benefits. I was in a really good job for many years. I thought I had it all planned out. I planned to have a baby, expected to go back to work straight away... Then my son was born with a heart condition which then developed into severe complications and he was hospitalised for two years in hospital. I basically lived at the hospital because I had to give up my accommodation that I lived before. During the time I didn't get anything - because the child is in hospital you are not entitled to DLA, even though I was there 24/7 at his bedside. After two years I moved into a temporary accommodation.'

Another parent whose two sons have autistic spectrum disorders commented: 'With the two boys my husband has been in full time employment, he's had to drop off now because he is very depressed, he can't work. He is breaking down so he quit his job. He was an accountant. I was a nurse working in a hospital getting good money, I had to go part-time.'

Families are therefore heavily reliant upon DLA to provide additional financial support. They emphasise that DLA is not an *additional* amount of money; it is used on a daily basis to meet their child's additional needs.

However, take up of disability living allowance (DLA) and associated benefits is low - particularly among disadvantaged groups - its administration is erratic, and short-term awards and the constant downrating and/or removal of DLA generates considerable financial insecurity. There are a number of

outstanding issues within the current system that need to be addressed if DLA is to support moves to greater financial equality for disabled people.

Stigma: the stigma associated with being on disability benefits is a particular source of concern. High level campaigns about benefit fraud and the sort of stigmatising language that has characterised much of the debate around welfare reform actively deters disabled people from applying for the disability benefits to which they are entitled.

CPAG has long argued that ministerial language about benefit fraud has a negative impact on people's perceptions of work, poverty and the welfare state. However, recent speeches by both the Secretary of State¹ and the Minister of State² have focused on the need for benefit sanctions, and this has led to a series of unhelpful, hard-line media headlines such as: 'Strip 'lazy' Britons of benefits, says Hutton' (Daily Mail online, 18th December 2006); 'No dole for the new jobless' (The Sun online 23rd January 2007); 'Lone parents face cash cuts if they shun work' (Daily Mail online, 30th January 2007); 'Benefit cuts for workshy lone parents' (Telegraph online, 31st January 2007); 'Learn English or lose jobless benefits' (Daily Mail online, dated 12th February 2007).

At the roundtable discussion Anne McGuire MP, the Minister for Disabled People questioned the focus on fraud and emphasised that disabled people are entitled to receive benefits, and that access to benefits was very closely associated with choice and control. She commented: 'We are very clear that there is no shame in claiming what you are entitled to; and certainly that is a message I hope that is reiterated time and time again certainly by DWP ministers who get a specific remit in this respect and I know I can speak for all my colleagues in DWP (when I say) we don't see benefits as a guilt trip for anybody, there are entitlements there... these are not disabled people who are defrauding the system... So I think we want to tackle that attitudinal issue and the office of disability issues is crucial in that and we are certainly working extensively.'

Bruce Calderwood agreed that 'one of the things we really need to do across government is to try to ensure that we give out consistent messages and take a lead in terms of how we as government talk about disabled people, we operate in terms of disabled people and families of disabled people and that sets the tone, we hope, for society to follow.'

The ODI should ensure that the language utilised by Ministers and policies emanating from different government departments challenge (and do not compound) stigmatising and discriminatory attitudes towards disabled people or benefit claimants.

1 to the Institute for Public Policy Research (16th December 2006), where John Hutton used the phrase 'can work, won't work culture' and Commonwealth club (230th January 2007)

2 At a Portcullis House event (23rd January 2007) and to the Work Foundation on the 12th February 2007

Lack of information: families see a huge range of medical, social and educational practitioners who should alert them to their potential benefit entitlement. However, although DLA makes a significant difference to parents and children's lives many families are unaware of the existence of DLA or question their right to claim it. Low take up of DLA suggests a serious lack of lack of joined up thinking which impedes the effectiveness of a more preventative approach to disability and poverty.

At the roundtable discussion the Minister for Disabled People commented: 'We need to start to look at how we get that pool of information because DLA has been around for a long time, it is not a new benefit, it is not something that is mystical, it is not something that we hide. I think it is concerning that we don't have that pool of information or that some people within the system - and I use that word advisedly - some people in the system may not think it is their business to know that if you are a parent of a disabled child you are entitled to claim for DLA. They might block it out, I am a teacher therefore I don't do benefits; or I am a nurse and I do don't education or support. And it is not about asking them to do the thing it is just about asking them to gather up the knowledge...' **We urge the ODI to implement a national take up campaign which is supported by specialised local take up campaigns. Take up should be monitored at a national and a local level relative to need. (More disadvantaged groups are more likely to be affected by disability so take up should be higher among these groups.) We urge the ODI to work with all government departments to increase awareness of DLA and improve take up. This requires a significant improvement in awareness and training within the medical, educational and social services professions.**

A complex system and poor decision making: Families who do apply for DLA report difficulties getting hold of and filling in forms and difficulties gathering evidence from medical and educational practitioners. Poor decision making results in high levels of successful appeals. It is not known how many families will give up without attending a tribunal.

Although a great deal can be achieved by simply ensuring that families receive the disability benefits to which they are entitled, there are a number of problems within the current system than need to be addressed. In particular, the adequacy of DLA and Carer's allowance needs to be reviewed in the light of additional costs and cumulative caring responsibilities.

Although the mobility component of DLA provides a valuable gateway to social inclusion, accessing it is particularly problematic, and it does not take into consideration the needs of the family. At the roundtable discussion, a disabled young person highlighted an important issue with regard to the mobility component of DLA.

'Despite him actually receiving the higher mobility allowance it doesn't allow the family sufficient to be able to have a contract car through motor mobility to accommodate the family. Because it is based on (his) individual needs it still doesn't allow for a vehicle that will transport the whole family... As he has

grown-up they have still not been able to go on family trips because the sort of vehicle that they could get doesn't accommodate what the family's needs are.'

We urge the ODO to monitor the take up and adequacy of the mobility component of DLA which facilitates social inclusion and supports disabled people who want to move into paid employment.

At the roundtable discussion Kim Archer, Customer External Relations Director at DCS reported on plans to involve parents in a working group which aims to improve the dissemination of information about DLA, and improve the claiming process for families with disabled children. This is very welcome. However, although one of the most disadvantaged groups in the UK is disabled parents, we are concerned that policies to support them and their children are not a priority for Government. **We urge the ODI to ensure that the views and opinions of disabled parents, families with disabled children and disabled young people always be sought when implementing changes to the benefit and tax credit system. We also urge the ODI to ensure that the needs of disabled parents are also addressed, and they too are consulted.**

In the following section we address the issues raised in the consultation.

Disabled children – being able to benefit from access to all forms of education

Educational costs

Disabled children and children with special educational needs are particularly badly served by the educational system. They incur higher educational costs because of their additional needs and are more likely to be excluded from schools because of health and/or behavioural problems and problems with housing etc.

CPAG would like to emphasise that *all* children from low income families are disadvantaged by an education system that charges for a wide range of activities that enhance educational outcomes – such school trips, music lessons and after school clubs. Some schools also use expensive uniforms as an overt form of selection in order to limit the intake of children on free school meals and/or are cutting back on special needs support to reduce the intake of children with special needs. We are also concerned that extended school provision which can charge for services provided may exclude disabled children whose families are less likely to be in work and are therefore unable to claim the childcare element of working tax credit.

DLA – improving educational outcomes

Research undertaken by CPAG and Contact a Family suggests that parents with disabled children often use their child's DLA to provide additional educational support for their children to compensate them for the educational disadvantage they experience as a direct result of their disability or special needs. At the roundtable discussion, a parent comments: 'And the Disability Living Allowance for us for my eldest son has meant that we have been able

to afford to support his education at a time when the local LEA haven't and currently we have been supporting him while he has been off school because there hasn't been adequate provision. Without that we wouldn't have been able to. And certainly in the past he also has dyslexia, we wouldn't have been able to support that because he wasn't supported properly in school.'

Furthermore, there are concerns that some services – including educational services – are targeting DLA to finance additional support. A parent with a disabled child who also works in a special school comments 'Where I am working education is not supplying nappies it is only the PCT that will supply nappies for the home. So now we are telling parents you have to use your DLA to buy your nappies and I feel a real hypocrite because I know you can't stretch this DLA any further.' Such charging practices means that DLA cannot be used to secure the additional educational support that parents feel their child needs. **We urge the ODI to gather evidence about the sort of additional educational costs incurred by disabled children, the extent which these generate educational exclusion and to monitor charging policies with regard to such costs.**

The role of schools in improving take up of DLA

As discussed above, despite the positive role DLA plays in enhancing educational outcomes, parents report that schools often fail to alert families to their potential entitlement and that when they are prevailed upon to provide supporting evidence for an application for DLA they show little or no understanding of what sort of evidence is needed, why a child needs additional financial support, or the way in which DLA can be used to support a child's education.

Headteachers, SENCOs and teachers need to understand the importance of ensuring that children who are disabled or have special educational needs access their full DLA entitlement, and need training to ensure that the evidence they provide supports and does not undermine applications for DLA. The ODI should monitor the way in which information about DLA is disseminated via schools, and should monitor the impact that supporting evidence from schools has on take up of DLA.

Disabled people having the same degree of access to employment as non-disabled people

CPAG supports the Government's drive to increase the employment rate among disabled people who are willing and able to access work. We believe that the ODI should ensure that disabled people who can work are supported – but not compelled – to access employment, and that those who cannot work should receive the disability benefits to which they are entitled, and that these should reflect additional costs.

We are concerned that the over-focus on employment as the route out of poverty has marginalized people for whom work is not possible and demeans the role of carers. Although we agree that parents affected by disability should be supported if they want to work, the ODI should ensure that 'security for

those who cannot work' is a reality for families affected by disability who are unable to work. Although many disabled parents would like to work, in a *Route out of Poverty* they highlight ongoing barriers to employment – including discrimination among employers, increased stress levels, health problems and additional childcare and transport costs.

Parents with disabled children also experience significant barriers to employment. At the roundtable discussion, a lone parent with a severely disabled child who is keen to get back into work reported that her personal advisor at Jobcentre Plus had little understanding or knowledge of the sort of specialist support she needed to access employment and that attending work focused interviews was therefore a waste of time. She comments 'My child started school in 2005 and once he settled basically I would like to go back into work. However, there is no support in regard to specialist child care and looking at the school holidays I believe it is 14 weeks a year, what am I going to do regarding childcare?' She adds '...there is loads of appointments with the child, hospital appointments, meetings, calling for prescriptions, a lot of phone calls, a lot of letters, school holidays... The structure is just not there and the help is not there: specialised childcare is not there. Even if you go back to work I think the working tax credit wouldn't cover probably half of the costs because most of the kids need one-to-one supervision.'

Low paid employment

The Joseph Rowntree Foundation and New Policy Institute's *Monitoring poverty and social exclusion* report indicates that disabled people are more likely to be unemployed. It concludes that the fact that 'at every level of qualifications, disabled people are both more likely to be low paid and more likely to be wanting but lacking work shows that the problem cannot lie solely with disabled people themselves....[this situation] can only arise if employers perceive disabled employees differently from non-disabled ones...this is evidence that the labour market effectively discriminates against disabled people.'³

Discrimination among employers and a need for greater flexibility often results in parents who are disabled or have disabled children moving into low paid, part-time, unskilled jobs. We urge the ODI to monitor the quality, pay and sustainability of jobs being accessed by disabled people as a result of welfare to work programmes. Are they being compelled to engage in work focused activities that do not reflect their parenting and/or caring responsibilities? Are they moving into low paid jobs that do not safeguard them or their children from poverty?

Welfare reform and parenting responsibilities

We urge the ODI to ensure that the Harker⁴ report's recommendation that welfare to work programmes take note of parenting responsibilities is implemented. We are concerned that the welfare reform programme does not

3 G Palmer, J Carr and P Kenway, *Monitoring Poverty and Social exclusion 2005*, (Joseph Rowntree Foundation and New Policy Institute, 2005), p 14/15

⁴ L Harker, *Delivering on child poverty: What would it take?* A report for the DWP by Lisa Harker (The Stationery Office, 2007)

specifically acknowledge the need to provide additional support for parents who are disabled and/or trying to balance caring and parental responsibilities and employment. We fear that the proposed increase in compulsion and the threat of benefit sanctions may have a negative impact on some disabled parents, particularly those with learning disabilities or mental health problems, and on some disabled young people who are moving into a bewildering new system. As has been shown in the US, the inappropriate imposition of sanctions may *increase* child poverty in households that already disproportionately likely to be poor.

We urge the ODI to ensure that the needs of disabled parents and their children are a priority, and that welfare to work programmes and policies designed to support disabled people into work take note of parenting responsibilities. The impact of welfare reform upon disabled parents and disabled young people must be monitored. Are disabled parents or disabled young people with mental health problems or learning difficulties being subjected to benefit sanctions?

The costs of employment

Although many disabled parents report that costs go up if they move into paid work, anecdotal evidence indicates that DLA is often downrated or removed when somebody moves into work. **We urge the ODI to ensure that DLA supports and does not hinder access to employment. In particular, the ODI should monitor take-up of the mobility component of DLA as a means of supporting access to employment.**

Disabled people having housing provision, care support and equipment

We agree that the disadvantages that disabled people experience are compounded by poor housing, and that the need for expensive additional care and equipment saps already low incomes. As discussed throughout this submission, the stigma that is closely associated with claiming disability benefits actively deters disabled people from applying for the benefits to which they, or their children, are entitled. This renders families more susceptible to poverty, and leaves them unable to finance their additional care needs or purchase the equipment they need to lead a full and active life. We are also concerned that services are increasingly targeting DLA to finance their additional care needs and the provision of essential equipment. This saps the ability of DLA to lift families out of poverty.

We urge the ODI to ensure that charging policies do not place disabled people at further risk of poverty.

Transition to adulthood

CPAG is pleased that the ODI is also focusing on the transition to adulthood, a time that generates social, educational and financial changes for young disabled people and considerable stress for their families. Disabled young people are likely to live in poor families. Barriers to education are compounded by barriers to employment. Many will become poor adults.

The ODI has focused on the following areas:

Improve continuity and planning of service delivery

In *Out of Reach* (p. 65-66) families raised a number of issues that need to be addressed during the transition to adulthood. These range from difficulties when a young person who is 16 may not be able to take responsibility for their DLA, to problems understanding how changes in benefits for the young person may impact upon a family's access to tax credits. Families also report that sometimes a young person may lose their DLA if they move into work.

At the roundtable discussion, a welfare rights worker observes: 'Unfortunately, when it goes wrong it goes very badly wrong and the person that suffers is the severely disabled young person. So what we are doing as well is trying to promote incapacity benefit and income support for severely disabled young people. If you think it is difficult to find out about DLA, how many people actually know about entitlements for disabled young people at 16?'

It is essential that disabled young people have access to the financial support they are entitled to via the benefit system. **We urge the ODI to advocate and monitor the provision of benefit advice and take up during the transition to adulthood, particularly among disadvantaged young people – such as care leavers and young people from black and ethnic minority groups. The ODI should also ensure that the support that is available to help them access employment or education is appropriate and non-stigmatising.**

Disabled care leavers

A participant at the roundtable discussion highlighted the very particular problems that disabled care leavers experience accessing a complex, bewildering and impenetrable benefit system. In our response to *Care Matters: Transforming the lives of children and young people in care* we commented that 'The financial support provided to children and children in care, care leavers aged 16 to 17, care leavers aged 18 to 24, and care leavers aged 24+, are complex and vary according to the kind of care provided (residential care, foster care, or care provided by relatives or family friends) and the local authority in which they live. CPAG, which produces a number of guides including *The Welfare benefits and tax credit handbook*, experienced significant difficulties unravelling the intricacies and complexities of financial support on offer. This does not bode well for foster carers, friends and relatives or young people in care who are trying to negotiate their way through an often impenetrable system.'

We emphasised that 'Given that children and young people in care are more likely to be affected by disability, it is important that they know about and access the support that has been put in place to meet additional disability costs – primarily disability living allowance (DLA) which triggers additional support within income support and tax credits, and carer's allowance for people who fulfil the requirements. **It is important that the additional costs of caring for a disabled child are recognised irrespective of whether they are in residential care or private accommodation, and that action is**

taken to ensure that the additional support is targeted on meeting their additional medical and educational needs.

Independent living

The Government is keen to introduce systems that give disabled people greater choice and control over lives. Although we understand that the Government is currently piloting individual budgets, and to address barriers to accessing services, including house, transport, justice and leisure, families report significant problems accessing Direct Payments. They are therefore heavily reliant upon DLA to provide the financial support they need to maximise choice.

As discussed throughout this letter, we believe that access to DLA enhances reduces poverty, and enhances choice and social inclusion.

Conclusion

Equality for disabled people cannot be achieved if disability continues to be associated with poverty. Although employment provides a route out of poverty for some families, disabled parents and parents with disabled children continue to face significant barriers to employment. It is therefore essential to ensure that families access to disability benefits to which they are entitled whether or not they are in paid work. However, although research indicates that access to DLA does safeguard some families from poverty and that receiving the high rate mobility component increases choice and facilitates social inclusion for the whole family take up is low particularly among more disadvantaged groups.

We believe that improving take up of DLA would enhance equality and choice for disabled parents, families with disabled children and disabled young people's lives without any major changes to the system, and we urge the ODI to ensure that *all* government departments support moves to improve access to additional financial support via the benefit system, and avoid stigmatising language.

If you have any questions connected to this evidence, please do get in contact with my colleague, Gabrielle Preston, on 020 7837 7979 or gpreston@cpag.org.uk

Yours sincerely

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