



CPAG's response to the disability living allowance reform consultation

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1. Summary

1. CPAG welcomes the opportunity to comment on the consultation on the replacement of disability living allowance (DLA) with the personal independence payment (PIP).
2. The consultation identifies a number of problems with the way in which DLA is currently delivered and suggests that while the PIP will retain the key principles of DLA – to provide cash to disabled people to overcome barriers to ‘participating fully in everyday life’ – it will be delivered ‘in fairer, more consistent and sustainable manner’.
3. We welcome the Government’s commitment monitoring the introduction of the personal independence payment to see if it resolves or exacerbates the sort of administrative problems that currently impede the effective delivery of DLA to some groups.
4. Although the proposals identify some of the anomalies and discrepancies within DLA - in particular in and around its administration and delivery) - we are not convinced that introducing a new system at a time of significant cutbacks to the DWP will resolve these problems.
5. In the foreword, Maria Miller MP. Parliamentary Under Secretary of State and Minister for Disabled People argues that ‘By giving people the right level of support through personal independence payment, I hope that many more disabled people will be able to work and enjoy the advantages that an active working life can bring. That is why I believe that it is the right time to reform DLA.’
6. In June 2010, the Chancellor outlined significant spending cuts to cope with the deficit, and outlined an extensive package of cuts to benefits and tax credits, including reform of DLA in 2013, designed to generate savings of £360 million in 2013-14 and £1,075 million a year from 2014-15. Although these figures may change, they make it clear that the primary purpose of the proposed changes to DLA is to generate savings by reducing entitlement and possibly adequacy.¹
7. The consultation outlines a commitment to ‘ensure that everybody continues to receive the correct amount of benefit’ and yet signals a desire to significantly reduce the number of claimants. This can only be achieved by significantly reducing entitlement.
8. The Welfare Reform Bill 2011 suggests that reforming DLA will ‘create a more active and enabling benefit that supports people to overcome the barriers they face to leading full and independent lives. (Impact Assessment (1A). This ignores the vital role that DLA plays in doing just that.’
9. DLA provides vital support to many people who may now not qualify for support under the new system. The impact on some claimants could be devastating. Disability charities report that a ‘small but disturbing number of people saying they will kill themselves if their benefits are cut.’²

10. There are a number of contradictions in the overarching principles outlined in the consultation and the proposals. For example:
- A reliance on an 'objective evidence-based assessment' with a determination to focus on each individual's needs (which are inevitably and rightly subjective) will introduce considerable tensions into an assessment process which is clearly designed to reduce entitlement and focus support on 'the most vulnerable' (itself a subjective notion).
 - We are also concerned that many elements of the consultation are based on a range of false assumptions about the take-up and delivery of DLA - which have inflamed the media's damaging and divisive tendency to stigmatise claimants.
 - It also appears to ignore the fact that, far from generating barriers to employment access to DLA – particularly the mobility component – provides vital support to those moving into, and remaining in, work.
 - And while take-up of DLA has increased from a very low base-line in recent years – not least in rightful recognition of an increase in 'invisible disabilities' such as mental health problems, learning difficulties and behavioural problems – take-up remains low, particularly amongst the most disadvantaged groups.
 - We are concerned that the proposals will introduce additional layers of complexity at a time when the DWP, advice centres, and legal aid are experiencing significant cutbacks. It is hard to see how restricting entitlement and introducing periodic assessments for all claimants will 'simplify the application process'.
 - Nor does the reform adequately recognise issues in and around the introduction of the universal credit, and the impact that this is likely to have on both administrators and claimants.
 - The consultation also fails to distinguish between the existence of legislative changes and its effective implementation. Employment statistics show that despite the Disability Discrimination Act, disabled people continue to experience significant barriers to employment. Cuts to services delivered by local authorities and the voluntary sector are also likely to have a significant impact on disabled people.
 - The consultation suggests that access to aids and adaptations may be used to reduce support via the PIP. We think it is profoundly inequitable that accessing rightful entitlement to the support needed to facilitate social inclusion should be used to reduce entitlement to financial support. This dubious principle does not apply elsewhere in the system. In fact, considerable restrictions on the availability and delivery of support services and aids and adaptations to disabled people suggest that they will need more, not less, support via the PIP.
 - We are concerned that the consultation appears to ignore evidence on problems associated with the introduction of Employment and Support Allowance. Significant shortcomings and failures in the Work Capability Assessment (WCA) do not bode well for the equitable and efficient delivery of a completely new assessment process based on incompatible criteria.

11. Most worrying, the consultation fails to consider the impact that DLA and passported benefits play in reducing poverty in households affected by disability. Restricting entitlement to additional support to cover significant additional disability-related costs is likely to *increase* child poverty in such households.
12. A desk top analysis undertaken for CPAG suggests that *increasing* take-up of DLA would have a significant impact on reducing child poverty, while a combination of increasing DLA and adequacy would have a significant impact – and may in fact have enabled the previous Government to reach its 2010 target to halve child poverty from 1997 figures. **The aspiration to eradicate child poverty outlined in the Child Poverty Act will not be achieved until the link between poverty and disability is well and truly broken.**
13. Finally, it is important that the Government maintains a cross-department perspective when implementing radical changes to the social security system that are likely to have a significant impact on some of the most vulnerable children both now, and in the future. The proposals are at odds with the government's desire to focus on early intervention as a means of redressing cyclical disadvantage.
14. We believe the introduction of PIP needs to be seen in the context of extensive cuts in benefits, tax credits and services, which cumulatively are likely to have the greatest impact on households affected by disability. Reforming DLA at a time of significant changes in the social security system is extremely risky.
15. Despite a great deal of positive rhetoric in this – and other government documents – a reform process that is designed to 'ensure that expenditure on DLA is sustainable and focused on those most in need of additional support' is both counter-productive and short-sighted. It is at odds with the government's desire to support more people into work, and ignores the costs to the economy of failing to provide appropriate levels of support.
16. The Marmot Report argues that reducing health inequalities (that are largely driven by income poverty) would secure economic benefits of between £51 and £65 billion a year in increased productivity and taxes. Research published by the British Medical Journal also points out, spending on social protection narrows costly and wasteful health inequalities.³
17. Ensuring that children – and their parents - have the resources and investment they need today, will reduce their need for costly services in the future and increase their opportunities to access good jobs. Poor children today are the poor parents of tomorrow.

2. CPAG response to disability living allowance reform

1 - Introduction and context

18. The proposal to reform DLA need to be reviewed in the context of wider cuts that analysts and commentators calculate will have a disproportionate impact on the most vulnerable groups.⁴

19. The cumulative impact of wide-ranging cuts will have the biggest impact on groups that already experience the greatest risk of poverty – including women and children, and households affected by disability and large families.⁵
20. Wider cuts to public services are resulting in the erosion of additional sources of support upon which disabled people rely – for example public services and transport systems – and this will *increase* costs for disabled people at a time when financial support is being reduced.
21. The publication of the Welfare Reform Bill 2011 contains wide-ranging white paper on welfare reform is also directly relevant to the review of DLA, and its recommendations need to be cross-referenced with worrying proposals outlined.

Question 1 - What are the problems or barriers that prevent disabled people participating in society and leading independent, full and active lives?

Disability and poverty

22. Although the link between poverty and disability is complex, disabled people are more likely to live in poverty than non-disabled people because they are less likely to be in paid employment, are more likely to be reliant upon benefits, and they incur additional disability-related costs. Given ongoing systemic problems - such as inadequate benefit support, discrimination, poor employment prospects and fragmented service provision - becoming disabled is an extremely stressful and costly process which is likely to exacerbate underlying disadvantage for some of the UK's most vulnerable people.
23. In 2003, the DWP reported 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. However, the DWP emphasise that 'These figures cover income only, so the total will include disability benefits but there is no deduction for any extra disability-related costs.' Poverty levels are therefore much higher.⁶ They conclude 'these disadvantages can lead to a high risk of poverty and social exclusion.'⁷
24. Research undertaken in 2006 suggests that one in three disabled adults of working age are below the income poverty line, a rate that is higher than it was a decade ago. It is double the rate for working age adults without a disability.⁸
25. For adults and children affected by disability, The risk of living in poverty has remained The most recent Households Below Average Income (HBAI) confirms that 'Individuals [both adults and children] in families containing one or more disabled people were more likely to live in low-income households than those in families with no disabled person if they were not in receipt of disability benefits. Disabled individuals were also more likely to live in low-income households than non-disabled individuals.'⁹

Causes of poverty

26. *Extra costs:* Loss of income due to the onset of sickness or disability is usually accompanied by an increase in disability-related costs, which vary according to the severity of the disability.

27. Disabled people are at particular risk of poverty because high living expenses (due to extra heating, laundry costs and the need to finance special equipment, personal support or goods and services) are compounded by a greatly reduced earning capacity.
28. Research undertaken by CPAG and others identifies some of the additional costs incurred by parents with disabled children ¹⁰ and by disabled parents. ¹¹
29. *Moving out of paid employment:* the workplace the onset of ill-health or a disease likely to trigger a significant drop in income. As Burchardt points out, the onset of sickness or disability has an impact upon the whole family. 'Changes in the employment status of one individual can have knock-on effects on other household members too.' She reports that loss of employment impacts differently upon different households. For a lone parent, the impact is greatest, because there is no other adult to compensate for a sudden drop in earnings. However, even in couple household there is a financial impact on the whole household. If the earner becomes disabled in a one-earner couple household, the non-earning spouse is unlikely to access paid employment to compensate for the drop in earnings because they now have additional caring responsibilities, and the couple is likely to become a non-earning household. Even if the non-earner becomes disabled, the earner is quite likely to give up employment in order to care for the disabled family member. ¹²
30. *Poor working conditions:* An increase in conditions such as stress, depression and anxiety ¹³ indicates a link between being in low-paid, low status occupations and the onset of sickness or disability. The Department of Health has long accepted that 'a lack of job control, monotonous and repetitive work, and an imbalance between effort and reward are associated with a higher risk of coronary heart disease and other health problems and that 'sustained, chronic and long-term stress is linked to low control over life circumstances' which in turn is linked to low social status. ¹⁴ Health and safety is also an issue. In 1999, the Health and Safety Executive estimated that work-related stress costs employers at least £353m a year, and cost society at least £3.7 bn. ¹⁵ The Department of Health report that, 'although work is generally good for people's health, poor health and safety management increases the risk of occupational disease and injury.' ¹⁶ As Burchardt trenchantly observes, 'We may be able to do relatively little about the increased likelihood of ill health at older ages, but we certainly can do something about the risk of accidents at home, on the roads and at work, not to mention the prevalence of illness and conditions which are caused or exacerbated by poor living and working conditions.' ¹⁷
31. *Worklessness and In-work poverty:* Poverty statistics undermine the belief that work is the best route out of poverty – particularly for disabled people. HBAI shows that while the number of children in low income, workless families fell from 1.7m to 1.6m, the number in low income, working families has risen for the fifth year in a row, leaving well over half of children in poverty living in a family with a working adult. Although in-work poverty is a problem for both disabled and non-disabled parents, CPAG's report *At Greatest Risk* identifies higher rates of poverty amongst disabled parents who work compared to non-disabled parents, possibly due to 'the amount and/or type of work open to disabled parents ... the likelihood is that disabled parents are more likely to find low-paid and/or part-time work compared to non-disabled parents.' ¹⁸

32. *Barriers to employment:* The previous Government acknowledged that disabled people faces significant barriers to employment. In 2005 *Improving the Life Chances of Disabled People* reported that 'low educational attainment translates into low skill and hence low employability. In addition disabled people require support in the form of equipment, transport, structural changes to their working environment or support workers...A more integrated response would improve disabled people's employment chances and empower them to fulfil their roles and responsibilities.'¹⁹ Despite legislative changes, employment still provides an unreliable and often unrealistic route out of poverty for many disabled people.
33. *Benefits - Adequacy:* The adequacy of disability benefits has long been a source of concern. Barnes and Baldwin argue, 'If the 1980s saw a trend towards increased coverage in benefits for disabled people, this has been balanced by new restrictions and a steady erosion of their living standards. ... Benefit reforms have reduced the levels of income-replacement benefits, while also tightening eligibility criteria, with damaging effects on independence and autonomy as well as living standards. Disabled people were also badly affected by the 'simplification' of Income Support after 1988'.²⁰ CPAG is concerned that the proposed reform is part of continuing policies of a 'tightening' and 'targeting' of disability benefits designed to replace earnings.²¹
34. *Take up:* Improvements to disability benefits have been introduced. However, as the DWP acknowledges, 'Increasing levels of benefits will not help people unless the benefits are claimed.'²² Research indicates that disadvantaged groups – particularly from ethnic minority groups who also experience high levels of unemployment – are least likely to apply.²³ Given that government departments rarely see it as their responsibility to increase take up (as happened with tax credits) this role normally devolves to the voluntary sector and welfare rights units in local authorities and both of these are under attack from cut backs in local authority funding and legal aid cuts. Furthermore, inflammatory statements about benefit fraud by members of the Government which are regularly picked up the media ignore the fact that low-take up and not fraud is the main problem.²⁴ Stigmatising claimants prevents the most vulnerable people accessing the support they desperately need.
35. *Administration:* The overall inadequacy of the administrative system is also contributing to the difficulties people suffering from sickness and disability face. Poor decision-making (particularly in and around fluctuating conditions and 'invisible disabilities') is a particular problem and contributes to a high number of successful appeals. Significant cutbacks to departmental budgets, which will fall particularly heavily on the DWP, alongside cuts to the advice sector and legal support does not bode well for the implementation of an ambitious programme of reform.

Child poverty

36. CPAG is very concerned about high levels of poverty among children in households affected by disability, and we outlined our concerns in three of our reports: *At greatest risk: the children most likely to be poor*; *A route out of poverty: disabled people work and welfare reform* and *Out of Reach: benefits for disabled children* which include policy recommendations that relate specifically to disabled parents and disabled children.

37. A number of children and young people identified as facing the greatest risk of poverty are particularly susceptible to living in poverty. For example, children in care and care leavers are disproportionately likely to experience disabilities, special educational needs, behavioural problems and mental health issues. Many foster carers and families and friends who care for children are also disabled. Poor health is also an issue in some asylum-seeking and migrant groups. Restrictions on entitlement are likely to have a negative impact on these very vulnerable groups.
38. Although progress has been made reducing child poverty overall, the link between poverty and disability has remained stubbornly in place, and for some groups, the risk of poverty has increased since 2005/05.
39. For children in households affected by disability, the statistics are stark.
- The most recent Households Below Average Income (HBAI) 2008-2009, reveals that nearly one million children in poverty live in a household affected by disability (adult or child) (or 29.5% of the 2.8 million children in poverty (Before Housing Costs and After Housing Costs).
 - Around 605,000 children living in poverty have a disabled parent (BHC) – which represents around a fifth (21.5%) of 2.8 million children in poverty, and around 810,000 children living in poverty have a disabled parent (AHC) – which represents around a fifth (21%) of 3.8 million children in poverty. Around 395,000 disabled children live in poverty (BHC) and around 525,000 disabled children live in poverty (AHC).
 - However, HBAI confirms that disability benefits provide significant protection from poverty – although less so for disabled parents than disabled children.
 - For example, the risk of a child being in poverty in households with a disabled child but no disabled adult rises from 21% for those receipt of disability benefits to 41% in households not in receipt of disability benefits (AHC), and from 12% to 30% (BHC).
 - In a household with a disabled adult but no disabled child, the risk of poverty rises from 29% in households in receipt of disability benefits to 43% in households not in receipt of disability benefits (AHC, and from 22% to 31% BHC).
 - In households with both disabled children and a disabled adult, the risk of poverty rises from 30% in households in receipt of disability benefits to 50% in households not in receipt of disability benefits (AHC, and from 20% to 44% BHC).
 - Research undertaken by the DWP on DLA includes an analysis of ‘the percentage reduction in the chances of children in families affected by disability being in poverty when the family is in receipt of DLA?’²⁵ it concludes that a family’s access to DLA reduces the chances of their children being in the poorest quintile by more than 33%. (36% chance reduced to 22% chance.) It concludes that ‘the major reason for this is the effect the DLA itself has as this would only be likely to push someone up one quintile. As can be seen below receipt of DLA can make a significant percentage increase in household income – sufficient to raise someone from the poorest quintile into the next quintile.’²⁶

- **Restricting entitlement to additional support to cover significant additional disability-related costs is likely to *increase* child poverty in such households. The aspiration to eradicate child poverty outlined in the Child Poverty Act will not be achieved until the link between poverty and disability is well and truly broken: access to disability benefits play a vital role in tackling that link.**

Poverty and life chances

40. The Independent Review on Poverty and Life Chances signalled the government's determination to focus on the early years to redress cycles of disadvantage.
41. And yet a significant body of research consistently identifies income poverty as the single most important – and damaging – factor in a child's life. Income poverty has a profoundly damaging impact on the health and wellbeing of both the mother and the child. Protecting the health and wellbeing of the mother is of paramount importance – and this necessarily involves protecting her from income poverty before and after the birth of a baby.
42. As Jason Stelitz and Ruth Lister point out: 'Money matters. It underpins so much of the experience of families struggling to get by on low incomes.' They point out that 'As low-income families' incomes increase, so outcomes improve; children's lives in particular are enhanced.'²⁷
43. The *consequences* of income poverty are extensive and profound – and affect every aspect of children's lives.
44. A report of one of Task Groups collecting evidence for the Strategic Review of Health Inequalities chaired by Michael Marmot reports the following: ²⁸
 - the introduction of social protection systems as well as their generosity and coverage have significant impacts on health;
 - who receives benefits within the household affects the health outcomes for the family;
 - found serious difficulties facing those with long term medical conditions who are on the margins of the labour force. Collaboration between health and social protection systems is poor;
 - gave particular attention to gender and health and the implications this has for the social protection system [a] considered the fate of groups like asylum seekers who are excluded from its normal working.
45. Ensuring that children have the resources and investment they need today, will reduce their need for costly services in the future and increase their opportunities to access good jobs.
46. Living in poverty damages the health and psychological wellbeing of mothers/carers and this has an impact on their children, which in turn – perversely - undermines their ability to access educational or employment opportunities that might help increase incomes in the long-term.

Birth

- 'Poverty in and soon after childbirth is associated with a much higher risk of a low-weight birth, maternal depression in infancy and lower chances that the

mother will try breastfeeding. All of these are known to be associated with poor outcomes in the rest of childhood and in adulthood.’²⁹

- One third of births with low weight are associated with economic inequalities and this increases the risk of infant mortality and generates significant health problems throughout childhood and in later life.³⁰
- Children whose parents are poor are ten times as likely to die suddenly in infancy, and two and half times as likely to suffer chronic illness as toddlers, twice as likely to have cerebral palsy and over three times as likely to suffer mental health disorders.³¹

The early years

- Under 3 year olds in families with incomes of £10,400 or less are 2.5 times more likely to suffer life-limiting chronic illness, and two times more likely to suffer from asthma than under 3 years olds in families with incomes over £52,000 and over.³²
- Children born in 2000 who are being tracked by the Millennium Cohort Study show stark differences in health by the age of three.³³
- A report for the Sutton Trust shows that children growing up today in the poorest fifth of families are already nearly a year (11.1 months) behind those children from middle income families in vocabulary tests by the time they are five.³⁴
- Many illnesses associated with poverty – such as a significantly increased risk of developing ‘limiting chronic illnesses’ are associated with aspects of children’s living conditions. Research from Shelter shows that children in bad housing are twice as likely to suffer from bad health as other children.³⁵

Children’s mental health

- ‘In 2004, it was estimated that 10 per cent of 10–15-year-olds had some form of diagnosable mental health problem.’³⁶ Research from around the world has linked mental health problems with poverty in households.’
- The influential Marmot Review on health inequalities recognises the evidence ‘support[s] the fact that the early effects of living in poverty and the cumulative effects of poverty over time both have an impact on a child’s mental wellbeing’.³⁷

Young Adulthood

- Around 20% of young people aged 20 – 24 in the UK live in poverty. Young males face particular mental health risks, with suicide rates amongst this group particularly high.³⁸ Care leavers are more likely to experience health problems – including mental health problems – and face a very high risk.

Health in adulthood

- Childhood socio-economic disadvantage has been shown to heighten the risk of disability in adulthood (Kuh et al 1997). Childhood adversity, including economic disadvantage has been shown to increase levels of mental-health amongst adults. (Lunberg, 1997)³⁹

- Research from the New Policy Institute (NPI) shows that ‘A quarter of adults aged 45-64 suffer a long-standing illness or disability which limits their activity’.⁴⁰
- The NPI reports that ‘Adults in the poorest fifth are much more likely to be at risk of developing a mental illness than those on average incomes.’

Tackling poverty in households affected by disability

47. **CPAG has long argued that a benefit system that safeguards children from poverty and recognises the demands and responsibilities of all parents, particularly those who have additional needs – for example disabled parents and parents with learning disabilities and mental health problems – must be an integral part of any preventative strategy, particularly one that focuses on early intervention. Restricting entitlement to DLA is likely to do the opposite.**

Tackling benefit adequacy

48. While families who are able do try to use DLA to save up to cushion fluctuations in income that often generate costly debt and spend it in ways that maximise social and educational opportunities for their children.
49. Research shows that an award of DLA not only increases family income but it reduces stress levels, and enables families and their children to be more active participants in society. Overall, it enhances the health and wellbeing of both parents and children.⁴¹ It supports policies that focus on early intervention and aim to reduce costly health and educational inequalities.
50. Although the adequacy and take up of disability benefits has long been a source of concern (complexity, lack of information and poor administration – and the relentless stigmatisation of claimants - keeps take up low, while the level of support does not address the additional costs incurred)

Tackling take-up and adequacy

51. However, research also suggests that accessing DLA is difficult and that take-up is low, particularly for more disadvantaged groups who need it most.
52. Families also report that applying for benefits is stressful, difficult and often demeaning. A complex and impenetrable system means that families often do not get their full entitlement.⁴²
53. The constant stigma associated with claiming benefits has taken its toll. CPAG research suggests that families also report that although the incidence of benefit fraud is very low, they feel under permanent scrutiny not just from benefit officials and – more worrying – medical practitioners, but from members of the public. (p.79) It is therefore regrettable that the consultation consolidates misunderstandings about entitlement and take-up of DLA, and is using false assumptions to justify restricting access to DLA.
54. Qualitative research shows that flaws in the system prevent families from accessing the benefits to which they are entitled. It also shows that constant reassessment results in DLA being frequently downrated and removed, and then – more often than not – reinstated at appeal. This creates considerable financial instability in households, and additional costs for the DWP.

55. Both parents with disabled children, and disabled parents (and many people fall into both categories) report that while it makes a huge difference to their lives, it does not currently cover their additional financial needs.
56. The A report of one of Task Groups collecting evidence for the Strategic Review of Health Inequalities chaired by Michael Marmot reports the following: ⁴³
 - the introduction of social protection systems as well as their generosity and coverage have significant impacts on health;
 - who receives benefits within the household affects the health outcomes for the family;
 - found serious difficulties facing those with long term medical conditions who are on the margins of the labour force. Collaboration between health and social protections systems is poor;
 - gave particular attention to gender and health and the implications this has for the social protection system [a] considered the fate of groups like asylum seekers who are excluded from its normal working.

Work – a route out of poverty?

57. In her foreword to the consultation document, Maria Miller MP argues that ‘Just as we are committed to offering unconditional support to those who are unable to work, we know that work is the best form of welfare for those who are able to do so. That’s why I want as many disabled people as possible to benefit from employment – it is not acceptable for anyone to be trapped in a cycle of dependency. By giving people the right level of support through personal independence payment, I hope that many more disabled people will be able to work and enjoy the advantages that an active working life can bring.’
58. Although tackling discrimination in the workplace and maximising employment amongst sick and disabled people are laudable aspirations, research shows that a heavy reliance on work as the primary route out of poverty has proved to be a problem for families affected by disability.
59. In 2005, the Cabinet Office reported that nearly half of all disabled people of working age are economically inactive compared to only 15 per cent of their non-disabled counterparts. ⁴⁴
60. In 2006, *Monitoring poverty and social exclusion* provided a depressing overview of the disadvantages disabled people face in the labour market in the UK⁴⁵ shows that the numbers of disabled adults who ‘lack but want work’ is five times the number included in the official unemployment figures.⁴⁶ For any given level of qualification, a disabled person is between two and three times as likely as a non-disabled person to be lacking but wanting work. ⁴⁷
61. *Monitoring poverty and social exclusion* 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.’ ⁴⁸
62. Nick Jones also takes issue with David Freud’s statement that ‘the evidence is now overwhelming that employment is generally beneficial for individuals

and their families' pointing out that the research most often cited to support this is cautious in its claims and the statement that 'work is generally good for health and well-being' is qualified by a number of provisos which include: 'there is limited evidence on effect sizes and a need for further qualitative research'; 'most of the evidence is relatively short-term'. It concludes that 'Basically, there is a limited amount of high quality scientific evidence that directly addresses the question.'⁴⁹

63. As discussed above, despite the introduction of legislation, this situation has not improved.

Implementation of equality legislation

64. The patchy implementation of equality legislation and the failure of duties on employers and service providers to be robustly enforced is a problem. As this consultation paper demonstrates, the existence of the legislation suggests that there is significantly more support on offer than is actually the case, and this has inflamed an ongoing tendency to blame disabled people themselves – rather than ongoing structural inequalities – for many of the problems they experience.

2 - The new benefit: our proposals

Our approach to reform

The consultation proposes replacing DLA with a new cash benefit – personal independence payment 'which will contribute to extra costs of overcoming the barriers faced by disability people to lead full and active lives.'

The new benefit 'will reflect changes in society, such as legislation...and 'contribute to the extra costs of living independently, in a way that is right for each individual.'

The benefit will continue to take account of the social model of disability

The Government are 'Developing a new assessment in collaboration with a group of independent specialists in health, social care and disability, including disabled people.'

The personal independence payment will be 'based on need not income' – and will be 'a more active benefit, recognising changes to individual's situations and take account of the support that disabled people can access to help them live independently.' Will 'ensure that the award continues to reflect the individual's changing needs over time by building in periodic reviews'.

The new benefit introduced in 2013/14

The government will introduce a Bill that will 'set out the high level legal framework underpinning the new benefit.'

Question 2 – is there anything else about DLA that should remain the same?

65. The consultation document rightly identifies a number of element to DLA which it believes work well and may retain, for example:

- Ability to spend money in ways to reflect personal circumstances (so need cash support)
 - Non-means tested, and not taxable, and not dependent on paying NI
 - Available to those in and out of work
66. We agree with these statements.
67. It also identifies a number of problems with DLA which it claims the new benefit will resolve, for example:
- Although DLA is 'non-means tested benefit payable regardless of employment status... People are unclear about who can qualify and decisions about qualifications are inconsistent and subjective...many people incorrectly believe that DLA is an income-replacement benefit for people who are unable to work due to disability.'
 - The application form is 'lengthy' and requires 'detailed information';
 - [A]wards are reviewed if individual reports that changes' but there is currently 'no process to systematically review all awards.'
 - The current criteria – based on care and mobility – are 'subjective and unclear' with 'inconsistent results and support not always focused on those who face the greatest challenges.'
68. Although we agree that this list captures some of the problems in the current system, CPAG is not convinced that problems which are generated by poor information and problems with the administration and decision-making process justify introducing a completely new system, which, in a time of cut-backs to the DWP and advice sector, is very likely to experience exactly the same problems. The quality of decision-making is dependent on ongoing support and training.
69. As with DLA, those assessing and delivery the new benefit will be susceptible to stigmatising and misleading media coverage which often conflates DLA with incapacity benefit. Tackling discriminatory language is important to tackle ignorance and improve decision-making generally.
70. For example, moving into work often triggers a reassessment of and downgrading or removing of DLA by the DWP. This is regrettable, as research shows that disabled people incur significant additional costs when moving into work (such as additional transport costs, and childcare needs)⁵⁰ and that access to DLA, particularly the mobility component, provides crucial additional support that enables people to access.
71. As discussed below, the use of proxies for extra costs has not been shown to cause confusion or be inadequate and the DWP document cited in the consultation itself concludes that 'although the evidence from these studies is not immediately helpful, they do point the way toward research that could inform future efforts to assess AA and DLA.'⁵¹
72. CPAG therefore suggests that:
- DLA is disregarded in all means tests for other benefits. This is very important in protecting the incomes of low income disabled people and should be retained. Maximising take-up is a crucial issue.

- DLA is paid to people both in work and out of work, and to those in education or training. This continuity of support is important in overcoming barriers to participation and should be retained.
- The introduction, assessment and administration of PIP should reflect concerns around the WCA.
- It is important that a new assessment process is piloted and the findings published before any changes are introduced universally.
- Adequacy also needs to be addressed, and should more accurately reflect the real costs of disability – including particular ones incurred in households with children.
- Ensuring that both claimants and administrators understand issues in and around entitlement to DLA – for example, realise that people are entitled to DLA whether or not they are in work – requires improving administration and information, not reforming an entire system in a way that is clearly intended to *reduce* entitlement.
- No changes introduced until the impact on disabled people is fully understood. This means undertaking thorough research before legislating for change. Doing otherwise risks impoverishing the most vulnerable in society and may be at odds with Equality Legislation.

Question 3 – What are the main extra costs that disabled people face?

Summary of proposals

The consultation suggests that that ‘some evidence to suggest that individuals whose impairments have the greatest impact are likely to experience higher costs’ and is keen to target the new allowance on those ‘who face the greatest challenges and expense’, and ‘assess extent to which it fulfils these aims as it is introduced’.

Although work on the assessment still in progress, the government ‘want the assessment to provide a broader, more objective measurement of the impact of an individual’s health condition or impairment on everyday activities’ than those in the current form’.

For example, it will look at individual’s ability to: get around, interact with others, manage personal care and treatment needs and access food and drink – so the following could determine levels of support:

- Ability to plan and make a journey
- Understand and communicate with others

The assessment needs to reflect changing and fluctuating conditions.

73. A recent Demos report ⁵² reports that although the additional costs of disability are hugely wide ranging and therefore difficult to quantify, it is well known that disabled people are at particular risk of poverty because high living expenses (due to extra heating, laundry costs and the need to finance

special equipment, personal support or goods and services) are compounded by a greatly reduced earning capacity.

74. Loss of income due to the onset of sickness or disability is usually accompanied by an increase in disability-related costs, which vary according to the severity of the disability.
75. Families incur additional disability-related costs irrespective of whether they are entitled to – or receive – DLA and passported benefits.⁵³
76. The DWP has long accepted that extra disability-related costs ‘can take many forms’⁵⁴ and various approaches to measuring extra costs have been developed.⁵⁵ In 2004, the Centre for Research in Social Policy (CRSP) has formulated budget standards for disabled people with different needs arising from physical or sensory impairments. Developed by disabled people themselves through a series of focus groups, the budgets reveal the minimum resources necessary to meet disabled people’s needs, so that they would achieve a ‘level playing field’ with people without disabilities.⁵⁶
77. More recently, although the DWP accepts that measuring extra costs ‘conceptually difficult’ it confirms that ‘all studies conducted to date show have concluded that there are extra costs incurred by disability’ and that ‘Most studies conclude [that these] are not met fully through services, and the cost of private provision to meet needs is not fully covered by extra costs benefits.’⁵⁷
78. A review of international evidence on disability-related costs cited in the consultation ‘yielded very little information about how to objectively determine the size or adequacy of allowance payments’. However, it reports that ‘most of these programmes initially set allowance rates on some measure of reasonable expenses for relevant services; over time, adjustments are made to reflect inflation and political and fiscal realities.’⁵⁸
79. The research suggests that while benchmarks based on the costs of extra goods and services used by individuals are likely to be too low because many people with disabilities face income constraints that lower standards of living, all studies that use expenditure equivalence approach show that the extra costs of disability are very large. It reports that ‘the studies do point towards research that could inform an assessment of AA and DLA. It concludes that ‘Some progress could possibly be made through a new analysis of the data used in the UK study. A more ambitious approach would rely on collecting comparable expenditure data from samples of AA and DLA’. It concludes that ‘although the evidence from these studies is not immediately helpful, they do point the way toward research that could inform future efforts to assess AA and DLA.’ (p.32)

Disabled parents and extra costs

80. 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, and these include:

Services

- Disabled parents are particularly disadvantaged by poor service provision. This compounds issues in and around poverty, 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 takeaways 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 also 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.

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.⁵⁹

Barriers to employment

81. One of the greatest additional costs incurred by disabled parents – many of whom are lone parents – is difficulties in and around accessing paid employment.
82. Disabled parents who do manage to overcome barriers to employment emphasise that moving into work generates additional costs for them (some of which are generated by additional caring and parental responsibilities) and for their employer. They point out that the stress of working alongside managing both their caring and parental needs generates considerable costs for medical services. (‘...The times she went into hospital were the times the work stress as the worse’).⁶⁰

DLA – meeting additional costs?

83. The consultation document points out that DLA ‘aims to contribute towards extra costs – using care and mobility as proxies’ but is concerned that awards are ‘not based on individual’s costs, but on the severity of care and mobility needs.’ It is also keen to review the adequacy of DLA as part of ‘wider range of support and services available to disabled people.’
84. The consultation document suggests that there ‘is currently conflicting evidence on the factors that affect extra costs that disabled people face in the 21st Century’, but does not clarify how costs will be measured, or what impact this will have on the level of support provided.
85. It is not clear how an individual’s additional costs will be utilised to establish levels of support in the new benefit. It is also worrying that the provision of support and services - which are likely to suffer significantly as a result of wider cuts - are being used to justify cuts in support via benefits. This will add

to the negative impact that the cumulative impact of cuts to benefits, tax credits, services and support will have on disabled people over time.

86. **Restricting access to financial support will inevitably damage children in households affected by disability. It is extremely important that any reform of DLA recognises and meets the additional costs incurred by families with disabled children, and by disabled parents (as a consequence of the combination of both their disability and their parental responsibilities).**

Question 4 – The benefit will have two rates for each component:

- **Will having two rates per component make the benefit easier to understand and administer while ensuring appropriate levels of support?**
- **What, if any, disadvantages or problems could having two rates per component cause?**

Summary of proposals

The personal independence payment' will be introduced in 2013/14 and will have two components:

- Mobility – awarded on ability to get around
- Daily living component – awarded on their ability to carry out other key activities necessary to participate in daily life

Payment of *both* components will cease to be paid after that the individual has been in that hospital or care home for 28 days (84 for children) but underlying entitlement will remain in place. Where person is paying for their own care, payment will cease throughout (by 2012).

Eligibility

The individual must have a long-term disability. 'To ensure that support goes to those with the greatest need' the personal independence payment will only be available to those with a long-term health condition or impairment which must last at last 12 months, and claimants must:

- Must meet eligibility requirements for 6 months - 'Qualifying Period'
- And must meet them for a further 6 months – 'Prospective Test'

(The Government will consider how to apply these rules to those with varying and fluctuating conditions.)

87. The consultation document suggests that DLA will be replaced with a new cash benefit – personal independence payment – 'which will contribute to extra costs of overcoming the barriers faced by disability people to lead full and active lives' and will be is designed to 'reflect changes in society', such as legislation – and 'contribute to the extra costs of living independently, in a way that is right for each individual.'

88. The consultation suggests that personal independence payment will be 'based on need not income' – and will be 'a more active benefit, recognising changes to individual's situations and take account of the support that disabled people can access to help them live independently.' Will 'ensure that the award continues to reflect the individual's changing needs over time by building in periodic reviews'.
89. Given that many of the people administering the new system will have been directly involved in delivering DLA, a high level of training will be needed to ensure they understand the changes in emphasis when supporting – or assessing - applications.
90. Although work on the assessment is still in progress, the government 'want the assessment to provide a broader, more objective measurement of the impact of an individual's health condition or impairment on everyday activities' than those in the current form'.
91. However, there is a direct tension between an assessment process that is 'objective and evidence-based' and one that has 'stronger focus on an individual's specific needs'.
92. As discussed above, although take-up of DLA has increased in recent years, it remains relatively low – particularly in groups who face the greatest risk of poverty. Many people assume they are not entitled, because they do not view themselves as 'disabled', and many more are confused about the care component, which they are entitled to claim irrespective of whether they finance additional care or not.
93. In *A route out of poverty? Disabled people, work and welfare reform* CPAG highlights the importance of ensuring that parenting responsibilities are taken into account when gauging the level of support needed in welfare to work programmes (findings that were echoed in the report by Lisa Harker for the DWP ⁶¹). This principle should be applied in an assessment of entitlement to DLA.
94. Although having a benefit that recognises different needs and costs is therefore welcome (particularly if parenting responsibilities are included), caution is needed when introducing radical change to ensure that it does not have a negative impact on claimants - for example:
 - It is a source of concern that it is being introduced time of significant cuts to the Department, and other services and support currently involved in its administration (including an independent advice services and legal aid) will introduce a raft of additional administrative problems that will prevent families who are entitled from receiving the support they so desperately need.
 - Although replacing the care component with a 'living component' could introduce greater clarity into the system – and ensure that the particular experiences of disabled parents are better reflected – it may introduce additional complexity into the assessment process.
 - Issues around how one component interacts with and affects access to the other component need to be addressed.
 - It is important that this change is not used to *reduce* entitlement – although that is clearly its intention. The quality of decision notices and information and

the provision of adequate independent advice to claimants is the best way to ensure that claimants and decision-makers understand and follow the criteria

Question 5 – Should some health conditions or impairments mean an automatic entitlement to the benefit, or should all claims be based on the needs and circumstances of the individual applying?

Automatic entitlements

- The Government assumes that because some of these are based on medical condition rather than need so support is 'not always appropriately targeted', and they will therefore 'treat each application individually'.
- This response identifies some of the problems with the adequacy, administration and delivery of DLA and will consider whether the introduction of the personal independence payment will resolve these, and/or introduce additional problems.

95. The consultation document also outlines the Government's intention to move away from a system that awards automatic entitlement for certain conditions – alongside a new periodic review of all Payment Independence Payment awards – on the basis that the impact of an impairment or health condition may change over time.
96. We recognise the need for a system of exemptions to be fair and transparent
97. However, the system must recognise that constant assessments take a high toll on claimants and administrators alike. For example, parents with disabled children with a lifelong or long-term condition or disability point out that even when their child's condition – and its impact – remained the same, constant re-assessments of their children's entitlement to DLA often generated seemingly arbitrary decisions to downgrade or remove the benefit – only to have it reinstated at appeal (as and when the parents had the time, energy, knowledge and expertise to go to appeal).⁶²
98. Given the costs of administering the system, retaining existing automatic entitlements to higher rate DLA is an efficient and effective way to allocate resources. It will not be cost effective for the Government to make people go through an assessment process (and potentially repeated assessments / reviews) where there is clear entitlement to the benefit. This is not only likely to result in people losing their benefit even though they are entitled to receive it, but it will generate additional administrative costs at a time of cutbacks. The whole process is extremely stressful for claimants, and may well exacerbate their condition.
99. The idea of using certain conditions or treatments as a proxy for a level of need where these are well understood has the potential to improve consistency of decision making, simplify entitlement from the claimant's perspective and reduce costs of administration for the DWP.
100. Although the extension of this to other common conditions/treatments (while retaining consideration of the needs of the individual if it is greater than the impairment /treatment) might be helpful, the specific focus on social rather

than medical models of disability, and the desire for the new benefit to reflect 'individual need' and 'changes in society' may render this difficult to achieve.

Question 6 – How do we prioritise support to those people least able to live full and active lives? Which activities are most essential for everyday life?

Eligibility

The individual must have a long-term disability. 'To ensure that support goes to those with the greatest need' the personal independence payment will only be available to those with a long-term health condition or impairment which must last at least 12 months, and claimants must:

- Must meet eligibility requirements for 6 months - 'Qualifying Period'
- And must meet them for a further 6 months – 'Prospective Test'

(The Government will consider how to apply these rules to those with varying and fluctuating conditions.)

The personal independence payment will be 'based on need not income' – and will be 'a more active benefit, recognising changes to individual's situations and take account of the support that disabled people can access to help them live independently.'

The Government will 'ensure that the award continues to reflect the individual's changing needs over time by building in periodic reviews'.

The Government also want to 'focus resources on individuals whose impairment have most impact on their lives' and to 'assess individual's ability to carry out a range of activities key to everyday life, including some related to a broader definition of mobility.'

101. The consultation document reiterates the Government's commitment 'to helping disabled people to exercise choice and control over their lives' and stresses that the personal independence payment will maintain the key principles of DLA – provide cash to disabled people to overcome barriers to 'participating fully in everyday life...in fairer, more consistent and sustainable manner'.
102. The consultation document reports that 'definitions currently used are subjective and reflect views of disability from the 1990s' – and it is important that the Government draw upon a raft of research suggesting what changes in the population's health have occurred.
103. It is important that the new assessment supports the government's overarching aim to generate equality of outcome with that expected for people without a disability.
104. Although it is important to ensure that those in greatest need receive the support they need, we are concerned about that the desire to target support on 'the most vulnerable' is often both subjective and restrictive – and may well

result in decision-makers likely to focus on medical rather than social model of disability.

105. Research shows that restrictive entitlement renders it less, not more, likely that people will get the support to which they are entitled. Fran Bennett reports that 'Child benefit has reached more children living in low-income families than any of the benefits or tax credits specifically designed for them, and also reduces the numbers who need them. Means-tested systems have been described as better at excluding all the better-off than at including all those living on low incomes.'⁶³
106. People with mental health issues experience significantly different barriers from those with physical or sensory impairments, and this needs to be reflected in the design and delivery of the personal independence payment – as well as the assessment process.

Question 7 – How can we best ensure that the new assessment appropriately takes account of variable and fluctuating conditions?

107. We welcome the fact that the government is keeping an open mind on how best to ensure that the new assessment takes account of variable and fluctuating conditions.
108. The change from a 'care component' to a 'daily living component' may better capture variable and fluctuating conditions – and indeed the variable impact that parenting responsibilities have on a disabled parent's needs.
109. However, clear criteria will be needed to clarify what is a subjective assessment of such impacts on a person's ability 'to carry out other key activities necessary to participate in daily life.'
110. Lessons and concerns about the WCA should be utilised.

8. Should the assessment of a disabled person's ability take into account any aids and adaptations they use?

- **What aids and adaptations should be included?**
- **Should the assessment only take into account aids and adaptations where the person already has them or should we consider those that the person might be eligible for and can easily obtain?**

111. We are very concerned about a proposal that in effect will penalise families for accessing the adaptations and aids they need to overcome some (by no means all) of the barriers they face.
112. The consultation document is also keen 'to take account of the support that disabled people can access to help them live independently' will be included in the assessment.
113. Although the availability or otherwise of additional services, support and adaptations is vital in facilitating disabled people's ability to access 'everyday activities', it may make sense to review their availability and cost in the assessment process – but to maximise rather than reduce support.
114. It would be extremely worrying if the assessment process (as is the case with some elements of the consultation itself) is based on possibly hypothetical access to adaptations. This may result in the decision-maker assuming that

people are able to access adaptations when this is not actually the case and result in claimants being turned down unfairly.

115. In the current funding climate local authorities are likely to prioritise services to people receiving benefit, creating a potential catch 22.
116. The use of aids and adaptations can in itself result in extra expenses. DLA provides a vital financial resource if aids or adaptations need to be repaired. Removing entitlement based on their existence is perverse as it risks undermining the effectiveness of these vital sources of support.
117. Disability is a major theme in applications to the Social Fund. This is because people who are disabled are more likely to live in poverty, and partly because of the additional stress and strain that 'bulky objects' are put under.
118. To carry out the proposed removal of the higher rate mobility component for wheelchair users would undermine the intention of a cash benefit to compensate for extra costs. The ability to mobilise in a wheelchair does not imply that a disabled person is able to afford an adapted car such as those available through the Motability scheme.
119. The consultation document also falls into the trap of making false assumptions about the impact of legislative changes (such as the Disability Discrimination Act) on people's lives, so a transparent and realistic assessment of the impact that this has had on people's lives is important.
120. Keeping track of the availability and reliability of aids and adaptations will become increasingly complex at a time at a time of significant – and geographically variable – cutbacks in support.
121. Given that wide-ranging cuts to additional benefits and support are likely to result in a significant – and geographically variable - reduction in the provision of services, it is important that these too are reflected in the assessment process.
122. The provision and quality of housing is extremely important for disabled people, and changes to housing benefit and their impact on people's
123. housing needs should also be considered.

Question 9 – How could we improve the process of applying for the benefit for individuals and make it a more positive experience, for example:

- **How could we make the claim form easier to fill in?**
- **How can we improve information about the new benefit so that people are clear about what it is for and who is likely to qualify?**

The government argues that the current assessment for DLA – which consists of a claim form considered by decision-maker alongside additional evidence - means awards are 'subjective, inconsistent and do not always focus support on those who need it most.'

124. The stigmatisation of claimants has a profoundly negative impact on claimants and service-providers alike – including those administering the

system. Challenging discriminatory language and attitudes is vital to make applying for the benefit a more positive experience.

125. Research highlights a number of problems with the current form. These include difficulties getting hold of the forms in the first place (some families report that when they phoned the DWP to ask for a form to be sent to them, staff 'can seem difficult and obstructive and proffer incorrect advice.'
126. Although improvements to on-line applications can help, this presupposes people have access to the internet, and/or can visit organisations that do.
127. As the consultation suggests, the forms are lengthy, complicated and often upsetting to fill in. It is frustrating to be compelled to provide information that has been endlessly provided many times to many different departments and service providers over and over again.
128. However, although we agree that reducing the length of the form would be welcome, the current requirement for a plethora of information on the current form still generates disagreements and anomalies in the decision-making process, with many families missing out on their entitlement or receiving the wrong award.
129. Streamlining and simplifying the form requires adequately funded advice services with trained staff to ensure that relevant information is not missed out by claimants.
130. A system of extending automatic entitlement based on condition would reduce processing times in these cases and allow relevant information to be gathered quickly and efficiently from medical professionals if necessary.
131. DLA recognises that environmental factors that generate barriers drive up disability costs – not just an individual's impairment or condition. It will be a challenge to establish an assessment which looks at both the functional impact of a person's disability, as well as one that takes into account the social and environmental factors impacting on an individual's day-to-day costs.⁶⁴

Making the claim form easier to fill in

132. It is important that the form helps claimants understand the sort of 'key activities' that will be of interest to decision-makers to keep take-up high and appeals low.
133. Although it is certainly the case that current form is extremely negative, and often depressing, it is important that attempts to make applications more positive are not then used as an excuse to deny people additional support.

Improving information about the new benefit so that people are clear about what it is for and who is likely to qualify

134. Although the Government may well be reluctant to flag up the availability of support which is likely to be restricted, the production of clear information will help inform the development of the application form. Clear and accessible advice and information about personal independence payment must be made widely available.

135. Informing current and prospective claimants about the proposed changes and purpose of personal independence payment is vital. For example, the provision of on-line information and a public television campaign might be helpful.
136. The provision of printed information and leaflets is also vital, not just in Jobcentre Plus and advice centres (if there are any left) but in ordinary places that people are likely to visit – such as hospitals, health centres, nurseries and schools, and the workplace.
137. Targeting information in different languages in cultural and religious centres will also help maximise take-up in some black and minority communities who are currently less likely to apply for DLA.
138. Our research strongly suggests that families are heavily reliant upon and value the support of *independent* welfare rights workers, who provide continuity of support throughout the application process, re-applications and appeals.
139. Research indicates that the provision of welfare benefits advice in primary care settings increases take up and improves health.⁶⁵
140. Given high rates of unemployment, providing information, advice and support in contracted out services within the Work Programme also provides an important opportunity to flag up entitlement – and ensure people have the additional support they need to cover the costs of engaging in work-related activities and/or access employment. Maximising income is a vital way of improving health and enhancing an individual's capacity to access employment.
141. Access to additional support provides a valuable way of enabling people who might otherwise be forced to leave their job to retain employment. Employers should be encouraged to ensure that employees are aware of and have access to the support and advice needed to enable them to access their full entitlement.

Question 10 – What supporting evidence will help provide a clear assessment of ability and who is best placed to provide this?

The assessment will vary depending on the individual's needs, likelihood of their health condition or impairment changing, and potentially, the successful use of aids and adaptations, and will use self-report forms, medical evidence.

Once the benefit is introduced in 2013/14, new claimants will submit a claim for PIP and will be assessed under the new system – which may include face-to-face discussion with an approved healthcare professional and gathering additional evidence from one or more sources, such as:

From the individual

From the individual's General Practitioner

From other supporting healthcare professionals

-
142. For families – who may not view themselves or their children as ‘disabled’, or think they are entitled to carer’s allowance – access to practitioners who encourage them to apply for additional support makes all the difference. Conversely, medical practitioners who do not understand the purpose of DLA may actively discourage families from applying. Training and understanding is essential.
 143. The collection of evidence for DLA is notoriously difficult. Applicants – those providing evidence - are often unclear about the need for supporting evidence, and what this should involve.
 144. The quality of the evidence provided is also extremely variable, depending on the time, expertise and commitment of the person providing the evidence. It is therefore important that people should trust the person they ask for additional evidence, and feel that the person understands their particular needs. This would suggest that evidence should be sought from a wide-range of service-providers with whom they have an ongoing relationship (such as health visitors, GPs, teachers, paediatricians, mental health practitioners)
 145. Given the clear medical and social benefits that accessing DLA can make, it is important to ensure that the new benefits is on doctors’ radars so that they encourage people who may be entitled to apply to the new benefit as well.
 146. Given the vital role that the provision of additional evidence plays, it is extremely important that service-providers and individuals who are most likely to be prevailed upon to provide the evidence are well informed about entitlement and purpose, and are given the time and resources necessary to provide the right kind of supporting evidence. This would reduce the high level of successful appeals.
 147. Given that providing the sort of high-quality, detailed evidence is time-consuming, it is perhaps not surprising that some service providers (for example, medical practitioners and teachers) are may be reluctant to spend much time providing it. Some may expect payment for doing so.
 148. Given that the personal independence payment is also intended to reflect individual need rather than medical conditions, it is important to ensure that personal evidence (by claimants, and those they know and/or are involved in caring for them) is given sufficient weight and credibility, and is drawn upon when gathering further evidence.
 149. Difficulties with the assessment process have been well documented in the review of the Work Capability Assessment for Employment and Support Allowance ESA. Unless these are resolved, the quality of assessments may erode the recent improvements in the standard of DLA decision making. Particular issues relate to the difficulty of getting an appointment for a home visit.
 150. A recent article in the British Medical Journal ⁶⁶ explores significant shortcomings in an assessment process being administered by Atos which may well be replicated in PIP.

Question 11 – An important part of the new process is likely to be a face-to-face discussion with a healthcare professional.

- **What benefits or difficulties might this bring?**
- **Are there any circumstances in which it may be inappropriate to require a face-to-face meeting with a healthcare professional – either in an individual's own home or another location?**

151. Given the desire to focus on the social rather than the medical model of disability, it is important to ensure that healthcare professionals include practitioners who deal with the full range of social rather than medical problems. While health visitors span both camps, it is important that the right practitioners be used, many of whom will not be in the medical profession.
152. Disability organisations are rightly concerned that the involvement of a “face-to-face meeting with an independent healthcare professional” appears to be very similar to the Work Capability Assessment (WCA). Given the current problems with the assessment and surrounding processes, this is causing increased anxiety to many disabled people.
153. Meetings with healthcare professionals are obviously inappropriate where there is a diagnosis of terminal illness. They are also particularly difficult for claimants with mental health problems. All claimants should be encouraged to have someone with them to help them explain their difficulties.

Question 12 – how should the review be carried out? For example

- **What evidence and/or criteria should be used to set the frequency of the reviews?**
- **Should there be different types of review depending on the needs of the individual and their impairment/condition?**

Reviewing awards and reporting

The new benefit will be simpler – so people should know when they need to report a change in their needs. However, when needs change gradually they may not notice.

Most over and under-payments of DLA are due to unreported changes in people's circumstances (see Fraud and error and other incorrectness in DLA: the results of the Benefit Review of DLA, 2005) so support not always targeted on those who need it most – and some may receive incorrect amounts for a significant period of time.

The Government want the personal Independence Payment to ‘recognise people's changing needs over time’, will ensure that ‘everyone continues to receive the correct level of award and that it is ‘better equipped to reflect further changes to our society’ (what does that mean?).

They will therefore, periodically, review all personal independence payments.

Assessment will vary depending on the individual's needs, likelihood of their health condition or impairment changing, and potentially, the successful use of aids and adaptations – and will use self-report forms, medical evidence etc.

The benefit will reflect ‘changes in society’, such as legislation – and ‘contribute to the extra costs of living independently, in a way that is right for each individual.’

What evidence and/or criteria should be used to set the frequency of the reviews?

154. For people with fluctuating conditions, there are real challenges for the review process and, in particular, the increased obligations on the individual to report changes in circumstance.
155. Asking people with unpredictable and fluctuating conditions such as MS to report every change in their condition would be extremely onerous and stressful. Rather than introducing penalties, the Government should be encouraging people to report any changes by making it as easy as possible to do so, and offering clear information about what reporting a change in circumstance could mean for people.
156. Our research also shows that frequent assessments and reviews are stressful and take a considerable toll on the health and wellbeing of both parents – and their children – and we are reluctant to see these increased.
157. Frequency should continue to be set by decision makers, and be appropriate for the individual. There is a strong case for indefinite awards where needs are long term and conditions are not controllable/going to vary, or medical evidence indicates that everything possible has been tried to control conditions and there is no expectation of improvement. It causes confusion and upset currently when awards are reassessed for severely disabled people whose condition is not going to improve.
158. Regular reassessments – which are likely to be conducted by different decision-makers with different (subjective) criteria, also generate mistakes, which lead to fluctuating awards and incomes. Families who lose DLA may be plunged into debt. Even those awaiting the outcome of an appeal may find it very difficult to make ends meet, and this means that even when DLA is reinstated at the previous level, much of it is used paying of existing debts.
159. This means that a benefit designed to meet the extra costs of disability actually contributes to individual as well as administrative costs.
160. Regular reviews may generate confusion about the need to report ‘changes in circumstances’, and this is particularly worrisome given the introduction of greater conditionality and sanctions into the system.
161. If they are to be conducted regularly and well, periodic reviews will be costly – for claimants, those providing additional evidence, and decision-makers. It is by no means clear that these resources will be provided at a time of significant cuts across all sectors involved in the process.
162. Increasing the number of assessment is also likely to increase the number of administrative and customer errors – and this too is extremely costly, and may result in significant problems for claimants in an increasingly punitive system.

Should there be different types of review depending on the needs of the individual and their impairment/condition?

163. Given the above problems and provisos, it is clear that just as the initial assessment needs to be sensitive to and reflect the differing needs and of individuals and their impairment/condition, as will periodic reviews.

Question 13 – The system for PIP will be easier for the individual to understand, so we expect people to be able to identify and report changes to their needs. However, we know that some people do not currently keep the Department informed. How can we encourage people to report changes in circumstances?

Penalties for not reporting changes in circumstances

In line with the Government's new strategy on fraud and error, there will be penalties for failing to report changes in circumstances. If an individual is found to have knowingly withheld information about a change in circumstance which would have resulted in a reduction in benefit, they will have to repay the amount claimed. In addition, a penalty or a prosecution may result.

164. CPAG is particularly concerned about the assumption that because the personal independence payment will be 'easier to understand' this justifies the introduction of penalties for those who fail to report changes in circumstance.
165. Apart from the fact that this is a big assumption, we are extremely concerned that some of the most vulnerable claimants deemed to have 'withheld information about a change in circumstances which would have resulted in a reduction in benefit' may face a penalty or even a prosecution.
166. Using a supposedly 'easier to understand' system (and there nothing in the proposals to suggest this will be the case) in order to increase conditionality, at a time when many claimants will be struggling to make sense of a raft of other changes in and around universal credit, at a time when access to advice and support – and legal aid - is being cut back seems very unfair.
167. Confusion about the need to identify and report changes in needs are generated by a necessarily burdensome and complex bureaucratic system. People with mental health problems and learning difficulties are likely to find it particularly difficult to keep track of this requirement.
168. There is considerable misunderstanding about the difference between fraud and error, and a failure to differentiate between the two has inflamed stigmatising language about claimants, and is a constant source of dispute. Introducing additional penalties may well result in genuine claimants losing entitlement.
169. Extensive research on sanctions both internationally and in the UK suggests that they are likely to be ineffective and have a disproportionate impact on the most vulnerable claimants.⁶⁷ Research suggests that the imposition of sanctions on families with children can have a profoundly negative impact on the health and wellbeing of children.⁶⁸

Question 14 – What types of advice and information are people applying for PIP likely to need and would it be helpful to provide this as part of the benefit claiming process?

170. As discussed above, there is a distinct lack of information about DLA in places families are likely to see it (such as schools and GPs surgeries, Children's Centres etc). Many families are heavily reliant on the information provided by other families who receive DLA, and on the support and advice provided by independent welfare rights workers.
171. Our research suggests that families are heavily reliant on the advice and support of independent welfare rights workers.
172. It is important to ensure that access to accurate information and advice is an integral part of the benefit claiming process and reduces the need for costly appeals. However, in a context of significant cutbacks to local authority and voluntary welfare rights provision and to legal aid, it is hard to see who will provide this. There is evidence that even in the current situation, the information provided by the DWP is not always available or indeed accurate.
173. An increased reliance on the provision of information on-line poses problems for people who may not have access to a computer, and/or face additional barriers to accessing such information.
174. Successful take-up campaigns – such as distributing leaflets in schools and health centres – need to be supported by access to advice and support.⁶⁹
175. Ensuring that other service providers who work closely with families (for example health visitors, teachers and those working in early year settings are an effective way of disseminating information and support. For example, CPAG has joined with Together for Children to pilot welfare benefits training for staff in Sure Start children's centres.⁷⁰

Question 15 – Could some form of requirement to access advice and support, where appropriate, help encourage the minority of claimants who might otherwise not take action? If so what would be the key features of such a system and what would need to be avoided?

176. It is not entirely clear what the underlying purpose of this suggestion might be, but we are concerned that it opens the way to compel claimants – for example drug addicts – to access services and support or lose their entitlement to benefit. This is an unacceptable infringement of people's rights, and risks preventing some of the most vulnerable and hard-to-reach claimants from accessing vital financial support which has the potential to significantly improve quality of life.

Question 16 – How do disabled people currently fund their aids and adaptations? Should there be an option to use PIP to meet a one-off cost?

177. Financing aids and adaptations on inadequate incomes is a struggle, with families struggling to negotiate complex rules, borrowing money or accessing the Social Fund. Although many families use DLA to finance aids and adaptations, constant changes in award sometimes render this an erratic source of funding.
178. Although research on the Social Fund suggests that one-off payments provide valuable *additional* support to purchase aids and adaptations that are essential to enable people to access educational, social and employment opportunities, this does not obviate for additional income to cover many other additional costs.

179. The constant need to finance the constant need to maintain, replace or update the equipment provided is also an issue, and it is important to ensure that disabled people are not constantly having to re-apply for support to cover such costs.

Question 17 – What are the key differences that we should take into account when assessing children?

180. DLA is a vital component of Government support to enable families of disabled children live ordinary lives. It is likely to play a greater role as cuts in services and support to families with children – many of which will have a disproportionate impact on children with disabilities – begin to bite.
181. Access to DLA provides a vital way to target support on families during the early years (for some families, from birth) and supports the government's focus on early interventions.
182. As discussed above, poverty drives significant health inequalities from birth. Children whose parents are poor are ten times as likely to die suddenly in infancy, 2 ½ times as likely to suffer chronic illness as toddlers, twice as likely to have cerebral palsy and over three times as likely to suffer mental health disorders.⁷¹
183. Children born in 2000 who are being tracked by the Millennium Cohort Study show stark differences in health by the age of three. Many illnesses associated with poverty – such as a significantly increased risk of developing 'limiting chronic illnesses' are associated with aspects of children's living conditions. Research from Shelter shows that children in bad housing are twice as likely to suffer from bad health as other children.⁷²
184. Research also shows that increasing income – for example via DLA – has a positive impact on the health and wellbeing of both parent and children.
185. Children are still developing, and there is evidence of how development can be improved by increased household income. There is also evidence that increased income is spent on the children.⁷³ As discussed above, maximising family income via disability benefits is an effective way to support the government's desire to implement a preventative strategy by focusing support during the early years.
186. We outline below some of the other differences that should be into account when assessing children.

Assessing adequacy

187. Problems in the administration of DLA – particularly frequent reassessments of entitlement as children grow older – generate significant stress and costs for families. The process must reflect the realities of families' day-to-day lives, at a time when many parents will also be required to engage in onerous work-related activities.
188. There is ample evidence that parents with disabled children experience significant, and very particular costs. Research also suggests that although DLA provides vital additional financial support, and triggers awareness of and entitlement to a range of services, that it does not address families' financial needs.

Extra costs

189. Families with disabled children, additional costs include the following⁷⁴

- **Wastage** (children with behavioural problems can be destructive and wasteful)
- **Food** (children with autistic spectrum disorders are susceptible to advertising for particular – and often expensive – foods advertised on television)
- **Clothing** (replacing clothing that is lost and damaged is very expensive)
- **Heating and laundry** (it is a constant struggle to keep clothes and bedding clean, and houses warm)
- **Toys and equipment** (entertaining children who spend a lot of time indoors is very expensive)
- **Costs for families with two or more disabled children** are considerably higher – particularly when the children have different needs and preferences.
- **Transport** (this is one of the biggest sources of additional expenditure).
- **Hospital visits and medical appointments** (are extremely costly, and include public transport and/or driving, parking costs, providing additional food and bedding for children – and having to be available to visit and care for child during long hospital admissions, which makes working extremely difficult)
- **Childcare** (specialist childcare is extremely expensive – and rare)
- **Leisure pursuits** (a parent with two disabled children may have to pay somebody to take one of the children out, while caring for the other child at home)
- **The costs of ill-health** (when the stress of caring takes its toll on parent's health, they have to pay somebody to help care for their children and/or sick relatives)
- **Medical and therapeutic support** (many parents have to finance additional services and therapies to support their children's needs.
- **Collecting evidence for application** (because of the poor quality of medical evidence, some families end up paying for medical assessments)
- **Social costs** (financial costs exclude families from participating in society, and this takes its toll on parents and children, and leads to:
 - Family breakdown
 - Ill-health and disability among parent-carers)
 - Additional caring responsibilities

190. More recently, Contact a Family has updated research on additional costs.⁷⁵ Their research suggests that;

- Almost a quarter are going without heating (23%). Up from 16% in 2008.

- One in seven (14%) are going without food. Down from 16% in 2008.
- More than half have borrowed money from family or friends (51%) to keep financially afloat or pay for essentials, such as food and heating. Up from 42% in 2008.
- More than 40% have applied for a charity grant. Up from 25% in 2008.
- Almost three quarters (73%) are going without days out and leisure time with the family. Up from 55% in 2008.⁷⁶

Increase to qualifying period

191. We share Every Disabled Child Matters' concerns that while the Government is committed to retaining special rules for people who are terminally ill, increasing the qualifying period from three months to six months before entitlement to DLA will mean that that children born with a disability will have to wait until they are six months old before being entitled to DLA. This could have a detrimental effect on families with disabled children at a crucial early stage in their child's life and is at odds with the Government's focus on early intervention and support.
192. Children should receive DLA from the moment that the assessment process begins and entitlement seems likely.

Assessment and Reassessment

193. Disabled children already have their DLA eligibility reassessed at regular intervals – aged 2, 5, 11, 14, 16 and 18 and we do not believe that children should be reassessed any more regularly than they currently are. The government could review the current frequency of assessments which – as discussed above – results in the frequent downgrading and removal of DLA, which is often reinstated at appeal. This generates hard-to-manage fluctuations in income which damage the health and wellbeing of parent/carers and children, and may plunge families into debt.
194. Although families find the constant focus on what their child cannot do distressing and dispiriting we hope that a change in focus will not render it significantly more difficult to establish entitlement and result in families losing support – particularly when going through periodic reviews which may be administrated by people with little understanding or knowledge of the impact that a range of disabilities (including more 'invisible' conditions, such as autistic spectrum disorder and ADHD) have on children as they grow older.
195. Research shows that the constant requirement to provide the same information to a range of service-providers involved in the care of disabled children is time-consuming and generates considerable stress for families. We therefore condone the Government's desire to ensure that information is shared between assessments. However, constant assessments within education, health and social services are both costly to the state, and a source of stress and anxiety, and these too should be reviewed. It is also important to ensure that mistakes made in assessments elsewhere do not have a negative impact on access to PIP.

196. While we welcome information sharing between assessments, Sharing information between assessments could help, but it is important that an incorrect assessment does not deny a child support throughout the system.
197. We are extremely concerned by the consultation's suggestion that assessments for DLA may take into account whether 'a child's support needs are being met from public funds by another institution, such as school.' Entitlement to PIP should be used to trigger access to the support to which children are entitled, not be used an excuse to reduce financial support intended to meet some of the extra costs incurred by families.
198. It is perverse and unjust to impose a financial penalty on parents whose child is receiving support from public funds. This is roughly the equivalent of imposing greater taxation on families who utilise the NHS or access state education.
199. Similarly we share concerns about the Government's proposals to penalise families for having the adaptations and aids their child needs to overcome some (not all) of the barriers they face.

Mobility Component of DLA

DLA – the mobility component

'Care homes are required, where practicable, to promote the independence, participation and community involvement of their residents. Local authority contracts with care homes will cover services to meet a resident's assessed needs. This will cover activities of daily living which may include providing access to doctors, dentists and local services such as libraries and banks. Consideration was given to the equality impacts of the measure when the proposal was being developed. The Equality Impact Assessment for removing the mobility component of disability living allowance from state funded care home residents after 28 days will be published with the proposed legislation.' Maria Miller MP, written answers and statements in the House of Commons, 10 January 2011 ⁷⁷

200. CPAG is concerned that the removal of the mobility component from children and adults in residential care homes is unfair, and will have a significant impact on the ability of claimants and their relatives to access the sort of social activities the Minister describes (which are themselves under threat).
201. We are particularly concerned by the Governments proposals to remove the mobility component of DLA from disabled children in residential schools or care for more than 84 days a year. Although the government cites 'double funding' to justify this mean-spirited reduction in support, financially pressed residential special schools and colleges are often unable to provide the transport needed to ensure that children regularly visit families – and vice versa. Some use DLA to finance outings and excursions that might otherwise not take place.
202. Removing the mobility component of DLA from these children severely restricts their ability to live independent lives. We also believe that it is in contravention of Article 31 of the UN Convention on the Rights of the Child

Changing the rates of DLA

203. Families often misunderstand the purpose of DLA (they may not view their child as disabled) and many are confused about the 'care component'. (Many assume that as parents they are not entitled, or that this is covered by carer's allowance).
204. However, while we therefore welcome the idea of a 'daily living' component to replace the existing care component of DLA, we are concerned that the reduction from three to just two components will be used to restrict entitlement and generate savings.

3 - Delivering the new benefit

Question 18 - How important or useful has DLA been at getting people to access other services or entitlements? Are these things we can do to improve these passporting arrangements?

205. Families report that access to DLA is an extremely effective way of flagging up the availability and entitlement to other services. However, if access to those services reduces entitlement to the benefit, this is likely to become a double-edged sword.
206. DLA is a vital passport to many other services, although the Government must ensure that it is not the only route to access services such as in the Blue Badge scheme – or the Independent Living Fund.
207. DLA also enables disabled workers to access Working Tax Credit while working a reduced number of hours. It remains to be seen whether this additional support will be reflected in the new universal credit.
208. DLA also passports claimants to higher level of both means-tested benefits and tax credits (for both children and adults) – and to carer's allowance.
209. DLA increases the potential level of housing benefit (HB) thus increasing the amount payable towards rent (although recent reform of HB may nullify this.)
210. It triggers vital support which enables lone parents to continue caring for their disabled children over the age of five, because they will count as carers (if their child is receipt of highest or middle rate care).
211. DLA can trigger access to community care grants for people moving out of residential care into the community. However, as the government proposes to abolish the centrally administered Social Fund and hand it over to cash strapped local authorities this potential benefit may disappear or be retained only in local governments with a more generous settlement under the latest cuts to local government funds.
212. DLA also plays an important role in generating additional support in tax credits and this needs to be safeguarded and built-upon in the new system in a way that interacts effectively with the universal credit (UC). For the moment however, we are concerned that that unless the new system firewalls the different elements of UC, when doubt about the adult's entitlement arises (for example, because of issues around conditionality or income) the whole of UC could be suspended, thereby threatening a child's benefit element and the disability element of benefit. (At the moment, while for adults this will be the

component of ESA but for children the additional element will depend on DLA.) The system of premiums is confusing due to their names, and this is not a reason to take away the vital extra support provided.

213. The suggestion of a move towards the habitual residence test is worrying. There is an existing, simple presence test, so this seems likely to mean a right to reside test being applied. This will make the PIP more similar to the UK's means-tested benefits, undermining the stated commitment to an extra costs benefit in the consultation. It will complicate the benefit and exclude some of the most vulnerable claimants.

Question 19 – What would be the implications for disabled people and service providers if it was not possible for PIP to be used as a passport to other benefits and services?

214. Although – as discussed entitlement to PIP should not be the only trigger for additional services and support (particularly if entitlement is reduced), the main reason that DLA constitutes protection from poverty is precisely because it triggers additional support elsewhere in the system – in particular disability premiums and carer's allowance. The failure to use PIP as a passport to the benefits and services would therefore have a significant impact on disabled people and their families.
215. Disabled people would find it more difficult to know what is available and what they might be entitled to, and service providers would face extra costs in assessments, reducing funds available for services.
216. It would introduce the need for additional assessments to trigger entitlement, elsewhere in the system, and this would generate additional costs for both individuals and administrators.

Question 20 – What different assessments for disability benefits or services could be combined and what information about the disabled person could be shared to minimise bureaucracy and duplication?

217. As discussed above, while it clearly makes sense to share the information provided in different assessments, it is important to ensure that this does not result in incorrect information becoming entrenched in system and denying people support across the board. The failure to appeal an incorrect assessment in one area should not have an impact on access to support elsewhere in the system.
218. The sharing of outdated ESA85 reports already accounts for significant numbers of negative DLA decisions which are frequently overturned. If a decision refusing benefit based on a report is appealed, then the report should not be shared until the appeal has been determined, and then only if the decision is upheld. Before sharing reports that have not been appealed or are over 6 months old, they should be given to claimants for comment about what has changed since they were produced.
219. The information required and provided may differ according to the demands of the assessment, and it is important to ensure that criteria are streamlined and coherent.
220. The availability and quality of assessments may well fall prey to wide-ranging cuts, and it is important that this does not undermine a fair and swift assessment process.

4 - Impact Assessment and Equality Impact Assessment

Question 21 – What Impact could our proposals have on the different equality groups and what else should be considered in developing the policy?

221. The imposition of stringent restrictions to financial support alongside to reductions in the additional support needed to maximise social inclusion for disabled people constitutes a significant erosion of rights and entitlements and therefore undermine the Government's commitment to 'maximise the dignity of disabled people' and arguably be at odds with Equality legislation.
222. The Spending Review (SR) introduced a raft of additional cuts. The Treasury's own modelling shows 'will hit those in the bottom half of the income distribution more as a share of their income than those in the top half.'⁷⁸
223. Measures announced in the SR will hit women twice as hard as men. It suggests that 'of the £8.5 bn being raised by cutting direct contributions to individuals, £5.7 bn – two thirds – is coming from women, while £2.7bn is being raised from men.'⁷⁹ The Women's Budget Group calculate that women (particularly lone parents) will be disproportionately affected by the cuts outlined in the Spending Review.⁸⁰
224. Like many other groups, CPAG is concerned that the cuts being imposed are likely to have a disproportionate impact on some of the most vulnerable groups, including women, those affected by disability, and some BME groups.⁸¹
225. It is important that the introduction of PIP ameliorates and does not compound this worrying development. The situation needs to be closely monitored.
226. It is clear that the intention of this – and reform elsewhere in the system - is to restrict the support available to many who face the greatest barriers to work.
227. The proposal will leave more disabled people in poverty unless the means-tested support system is amended to reflect that extra costs faced by disabled people. By removing support it risks increasing inter-generational poverty and will harm the chances of the children of disabled people to achieve their potential.
228. The UN Convention on the rights of the child states that: '*State parties shall recognise for every child the right to benefit from social security, including social insurance, and shall the necessary measures to achieve the full realization of this right in accordance with their national law.*' (Article 26) and that '*States Parties recognise the right of every child to a standard of living adequate for the child's physical, mental, spiritual and social development*' (Article 27). We are concerned that – when placed in the context of wider cuts to social security - the proposals are at odds with this requirement.

22. Is there anything else you would like to tell us about the proposals in this public consultation?

229. Although some elements of the consultation constitute a genuine attempt to resolve some of the difficulties in the design and delivery of DLA, the overall proposals read as a disingenuous attempt to discredit the existing support in order to justify reducing – rather than improving - it.
230. We are also concerned that the proposals undermine the government's wider desire to tackle poverty, focus on the early years, and improve life chances. Research clearly shows that income poverty drives the sort of educational and health inequalities the government is keen to redress.

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- 1 Disability Alliance calculates that these cuts will result in expenditure on DLA being reduced by 20% (over £1 billion) which they calculate will result in one in three recipients losing their entitlement.
- 2 See, Randeep Ramesh, 'Disability grant cut: a life and death issue' in *The Guardian* 14 February, 2011.
- 3 See *British Medical Journal* 2010; 340:c3311
- 4 James Browne, Peter Levell, 'The distributional effect of tax and benefit reforms to be introduced between June 2010 and April 2014: a revised assessment', IFS Briefing Note BN108, August 2010
- 5 Households Below Average Income (HBAI) shows that over a third of all children in poverty come from a larger family (both before and after housing costs). The risk of children in larger families being in poverty is 40 per cent, contrast to a 27 per cent risk for only children (after housing costs). The risk of children in larger families being in poverty is 31 per cent, contrast to a 19 per cent risk for only children (before housing costs). HBAI also shows that nearly one million children in poverty live in a household affected by disability (adult or child) and this represents a third of all children living in poverty (both before and after housing costs).
- 6 Tania Burchardt and Asghar Zaidi calculate that 'The fully adjusted figures indicate that the 'true' poverty rate among disabled people (based on 1996/7 data) is 61% or three in every five people.' See 'Poverty and disability' in *Disability Rights Bulletin*, summer 2003 in which they discuss Comparing incomes when needs differ: equivalisation for the extra costs of disability (CASEpaper 64, 2003)
- 7 DWP, *Opportunity for all: fifth annual report* (DWP, 2003) p.24
- 8 G Palmer, J Carr and P Kenway, *Monitoring Poverty and Social exclusion 2005*, (Joseph Rowntree Foundation and New Policy Institute, 2005), p 9
- 9 HBAI 2008-2009
- 10 See G Preston, *Helter Skelter: Families, disabled children and the benefit system* (CASEpaper92, Centre for Analysis of Social Exclusion, February 2005) and G Preston with M Robinson, *Out of Reach: benefits for disabled children* (CPAG, 2006)
- 11 See G Preston (ed), *A route out of poverty? Disabled people, work and welfare reform* (CPAG, 2006)
- 12 See T Burchardt, *Being and becoming: social exclusion and the onset of disability*, (CASE report 21, 2003) p. 42
- 13 T Burchardt, *Being and becoming: social exclusion and the onset of disability*, (CASE report 21, 2003, p 24.
- 14 Department of Health, *Choosing Health White Paper* (2004)
- 15 C Mackay et al, 'Management Standards' and Work Related Stress in the UK: policy background and science' in *Work and Stress*, vol 18, no.2 pp 91 – 112, 2004
- 16 Department of Health, *Choosing Health White Paper* (2004)
- 17 T Burchardt, *Being and becoming: social exclusion and the onset of disability*, (CASE report 21, 2003), p.64
- 18 H Stickland and R Olsen, 'Children with disabled parents' in G Preston (ed) *At Greatest Risk: the children most likely to be poor*, (CPAG 2005), p. 145
- 19 Cabinet Officer, Prime Minister's Strategy Unit, *Improving the Life Chances of Disabled People* (a joint report with DWP, Department of Health, Department for Education and Skills, Office of the Deputy Prime Minister, January 2005)
- 20 See, for example, H Barnes and S Baldwin 'Social security, poverty and disability' in John Ditch ed. *Introduction to Social Security*, Routledge, London, 1999, pp. 156-176
- 21 See T Burchardt, *The Evolution of Disability Benefits in the UK: Re-weighting the basket*, (CASEpaper 26, 1999) p. 8
- 22 *Opportunity for all*, p. 106
- 23 See K Roberts, D Lawton. *Reaching its target? Disability living allowance for children* (Social Policy Report No. 9, Social Policy Research Unit, University of York, 1999) and R Chamba, W Adham, M Hirst, Michael, Dawton, Dot, B Beresford. *On the edge: Minority ethnic families caring for a severely disabled child* (Policy Press, May 1999)
- 24 Citizens Advice calculates that around £17.5 billion of benefits and tax credits remain unclaimed, and this contributes to high levels of poverty in the UK.

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- 25 See S Royson, Benefit Simplification and the Customer, (DWP, 2007) - <http://www.dwp.gov.uk/docs/simplification-and-the-customer.pdf>
- 26 See S Royson, Benefit Simplification and the Customer, (DWP, 2007) - <http://www.dwp.gov.uk/docs/simplification-and-the-customer.pdf>
- 27 J Stelitz and Ruth Lister (eds) *Why Money Matters: Family income, poverty and children's lives* (Save the Children, 2008)
- 28 H Glennerster, Jonathan Bradshaw, Ruth Lister, Olle Lundenberg (with assistance from Katy Withers and Jan Flaherty), *Reducing the Risks to Health: The role of social protection: Report of the Social Protection Task Group for the Strategic Review of Health Inequalities in 'England, post 2010* (CASE report 139, June 2009)
- 29 Bradshaw and Mayhew, 2005 – quoted in H Glennerster, Jonathan Bradshaw, Ruth Lister, Olle Lundenberg (with assistance from Katy Withers and Jan Flaherty), *Reducing the Risks to Health: The role of social protection: Report of the Social Protection Task Group for the Strategic Review of Health Inequalities in 'England, post 2010* (CASE report 139, June 2009), p.3
- 30 See *Unhealthy lives: intergeneration links between child poverty and poor health in the UK*, briefing by Donald Hirsch and Professor Nick Spencer, published by End Child Poverty with support from GMB.
- 31 *Unhealthy lives: intergeneration links between child poverty and poor health in the UK*, briefing by Donald Hirsch and Professor Nick Spencer, published by End Child Poverty with support from GMB.
- 32 Bradshaw and Mayhew, 2005 – quoted in H Glennerster, Jonathan Bradshaw, Ruth Lister, Olle Lundenberg (with assistance from Katy Withers and Jan Flaherty), *Reducing the Risks to Health: The role of social protection: Report of the Social Protection Task Group for the Strategic Review of Health Inequalities in 'England, post 2010* (CASE report 139, June 2009), p.3
- 33 Kirstine Hansen, Heather Joshi, Shirley Dex, *Children of the 21st century (Volume 2): The first five years*, Policy Press February 2010) - [http://www.policypress.co.uk/series_results.asp?ds=The UK Millennium Cohort Study series&sf1=series_exact&st1=THEUKMILLENNIUMCOHORTSTUDYSERIES](http://www.policypress.co.uk/series_results.asp?ds=The+UK+Millennium+Cohort+Study+series&sf1=series_exact&st1=THEUKMILLENNIUMCOHORTSTUDYSERIES)
- 34 *Low income and early cognitive development in the U.K A Report for the Sutton Trust*, by Jane Waldfogel and Elizabeth Washbrook (1 February 2010). This report can be downloaded from: <http://www.suttontrust.com/research/low-income-and-early-cognitive-development-in-the-uk/>
- 35 *Against the Odds* (Shelter, 2006) quoted in *Unhealthy Lives*.
- 36 N Parry-Langdon (ed), *Three Years On: survey of the development and emotional well-being of children and young people*, Office for National Statistics, 2008
- 37 The Marmot Review appears to support Kendall and others' ideas that both a 'latency' and a 'pathway' model may be in play. GE Kendall, AM van Eekelen, J Li and E Mattes, *Children in Harm's Way: a global issue as important as climate change*, The Forum on Public Policy, 2009, available from <http://forumonpublicpolicy.com/spring09papers/archivespr09/kendall.pdf>
- 38 Bradshaw and Mayhew, 2005 – quoted in H Glennerster, Jonathan Bradshaw, Ruth Lister, Olle Lundenberg (with assistance from Katy Withers and Jan Flaherty), *Reducing the Risks to Health: The role of social protection: Report of the Social Protection Task Group for the Strategic Review of Health Inequalities in 'England, post 2010* (CASE report 139, June 2009), p.3
- 39 Bradshaw and Mayhew, 2005 – quoted in H Glennerster, Jonathan Bradshaw, Ruth Lister, Olle Lundenberg (with assistance from Katy Withers and Jan Flaherty), *Reducing the Risks to Health: The role of social protection: Report of the Social Protection Task Group for the Strategic Review of Health Inequalities in 'England, post 2010* (CASE report 139, June 2009), p.3
- 40 See <http://www.poverty.org.uk/summary/disability.htm>
- 41 See G Preston, *Helter Skelter: Families, disabled children and the benefit system*, (CASEpaper 92, 2005)
- 42 See G Preston (ed) *A route out of poverty: Disabled people, work and welfare reform* (CPAG, 2006), p.77
- 43 H Glennerster, Jonathan Bradshaw, Ruth Lister, Olle Lundenberg (with assistance from Katy Withers and Jan Flaherty), *Reducing the Risks to Health: The role of social protection: Report of the Social Protection Task Group for the Strategic Review of Health Inequalities in 'England, post 2010* (CASE report 139, June 2009)
- 44 Cabinet Office, Prime Minister's Strategy Unit, *Improving the Life Chances of Disabled People* (a joint report with DWP, Department of Health, Department for Education and Skills, Office of the Deputy Prime Minister, January 2005), p. 43
- 45 G Palmer, J Carr and P Kenway, *Monitoring Poverty and Social exclusion 2005*, (Joseph Rowntree Foundation and New Policy Institute, 2005), p 9
- 46 G Palmer, J Carr and P Kenway, *Monitoring Poverty and Social exclusion 2005*, (Joseph Rowntree Foundation and New Policy Institute, 2005), p. 13
- 47 G Palmer, J Carr and P Kenway, *Monitoring Poverty and Social exclusion 2005*, (Joseph Rowntree Foundation and New Policy Institute, 2005), p 14

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

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50 See G Preston, 'Disabled parents: living with disability' in G Preston (ed) *A route out of poverty: Disabled people, work and welfare reform* (CPAG, 2006).

51 D Stapleton, ~A Protik and Christal Stone, *Review of international evidence on the cost of disability*, (DWP, Research Report No 542, 2008), p.32

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