



Redbridge Concern For Mental Health and Run-Up

Response to Disability Living Allowance Reform
Public Consultation

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About Redbridge Concern for Mental Health

Redbridge Concern for Mental Health - established over 15 years ago – is a service user led organisation based in the London Borough of Redbridge dedicated to promoting, improving and protecting the mental health and emotional well being of the wider community.

We offer high quality services to local residents seeking mental health support. We also provide information and signposting as well as challenging the stigma and discrimination that people experience in their everyday lives.

Our Aims

- To develop high quality, culturally appropriate, accessible services for people recovering from and experiencing mental health problems.
- Work in partnership to influence mental health policy and to promote best practice in all aspects of service planning and delivery.
- Develop new ways of promoting service user involvement and helping service users to improve their lives.
- To improve people's health, care and well-being by promoting positive mental health.
- To challenge the stigma and discrimination that people experiencing and recovering from mental health problems encounter in their everyday life.

What does Run-Up Do?

Voice – Nothing about us without us

A key role of RUN-UP is to influence the design, delivery and management of local mental health services. In particular: to contribute experience and expertise to policy development as a 'critical friend' as well as to promote and monitor the effectiveness of user involvement in the planning, commissioning, managing and monitoring of services to ensure service users have a full say in policies and practices which affect their lives. Articulating views and experiences of our members by attending meetings, seminars, workshops and debating issues

Campaigning for full inclusion in society

We all want to live in communities where we can participate fully and equally. Many indicators show us that for people with mental health conditions this hasn't yet happened and there remains considerable work to be done to get to this point. People with mental illness commonly describe the stigma and discrimination they face as being worse than their main condition. Discrimination, stigma and prejudice can pervade every part of their daily life - their personal life, working life, sense of citizenship, their ability to maintain even a basic standard of living

Background to our Consultation Response

We have used a number of different mechanisms to capture the responses of the local community including:

- A public meeting on 3rd February 2011 held in partnership with the Redbridge LINk and the Redbridge User Led Organisation. Over 70 people turned up to the event as did another 20 or so at a subsequent event on 4th February¹
- The views, voice and experience of local mental health service users garnered over the years through a range of focus groups, network meetings and peer to peer support.
- Desktop research
- Advocacy and Representation

It is unfortunate that disabled people have to deal with a range of systems and processes so complex, elaborate and unresponsive to their needs that advocacy remains an important vehicle for advancing the interests of disabled people. This is particularly relevant for the proposed DLA reforms. It is a detailed document asking a lot of complex questions in a short time frame.

Please Note: As a result of the short time frames, the complexity and detail required to answer the questions coupled with the fact we have not been afforded the time, resources and capacity to debate, discuss and explore and respond to the many important issues in a meaningful way we have been unable to answer all the questions.

¹ A full and comprehensive list of responses can be obtained from Redbridge LINk, <http://www.redbridgelink.net/>

Executive Summary

Redbridge Concern for Mental Health and RUN-UP welcome the opportunity to participate in the debate about the future of Disability Living Allowance (DLA). We embrace the government's commitment to promoting social justice for disabled people and the promise to increase independence, participation and employment opportunities and we regard DLA as an essential component in this process. The Government's better understanding of the extra costs faced by disabled people and their families as well as the proposals to simplify the benefit and reduce bureaucracy and unnecessary administration also encourages us.

However, there are a number of issues in the proposals that we are deeply concerned and worried about.

Summary of key points and recommendations

1. We recommend the Government reverse the decision to cut DLA by 20%.
2. We believe the decision to cut DLA could be in breach of the Human Rights Act, 1998.
3. To ensure that all processes, systems, assessment, reviews and so on are set up with full regard to ***The UN Convention on The Rights of Persons with Disabilities***.
4. The Proposals do not give adequate voice to the experiences and insights of people with mental health conditions.
5. We recommend the Government rescind the decision to the remove DLA mobility component.
6. We are deeply concerned that the consultation process is out of kilter with Government good practice and undermines the Government's commitment to *Big Society; localism and the principle: **nothing about me without me***.
7. The proposed reforms contain tensions in the proposals between, on the one hand, the Social Model of Disability and, on the other hand, the Medical Model.
8. We recommend **careful setting up** of the assessment and review proposals and other process.
9. We strongly recommend **trailing of assessments, reviews and other systems and processes**.
10. We recommend independent, open and transparent academic research into disability costs. The DWP must be mindful of the fact that **assessment of fluctuating conditions at one point in a day can be**

extremely misleading: For instance, such an assessment may take no account of daily symptom fluctuations (stiffness in theumatoid arthritis, fatigue and weakness in MS), no account of fatigueability, and may contains no proper psychology/psychiatric assessment.

- Co produced, person centred and **multi-agency face –to face assessments**
- Specialist experts in mental health conditions
- Assessments must be needs-led
- The assessment process must identify the barriers that inhibit the disabled person and family life from living and ordinary life
- To ensure that there are **specialist experts in communication** where required
- To ensure that there are specialist experts in mental health conditions

11. Redbridge Concern for Mental Health recommends that Government adopts a Capabilities Approach - originally developed by Nobel Prize winner Amartya Sen and Martha Nussbaum and further refined by Professor Jonathan Wolff ² - as a methodology for understanding the activities essential for leading a flourishing, meaningful and purposeful life.
12. The Government to conduct national campaign to dispel myths and negative perceptions surrounding welfare benefit claimants, the poor, disabled and vulnerable.
13. We do not see adequate analysis, exploration and evidence of potential unintended consequences and perverse outcomes in the proposed reforms. For example, the impact on employment.

² Disadvantage, Jonathan Wolff and Avner De-Shalit, OUP 2007

Redbridge Concern opposes the Government's commitment to cut DLA component by 20%

There are certain groups in society that are particularly vulnerable and disadvantaged including those who are very young, very old or disabled or have complex mental health conditions and their interests need to be protected in a time of smaller budgets.

We are deeply concerned about the proposed cuts in the context of the wider reforms to the benefit system. It has been estimated that disabled benefit claimants will lose £9 billion in support over the course of this parliament. What is more, Maria Miller, Minister for Disabled People recently confirmed that the government is "looking at saving 20% of the Disability Living Allowance in line with the Chancellor's commitment in the Emergency Budget"³.

Claire Downey from Interface - a Redbridge based group for parents of disabled children said:

"We are also very concerned about the cumulative effect of local and national changes – we have local cuts and national cuts proposed (e.g. DLA, child benefit, and health services).

Put together all these cuts could chip away at all the support mechanisms and services our families rely on and cause even costlier family breakdown and deeper inequalities."

Study after study demonstrates the link between disability and poverty and that the disabled community is one of society's most disadvantaged groups. Reductions to and the withdrawal of benefits will – in our view - undermine the Government's aspiration to support disabled people to lead independent and active lives. Redbridge Concern for Mental Health, therefore, strongly **opposes the Government's stated commitment to cutting DLA by 20%.**

Human Rights Act, 1988

The decision to make cuts of 20% could be unlawful in light of Article 8 of the European Convention on Human Rights:

Everyone has the right to respect for his private and family life, his home and his correspondence.⁴

³ <http://ablemagazine.co.uk/exclusive-interview-maria-miller-mp-on-the-dla-consultation/>

⁴ <http://www.legislation.gov.uk/ukpga/1998/42/schedule/1>

We would also ask the Government to reconsider the 20% cuts in light of Part II, The First Protocol, Article 1, of the Human Rights Act 1988, Protection of property:

Every natural or legal person is entitled to the peaceful enjoyment of his possessions. No one shall be deprived of his possessions except in the public interest and subject to the conditions provided for by law and by the general principles of international law.⁵

Tension between the medical model and social disability model

The proposed reforms alternate between emphasising the social model of disability, in some parts and the medical model in other parts. For example targeting the benefit at those with the greatest health and care needs, rather than with most prohibitive disability costs. The two are not necessarily the same.

For instance, the recently published Demos research paper, Counting the Costs⁶, points out: “a test measuring the functional impact of a person’s disability may not be able to take into account the disabling social and environmental factors which the DLA and its successor seeks to compensate for.”

Someone who is unemployed, for example, reliant on public transport and with no social network will have very different disability costs to someone with a similar functional impairment who is working, has a suitably adapted car and home and a comprehensive network of family and friends.⁷

We object to decision to focus on ‘those with greatest need’

Following on from above, the decision to focus on ‘those with the greatest need’ risks leaving a large number of people with no help at all and also undermines the Government’s commitment in the proposals to the Social Model of Disability.

This approach neglects the fact that the additional costs of living with a disability do not necessarily correlate with the functional impact of someone’s disability. DLA is a vital source of support for those whose needs which do not qualify for social care, but nevertheless face significant additional costs and barriers to participation as a result of their functional impairment.

Lack of voice and details about the experience and insights of people with mental health conditions in the proposals

Study after study demonstrates that society continues to perpetrate injustice against people with mental health conditions in many fundamental ways, touching on some of the most central elements of a human being’s quality of life – health, education, and political participation, and travel, equality before

⁵ <http://www.legislation.gov.uk/ukpga/1998/42/schedule/1>

⁶ Counting the Cost, C Wood and E Grant, DEMOS (2010)

⁷ Ibid

the law, employment, autonomy, self respect and life itself.

It is our view that the proposals fail to recognise and acknowledge the depth, breadth and diversity of disabled people. In particular there is little narrative about the experiences and insights of people with mental health conditions. For sure, attitudes to disability have changed and have helped some disabled people lead more independent lives but for many others this has not been the case.

A very good illustration can be found in a Department for Work and Pensions commissioned report, *Realising Ambitions* (2009):

- While **62 per cent of employers** said they would consider recruiting people with physical impairments, fewer than **4 in 10 employers** said that they would recruit someone with a mental health problem.⁸

Furthermore, Andrew Lansley eloquently stated in the Department of Health's recently published paper (Feb 2011): *Delivering better mental health outcomes for people of all ages*⁹:

*"Stigma and the experiences of discrimination continue to affect significant numbers of people with mental health problems. This discrimination is damaging, unlawful and costly – for individuals, their families and carers, organisations, communities and society as a whole."*¹⁰

The Department of Health Paper continues to state:

*"People with mental health problems have worse life chances than other people. Part of this is the direct effect of the condition, but a very large part is due to the stigma, ignorance, prejudice and fear surrounding mental health. Which can stop people from seeking help; keep people isolated and therefore unable to engage in ordinary life, including activities that would improve their wellbeing; and stop people working, being educated, realising their potential and taking part in civil society."*¹¹

Peter Beresford, chair of national service user network Shaping Our Lives and professor of social policy at Brunel University:¹²

"Mental health service users/survivors have long had inferior access to disability benefits because of the failure of authorities to understand or

⁸ *Realising Ambitions: Better Employment support for people with a mental health condition*, December 2009, Department for Works and Pension

⁹ www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_12373

⁷ *Realising Ambitions: Better Employment support for people with a mental health condition*, December 2009, Department for Works and Pension

¹⁰ *Ibid*

¹¹ *Ibid*

¹² Peter Beresford, *Disability benefit helped me, it can help others. Stop punitive reform*, <http://www.communitycare.co.uk/blogs/adult-care-blog/2010/12/disability-benefits-helped-me-it-can-help-others-stop-punitive-reforms.html>

respect their difficulties. Yet the difference that the DLA can make to people's quality of life cannot be overstated. Disability benefits, health and social care services and support have to be seen as part of a whole - a whole which can make the difference for some service users between life and death; between having a life or contemplating extinction. I know the feeling, as do many mental health service users."

Removal of mobility component of DLA

Redbridge Concern for Mental Health is deeply concerned at the government's refusal to accept that the removal of the mobility component of Disability Living Allowance (DLA) for people in residential care which has been based on a false premise of 'double funding'. The proposed reform undermines the Government's commitment to protect the independence of disabled people.

The 'Don't limit mobility' report¹³, produced by 27 charities and organisations, shows that the plans will have a huge impact on people who currently rely on this benefit to be able to access their local communities. Removing the mobility component of DLA will reduce equal opportunities and restrict participation in family, social and cultural life for almost 80,000 disabled people living in residential care.

"The quality of life for residents will go way down and they will become imprisoned in their home. It will affect people socially and make it extremely difficult for care homes to take people to church, social visits, hospital appointments and day trips."

"People in residential care have been excluded"

Frank Spring, who runs the Friends of Dunelm – a fundraising group for a local Redbridge nursing home

"My sister will never lead an independent, full or active life due to her severe disability. An essential quality of her life is mobility allowance which gives her the opportunity to take trips away from the nursing home to attend church services, hospital and doctor appointments, disability clubs, social events and short holidays away. "

"Without the mobility allowance she would have no quality of life"

Attendee at the DLA Consultation Meeting Feb 2011

¹³ Don't Limit Mobility, The impact of the removal of the mobility component of Disability Living Allowance from adults and children living in state-funded residential care

DLA Consultation timeframe undermines commitment to ‘*Nothing About Me Without Me*’.

We have already expressed our concerns about the DLA Consultation being out of kilter with the Government’s Code of Practice on Consultations¹⁴. The short timeframe coupled with the Christmas and New Year holidays and the complexity of the questions in effect silences many of our local service users.

For example, some sections of the disabled community have communication needs and levels of cognitive functioning that require extensive time and support. Fairness requires that the reforms are suitable and address the needs of these hidden voice groups. The failure to adequately address the complex needs of this particular group seriously undermines the Government’s positive commitment to the principle: ***Nothing About Me Without Me***.

Furthermore, the speed at which the decisions are being made is counter to the Government’s commitment to *Big Society* and *localism*. The DWP has explained it has been engaging with large national disability organisations. But surely this runs counter to the commitment to engage with local communities, explore and learn from local knowledge and cultivate local voice.

Unintended consequences of cutting DLA benefit

- **Impact on employment:** Half of working disability living allowance (DLA) claimants will have to stop working if they are deemed ineligible for the benefit as a result of proposed government cuts, a survey by Disability Alliance has found.¹⁵
- **Impact on health and social care economy:** Neil Coyle, director of policy at Disability Alliance, said: “The full range of cuts will considerably impact upon disabled people but the DLA reform is particularly dangerous as it could lead to considerably higher state costs – to the NHS, councils and in lost tax contributions.”
- A possible unintended consequence is that the proposal could incentivise individuals not to take up aids and adaptations for fear this could jeopardise their entitlement to DLA.

Framing of proposals and questions

It is well documented by Nobel Prize Winner Daniel Kahneman and Amos Tversky¹⁶ the way questions and proposals are “framed” often has an influence on how people answer that question. We are particularly concerned

¹⁴ Code of Practice on Consultation, BERR (2008)

¹⁵ <http://www.communitycare.co.uk/Articles/2011/01/14/116108/disability-benefit-cuts-will-force-people-out-of-work.htm>

¹⁶ Kahneman & Tversky, 1973; Kahneman, Slovic & Tversky, 1982; Tversky & Kahneman, 1974

about a number of the statements in the proposals that are contentious and open to debate as well as the way in which information has been “framed” prior to the questions.

Firstly, the Consultation is being carried out against a background of negative stories surrounding welfare benefit claimants.

“I didn’t chose to be blind.....It really annoys and angers me that people think I’m a scrounger.”

Local Redbridge Service User

Secondly, we are disappointed and saddened that the Government has largely failed to counter this negative discourse despite the following facts:

- Public social spending is smaller in relation to national income in the UK than in all other European Union countries, apart from Iceland¹⁷
- Fraud is smaller than unclaimed entitlements¹⁸
- Taking all six income-related benefits together, there was between £6,930 million and £12,700 million left unclaimed in 2008-09; this compared to £38,110 million that was claimed and represents take-up by expenditure of between about 75 per cent and 85 per cent.¹⁹
- There is no analysis of the demographic patters and household structures in the proposals that undoubtedly have an influence on social security benefit expenditure.
- The DWP claim to have overseen a reduction in the level of fraud and overpayment in the benefits system in recent years and have always claimed that fraud in relation to DLA was very low. The DWP Information Directorate report on ‘Fraud and error in the benefits system’ for 2008-2009 estimated the level of fraud in relation to DLA at just 0.6%, a total of £60 million pound
- Despite government estimates that fraud is small by comparison with total social security spending public concerns about fraud in the social security system are high and have been rising.²⁰
- To inform the public of the fact that social security spending is dominated by pensions

¹⁷ John Hills, *Inequality and the State*, Oxford University Press (2004)

¹⁸ Ibid

¹⁹ http://statistics.dwp.gov.uk/asd/income_analysis/jun_2010/0809_Summary.pdf

²⁰ Ibid

- **Most benefits overpayment is not caused by fraud.** Ministers have recently claimed that £5.2 billion is lost each year in benefit fraud. According to the Institute for Public Policy Research, however, this is the figure for total benefit overpayments, more than 70% of which is down to mistakes and under a third to fraud. This means that around £3.8 billion was lost in 2009-10 through errors, compared with roughly £1.5 billion through fraud. And while both these figures may sound large, total overpayments account for less than 3% of benefit expenditure, and losses through fraud alone make up less than 1% of the benefits bill.²¹

²¹ *Most Benefits Overpayment is not caused by fraud*, <http://www.ippr.org/articles/?id=4353>

Question 1 – Problems that prevent disabled people participating in society and leading independent, full and active lives?

Society continues to perpetrate injustice against disabled people and particular on people with complex mental health conditions in many fundamental ways, touching on some of the most central elements of a human being's quality of life – health, education, political participation, travel, autonomy, equality before the law, employment, self respect and life itself.

Life Itself - people with all types of mental disorder have an increased risk of premature death

There is strong evidence that people with a diagnosis of a mental illness have less access to primary healthcare and receive inferior care for diabetes and heart attacks. This is despite the fact that rates of physical illness and poor dental health among people with severe mental illness are much higher than in the general population (Phelan 2001), with especially high levels of cardiovascular disease, obesity, diabetes and HIV/AIDS (Rethink 2005). This combination of high rates of physical illness and low rates of receiving effective treatment leads to the fatal consequences of discrimination and neglect: people with all types of mental disorder have an increased risk of premature death.²²

Poverty

The link between disability and poverty is well established. The Marmot Review, for example, states that people on low incomes lose 17 years of disability free life because they live in worse conditions than people on high incomes.²³

High levels of unemployment and unstable and low paid employment means disabled people are more likely to live below the poverty threshold and be dependent on benefits as a proportion of their income. Increased unemployment and a range of welfare and public service cuts following the economic downturn has only exacerbated the situation.

The Nobel prize-winning economist Amartya Sen described this as an 'earnings disadvantage' (the effect of disability on an individual's ability to earn an income) and a 'conversion disadvantage' (the effect of disability on an individual's ability to convert this income into a good standard of living). Disability-related costs are a fundamental feature of this second (conversion) disadvantage.

²² *Discrimination against people with mental illness: what can psychiatrists do?*, Graham Thornicroft, Diana Rose & Nisha Mehta, *Advances in psychiatric treatment* (2010), vol. 16, 53–59

²³ <http://www.marmotreview.org/>

Unequal access to employment

The right to work is enshrined in Article 23 of the Universal Declaration of Human Rights, which states:

“everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.”

Yet this remains a right that is too often denied to people with a mental health condition.

The employment rates for people with a mental health condition are low: with an overall rate of around 21 per cent, compared to around 74 per cent for the overall working age population and in the region of 47 per cent for all people declaring a disability as defined by the Disability Discrimination Act. Research shows that employment rates for those with a more serious mental health condition are considerably lower and have fallen steadily over four decades.²⁴

Surveys show that employers are reluctant to recruit people with a mental health condition. While 62 per cent of employers said they would consider recruiting people with physical impairments, fewer than 4 in 10 employers said that they would recruit someone with a mental health problem.²⁵

Discrimination and exclusion within the Workplace²⁶

- Ninety-two per cent of the British public believes admitting to having a mental illness would damage someone’s career.
- People whose mental health condition developed early in life may never have worked; others may not have worked since their condition developed.
- People with a mental health condition are twice as likely to lose their jobs as those who develop other health conditions.²⁷
- Despite increased awareness 72% of workplaces still have no formal mental health policy.²⁸
- And in the same research, nearly a quarter of respondents suggested that people with mental health conditions are ‘less likely’ to be reliable than other workers.²⁹

Travel

In many ways it can be more difficult for people with mental illness to

²⁴ *Realising Ambitions: Better Employment support for people with a mental health condition*, December 2009, Department for Works and Pension

²⁵ *Ibid*

²⁶ *Mental Health: Still The Last Workplace Taboo?*, Shaw Trust (December 2010)

²⁷ *Realising Ambitions*

²⁸ *Mental Health: Still The Last Workplace Taboo?*, Shaw Trust (December 2010)

²⁹ *Ibid*

travel than for others. As rates of unemployment among people with some type of mental illness are extraordinarily high and so many with more severe forms of illness depend on their family or upon welfare benefits for basic needs and to meet everyday costs. Discretionary travel, for example, to take a holiday is simply not affordable for most people with a psychotic disorder.³⁰

There can also be restrictions on driving³¹ which in turn can infringe upon a person's ability to travel, obtain insurance or earn a livelihood. Another barrier to travel is the need to declare a mental illness to obtain a visa (e.g. USA)

Insurance is also another hurdle:

- One survey in Britain found that a quarter of people with mental illness said they had been refused insurance or other financial services.³²

Discrimination and Stigma

People with mental illness commonly describe the stigma and discrimination they face as worse than their main condition. Discrimination can pervade every part of everyday life: personal, home and family life, work, aspects of citizenship, even people's ability to maintain a basic standard of living.³³

The Government has recognised the wide ranging and often devastating impact of discrimination and stigma, in the recently published paper (February 2011): Delivering better mental health outcomes for people of all ages³⁴:

Personal Safety

There can be no more important human right than to live life in safety and with security. Its absence prevents us from living our lives to the full. And, for some, its absence has led to the loss of life itself. Recent research from the Equality and Human Rights Commission finds that for many disabled people in Britain, safety and security is a right frequently denied. Violence and hostility can be a daily experience – in the street, on public transport, at work, at home, on the web – so much so that many disabled people begin to accept it as a part of everyday

³⁰ Graham Thornicroft *Shunned, Discrimination against people with mental illness*, OUP 2006

³¹ DVLA website,

www.direct.gov.uk/en/Motoring/DriverLicensing/MedicalRulesForDrivers/index.htm

³² Graham Thornicroft *Shunned, Discrimination against people with mental illness*, OUP 2006

³³ Graham Thornicroft *Shunned, Discrimination against people with mental illness*, OUP 2006

³⁴ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_12373,

life.³⁵

Within the disabled population, the evidence suggests that those with learning disabilities and/or mental health conditions are particularly at risk and suffer higher levels of actual victimization.³⁶ What is more, a number of studies clearly demonstrate that people with a diagnosis of mental illness are more likely to be the victims of violence than the general population.

The rights of citizenship and civil and political participation

Important political and personal rights available to citizens may be withdrawn from people with a mental illness or with a history of psychiatric treatment:

- The 1974 Juries Act excludes people who are taking treatment for a mental illness from jury service
- Complex regulations allow inpatients to vote as long as they have non-hospital addresses and they have the 'capacity to vote'. In practice many compulsory detained patients are disenfranchised.³⁷
- There has been a reluctance of the judiciary to accept as probative, the evidence of many victims of crime with a learning disability³⁸.

Housing

Studies have revealed the following issues:³⁹

- People with mental health problems are under-represented in owner-occupied accommodation, which is generally seen as the most socially valued and secure housing in the UK today.
- Compared with the general population, people with mental health problems are twice as likely to be unhappy with their housing and four times as likely to say that it makes their health worse.
- Mental ill health is frequently cited as a reason for tenancy breakdown.

³⁵ *Promoting the safety and security of disabled people*,
http://www.equalityhumanrights.com/uploaded_files/research/promoting_safety_and_security_of_disabled_people.pdf

³⁶ *Promoting the safety and security of disabled people*,
http://www.equalityhumanrights.com/uploaded_files/research/promoting_safety_and_security_of_disabled_people.pdf

³⁷ Ibid

³⁸ *Disabled People and European Human Rights*, L Clements and J Read, The Policy Press (2003)

³⁹ Johnson, R. et al, 2006, *Housing and community care*. Mental Health Today, November, pp. 25-28

- Housing problems are frequently cited as a reason for a person being admitted or re-admitted to inpatient mental health care.

Autonomy

Mental health legislation in England and Wales discriminates against people with a mental illness. When it comes to involuntary treatment, it fails to respect - without adequate justification - the 'autonomy' of people with a mental illness, in stark contrast to the treatment of people with a physical illness. It further discriminates against persons with a mental disorder by allowing a form of preventive detention on the basis of 'risk', without any offence having been committed. Mental health legislation thus carries underlying assumptions that people with mental disorders are not fully self-determining and that they are inherently dangerous.⁴⁰

Question 2 – Is there anything about DLA that should stay the same

There are a number that spring to mind. However, it is a difficult question to answer as one has to take into account unintended consequences and perverse outcomes that may occur as a result of the proposed reforms.

- To refrain from the 20% cut
- To retain the DLA residential mobility component

Question 3 – Extra costs faced by disabled people

It is abundantly clear that day to day expenditure on disability-related costs are real and often significant and that these extra costs can have a catastrophic effect on disabled people's disposable income, leaving them at much higher risk of poverty and financial exclusion. This is exacerbated by the fact that the disabled community experience higher levels of unemployment as well as unstable and low paid employment. In fact, researchers have estimated that once disability-related costs are taken into account the numbers of households with a disabled occupant assessed as living in poverty jumps from 23 per cent to between 40 per cent and 60 per cent.⁴¹

We recommend that the Government adhere to the following underlying principles:

*United Nations Resolution 48/96, annex, of 20 December 1993, Standard Rules on the Equalization of Opportunities for Persons with Disabilities:*⁴²

“States should ensure that the provision of support takes into account the costs frequently incurred by persons with disabilities and their families as a result of the disability.”

⁴⁰ G Szmukler, Institute of Psychiatry, *How mental health legislation discriminates unfairly against people with mental illness*, November 2010

⁴¹ Demos, *Counting the Cost*: <http://www.demos.co.uk/publications/countingthecost>

⁴² <http://www.un.org/esa/socdev/enable/dissre04.htm>

The UN Convention on the Rights of Persons with Disabilities

“to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”.

1. To take into account the higher levels of unemployment and entrenched disadvantage
2. To take into account the widespread stigma and discrimination people with mental health conditions face in the workplace and employment market.
3. To fully take into account the wider social, physical and economic disabilities

The DWP must also take into account the following facts:⁴³

- The high costs of living with a disability stem from a wide range of cost drivers
- No one proxy such as the functional impact of a condition or impairment, could adequately factor in this wide range of costs
- A test relying on functional impact may generate inaccurate estimations of disability costs.

Question 4 – Two rates for each component

Due to the time constraints on the consultation proposals and the complexity of the question we have not had time to debate, discuss and explore this issue in a meaningful way.

Question 5

We believe there has to be a two-pronged approach. Some conditions should be automatic (to avoid needless testing and bureaucracy) whilst the remainder need proper assessment. The assessment should be tailored to the disability being assessed. For example, partial blindness, a profound learning disability, arthritis, a mental health condition and muscular dystrophy all need different assessments.

Moreover, no one likes having to answer irrelevant questions or perform irrelevant actions. Moreover, for people with sudden onset conditions, their needs and the debilitating effects of treatment are immediate as are the additional costs.

⁴³ Demos, Counting the Cost: <http://www.demos.co.uk/publications/countingthecost>

"I am so tired and worn out from all the assessments. My daughter has a serious condition and she is never going to grow out of down syndrome. The last assessment I was asked how is the down syndrome going. I'm really worn out. This is unfair."

Local Redbridge Carer

We strongly recommend the following:

1. The DWP recognise the fact that the way of assessment needs careful setting up
2. **Pilot trials** to see how it is received and problems encountered

"Going through a diagnosis process is very intrusive and distressing. Most of the children in our group have profound, life long disabilities requiring substantial and critical amounts of care. We think these categories should automatically get the benefit."

Local Redbridge Carer

Question 6 – Activities essential for everyday life

Redbridge Concern for Mental Health recommends that Government should adopt a Capabilities Approach - originally developed by Nobel Prize winner Amartya Sen and Martha Nussbaum and further refined by Professor Jonathan Wolff ⁴⁴ - as a methodology for understanding the activities essential for leading a flourishing, meaningful and purposeful life.

As Nussbaum writes:

*"We ask not only about the person's satisfaction with what she does, but about what she does, and what she is in a position to do (what her opportunities and liberties are). And we ask not just about the resources that are sitting around, but about how those do or do not go to work, enabling the person to function fully in a human way."*⁴⁵

We do not believe the list below is exhaustive and unchanging but it forms the fundamental basis for allowing genuine flourishing for all citizens.

⁴⁴ Disadvantage, Jonathan Wolff and Avner De-Shalit, OUP 2007

⁴⁵ Nussbaum, *Women and Human Development*

1. **Life.** Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living.
2. **Bodily Health.** Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.
3. **Bodily Integrity.** Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction. (**Please note:** good health and bodily integrity do not require bodily perfection)
4. **Senses, Imagination, and Thought.** Being able to use the senses, to imagine, think, and reason—and to do these things in a "truly human" way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with experiencing and producing works and events of one's own choice, religious, literary, musical, and so forth. Being able to use one's mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to have pleasurable experiences and to avoid non-beneficial pain.
5. **Emotions.** Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one's emotional development blighted by fear and anxiety. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development.)
6. **Practical Reason.** Being able to form a conception of the good and to engage in critical reflection about the planning of one's life. (This entails protection for the liberty of conscience and religious observance.)
7. **Affiliation.**
 - I. Being able to live with and toward others, to recognize and show concern for other humans, to engage in various forms of social interaction; to be able to imagine the situation of another. (Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech.)
 - II. Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin and species.

8. **Other Species.** Being able to live with concern for and in relation to animals, plants, and the world of nature.
9. **Play.** Being able to laugh, to play, to enjoy recreational activities.
10. **Control over one's Environment.**
 - I. Political. Being able to participate effectively in political choices that govern one's life; having the right of political participation, protections of free speech and association.
 - II. Material. Being able to hold property (both land and movable goods), and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure. In work, being able to work as a human, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers.
11. **Doing good to others**

Being able to care for others as part of expressing your humanity.
Being able to show gratitude.
12. **Living in a law-abiding fashion**

The possibility of being able to live within the law; not being forced to break the law, cheat or to deceive other people or institutions
13. **Understanding the law**

Having a general comprehension of the law, its demands, and the opportunities it offers to individuals. Not standing perplexed facing the legal system

Question 7 – Assessment and Fluctuating Conditions

Lessons must be learned from the Work Capability Assessment. Professor Harrington in his Independent Review of the Work Capability Assessment states: “There is strong evidence that the systems can be impersonal and mechanistic, that the process lacks transparency and that a lack of communication between the various parties involved contributes to poor decision making and high rates of appeal.”⁴⁶

In addition the Review makes clear that “some of the descriptors may not adequately reflect the full impact of such conditions on the individual’s capability for work.”⁴⁷ This appears to be the case with more subjective conditions such as mental health or other fluctuating conditions.

There is also good evidence that the Work Capability Assessment has not been a fair or effective tool to determine whether or not someone with mental health problems is capable of working and early indicators are that many people found fit for work under the assessment later appeal and win.

⁴⁶ An Independent Review of the Work Capability Assessment, Malcolm Harrington, 2010

⁴⁷ *ibid*

The assessment process for fluctuating conditions must also take account of the fact that **assessment of fluctuating conditions at one point in a day can be extremely misleading**:

In other words, an assessment must take into account a range of factors such as:

- Daily symptom fluctuations (for example, stiffness in theumatoid arthritis, fatigue and weakness in MS)
- Fatigueability
- Psychological and psychiatric factors

Redbridge Concern recommends the following:

- The Assessment process set up, managed and delivered with full regard to the **UN Convention on the Rights of Persons with Disabilities**⁴⁸
- Co produced, person centred and **multi-agency face-to face assessments**
- Specialist experts in mental health conditions
- Assessments must be needs-led
- The assessment process must identify the barriers that inhibit the disabled person and family life from living and ordinary life.
- The assessment should take account of the needs of the whole family and individuals within it
- Healthcare professionals, in particular Doctors carrying out assessments adhere to *The Faculty of Occupational Medicine publication Good Occupational Medical Practice*.⁴⁹
- To ensure that there are **specialist experts in communication** where required
- Once a model has been established we **strongly recommend a pilot trial** to explore the advantages and disadvantages and the unintended consequences of the new assessment process.

⁴⁸ <http://www.un.org/disabilities/convention/conventionfull.shtml>

⁴⁹ Faculty of Occupational Medicine. Good occupational medical practice. 2010. www.facocmed.ac.uk/library/docs/p_gomp2010.pdf.

Question 8 – Aids and Adaptations

We find it difficult to understand this question, since aids and adaptations do not remove the fundamental underlying disability.

“There is a need to be clearer about how aids and adaptations will be taken into account”

Service User at DWP Consultation Event, February 2011

Nonetheless, we are very concerned by the proposed reforms that the new assessment will take into account more aids and adaptations. For example, the individual’s ability to get about in a wheelchair will be considered rather than ignoring it as under the current system. This could affect their eligibility for DLA as it is based on the incorrect assumption that using a wheelchair will mean all barriers and additional expenses are overcome.

A possible unintended consequence is that the proposal could incentivise individuals not to take up aids and adaptations for fear this could jeopardise their entitlement to DLA.

Question 9 – Improving the application process

Due to the time constraints on the consultation proposals we have not had time to debate, discuss and explore this issue in a meaningful way.

However, a very important point that needs making is the fact that over the last two decades there has been increasing ‘tough talk’ surrounding benefit claimants as well as heavily publicised clampdowns on ‘benefit cheats’.

This in our view has contributed to the impression that benefit abuse is widespread. **We strongly recommend, therefore,** that the Government do more to challenge the negative perceptions about the poor, disabled and vulnerable as the structural causes are now so evident.

Question 10 – Supporting evidence

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

Due to the time constraints on the consultation proposals we have not had time to debate, discuss and explore this issue in a meaningful way

Question 11 – Face-to-Face assessments

The Assessment process should be set up, managed and delivered with full regard to the UN Convention on the Rights of Persons with Disabilities.⁵⁰

⁵⁰ <http://www.un.org/disabilities/convention/conventionfull.shtml>

- The assessment process for fluctuating conditions must also take account of the fact that **assessment of fluctuating conditions at one point in a day can be extremely misleading**:
- In other words, an assessment must take into account a range of factors such as:
 - Daily symptom fluctuations (for example, stiffness in rheumatoid arthritis, fatigue and weakness in MS)
 - Fatigueability
 - Psychological and psychiatric factors
- Co produced, person centred and **multi-agency face –to face assessments**
- Specialist experts in mental health conditions
- Assessments must be needs-led
- The assessment process must identify the barriers that inhibit the disabled person and family life from living and ordinary life.
- The assessment should take account of the needs of the whole family and individuals within it
- Healthcare professionals, in particular Doctors carrying out assessments adhere to *The Faculty of Occupational Medicine publication Good Occupational Medical Practice*.⁵¹
- To ensure that there are **specialist experts in communication** where required
- Once a model has been established we **strongly recommend a pilot trial** to explore the advantages and disadvantages and the unintended consequences of the new assessment process.
- An 'objective face to face assessment' carried out by a generalist medical professional itself cannot properly assess the full spectrum of how a complex and fluctuating condition impacts on a person's independence.
- If face-to-face assessments are to be brought in for DLA, this must be treated as just one piece of evidence in the assessment process, and not as a definitive decision.
- A face-to-face assessment should be merely an additional piece of evidence, and other information, such as the application form and reports from specialist healthcare professionals must be given appropriate weight and not ignored in favour of a contrasting 'objective assessment'.

⁵¹ Faculty of Occupational Medicine. Good occupational medical practice. 2010. www.facocmed.ac.uk/library/docs/p_gomp2010.pdf.

- For employed disabled people, DLA can be vital to helping them stay in work as it can help fund additional support at home or with childcare that makes working feasible.⁵²
- To ensure that there are **specialist experts in communication** where required

Question 12 – How should reviews be carried out?

Due to the time constraints on the consultation proposals we have not had time to debate, discuss and explore this issue in a meaningful way.

We will, however, make following two points:

- **The review process should be set up, managed and delivered with full regard to the UN Convention on the Rights of Persons with Disabilities**
- It is worth stressing is that periodically reviewing all awards, especially for those diagnosed with long-term degenerative conditions and would be an unnecessary use of government resources, as well as causing undue stress for individuals.

Question 13 – Reporting changes in circumstances

- For people with fluctuating conditions and in particular certain mental health conditions, such as someone experiencing a psychotic episode this will be very challenging.
- It is onerous and stressful to continually have to report fluctuating conditions especially if there is a threat of penalties.
- We believe that periodically reviewing all awards, especially for those diagnosed with long-term degenerative conditions would be an unnecessary use of government resources, as well as causing undue stress for individuals.

“I’m so tired and worn out from all the assessments. My daughter has a serious condition and she is never going to grow out of down syndrome. The last assessment I was asked how is the down syndrome going. I’m really worn out. This is unfair.”

Question 14 – Advice and Information

Due to the time constraints on the consultation proposals we have not had time to debate, discuss and explore this issue in a meaningful way

⁵² Demos, Counting the Cost

Question 15 – Access advice and support

Due to the time constraints on the consultation proposals we have not had time to debate, discuss and explore this issue in a meaningful way,

Question 16 – Current funding of aids and adaptations

Due to the time constraints on the consultation proposals we have not had time to debate, discuss and explore this issue in a meaningful way.

Question 17 – Key Difference when assessing children

We fully endorse the statement in Every Disabled Child Matters:

‘EDCM thinks disabled children have a right to access the same services that all other children access, such as education, health and social care. These services should be tailored to meet each child’s individual needs. However, services such as schools have a limited remit as appropriate to their purpose – i.e. education – and should not replace financial support that is provided to promote independence and reflect the additional costs incurred by families who are attempting to lead ordinary lives as active citizens’

Questions 18 and 19- Regarding using DLA as a passport to other services

We believe it is essential that the passport links to other services are protected and extended.

However, due to the time constraints on the consultation proposals we have not had time to debate, discuss and explore this issue in a meaningful way.

Q 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?

Due to the time constraints on the consultation proposals we have not had time to debate, discuss and explore this issue in a meaningful way,

Question 21 – Impact on equality groups

Due to the time constraints on the consultation proposals we have not had time to debate, discuss and explore this issue in a meaningful way