



**Disability
alliance**

Joint Committee on Human Rights - Inquiry into the implementation of the right to independent living for disabled people Call for Evidence

Joint submission by the Disability Rights Partnership

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About us:

The National Centre for Independent Living produced this response for the 'Disability Rights Partnership'. This is the working title for the unification of Disability Alliance, the National Centre for Independent Living and Radar.

This response draws on the contributions from a wide range of our individual members and organisations, including several focus groups carried out on the UNCRPD. Due to the constraints of space we refer throughout to documents published previously rather than quoting from them in full.

Summary of key points

The Disability Rights Partnership welcomes the opportunity to respond to the Joint Committee on Human Rights' Call for Evidence. We believe that the inquiry into the implementation of the right to independent living for disabled people is very timely as the Government is taking us through significant reforms of welfare, health and social care.

Whilst we welcome some elements of these reforms, for example the shift of the focus from supply-led to demand-driven support and the commitment to simplify the system, we are concerned that some measures, including the changes to the Disability Living Allowance (DLA) and the Independent Living Fund (ILF), will impede progress towards full life chances of disabled people. Cuts to programmes that support independent living, both at a local and national level, for instance to Supporting People and Valuing People programmes, also put at risk the infrastructure that enables disabled people to genuinely choose and control how they participate in, and contribute to society.

The Right to Independent Living in Article 19 of the UN Convention on the Rights of People with Disabilities (UNCRPD) gives us a focus as well as a context in which to measure the Government's delivery of the right to independent living.

We strongly believe that the Government should, as a first step, confirm its commitment to the existing, or put in place an updated, Independent Living Strategy. This should be done working with disabled people and building on what we already have - accompanied with an action plan and milestones.

The Government should assess the impact of their current and proposed measures, on not only disability equality, but also ensure that they are in line with their human rights obligations, generated by the Human Rights Act and the UN Convention on the Rights of People with Disabilities (UNCRPD). They should do this by measuring cumulative impact, rather than assess the impact of each measure on an individual basis. By way of illustration, the impact on some disabled people's poverty will be compounded by both the fuel tax increases and the reduction of Personal Independence Payment, for those who rely on (adapted) cars to get around.

Involving disabled people at local and national level will not only help public authorities comply with their duties effectively. Done well, it will support people in a way that better meets their needs and promotes the delivery of independent living. The public sector equality duty in the Equality Act 2010 already provides a framework; the Government needs to make the involvement principle explicit through the specific duties.

Paid peer support is paramount to Independent Living: Local User-Led Organisations (ULOs) and smaller providers should be better supported. For example, they could be supported in researching and setting out their 'social return on investment', or conducting cost-benefit analyses to compare their costs and benefits against council management and other providers. Also, local authorities need to review their policies and practices around service agreements, 'payment by result' and preferred provider lists, to create a more level playing field against 'in-house' or large third or private sector providers.

The Government should, as a matter of urgency, review current or planned measures that reduce or localise support for disabled people (ILF, DLA, Social Fund). This goes beyond equality impact assessments, as we are concerned that some of these measures have unintended adverse consequences on disabled people's ability to live independently.

Currently, many disabled people and their families are unable to move from where they live, which limits their ability to access education or employment opportunities, live in improved housing or nearer their families. This would appear to be in contravention of Article 19 (a) of the Convention, which clearly states that disabled people should be able to choose where they live. This should be addressed immediately through legislative action to ensure that disabled people can move to another area with a seamless transition to an equivalent care and support package.

Responses to specific questions

1. Should the right to independent living continue to form the basis for Government policy on disability in the UK?

Yes, we believe that the right to independent living is fundamental to disabled people and should form the basis of government policy. It is the central plank upon which most other disability-related policy should be built, and of course is underpinned by Article 19 of the UNCRPD.

One in five people in the UK live with disability or health-conditions. Disabled people are parents, employees, employers, managers, MPs, home owners, transport users, students and members of every other conceivable interest group. However their ability to participate in society and to realise their full potential is often limited by the environment and by lack of support. The right to independent living is a vital measure to ensure that disabled people enjoy the same basic human rights and life chances as their non-disabled peers. Not meeting these needs and rights has significant and unnecessary adverse consequences for our society and the economy.

The realisation of independent living should be measured to assess government performance, focusing on equality of outcomes rather than just opportunities. Measures should include how many disabled people have been lifted out of poverty, are not isolated in their homes, are supported to take out Direct Payments, participate fully in education and employment, lead full economic lives, are represented in public life, etc.. This would exceed the Office for Disability Issues (ODI)'s notion of, simply, "having the same level of choice, control and freedom". Choice is a means to an end but not an end in itself. Choice is only meaningful if supported by information, action and resources, and if there is genuine choice. This includes, but is not limited to, choice between types of support that are accessible and based on clear entitlements to health, social care and welfare provisions.

2. Do existing policy statements, including the Independent Living Strategy, represent a coherent policy towards the implementation of the obligations in Article 19 of the UN Disability Rights Convention? Could current policy be improved? If so, how?

We do not consider that existing policy statements are an adequate coherent policy towards implementing Article 19. We observe with continued concern that the Government has not yet clarified if and how it will take forward the Independent Living Strategy (ILS). Furthermore, while we welcome some of the ambitions of national policy, many of these commitments don't filter through to disabled people's everyday experiences of independent living. The ILS should give disabled people and government a tangible and focused framework that helps to realise independent living progressively. Given that the UNCRPD does on its own not create a domestically

enforceable right, central government needs to ensure that there is a robust policy framework in place for local and national authorities to have due regard to human rights and equality in their policy making and delivery, and that they do not take steps that reverse progressive realisation of disabled people's independent living.

We are concerned that the latest government reviews of the statutory duties on local councils (Department for Communities and Local Government) and the 'Redtape Challenge' (Cabinet Office) do not adequately put their questions in context. They should consider 'how do we as a society want to live?' and on the minimum entitlements we as a society require in respect of support for disabled people. We need safeguards to ensure that equality and human rights of disabled people are not played off against needs that are thought to be more relevant to wider society. We are concerned that there appears to be a narrative that various protections against discrimination and duties to support disabled people cause unnecessary 'burdens', the abolition of which would not be detrimental to anyone. The evidence appears to be to the contrary, when even before there was a need for austerity measures, disabled people and carers experienced a lack of rights and access to basic support (eg social care from councils).

Many people who respond to these consultations may not understand the necessary detail, but will be happy to buy into the idea that these proposed changes are merely of a bureaucratic nature. It will not be until they themselves are affected directly or expected as carers to provide support that they understand the original requirements.

With regards to the public sector equality duty in the Equality Act 2010, it would be helpful to develop how this can be used as a driver for realising independent living. The ILS could help to set out steps or examples on how it could achieve this.

Current policy places great emphasis on the active choices of the disabled individual by 'putting purchasing power into people's hands'¹. This positive change of direction from previous notions of 'dependency' will help to empower disabled people and instigate whole systems change from a capacity-driven model to one that is led by (actual) demand and thus much more cost-effective. This is welcomed, although we do observe other impediments within the wider system to achieving this.

There is a lot of waste in the current system (eg for equipment which does not fit requirements and/or is not re-used or for repeat and overlapping assessments). We believe this could be reduced if disabled people "own" more of the decisions that affect them. Achieving this would be more likely if (paid) peer support was put in place for disabled people to take on such roles in the provisioning of their health and social care. The Government has very helpfully stressed the link between involvement and health outcomes², and the Health and Social Care Bill places a duty on the NHS Commissioning Board to promote choice. However, many people struggle to navigate by themselves through complex health and social care pathways. Others may not at all

¹ Coalition Manifesto, May 2010

² White Paper Equity and excellence: Liberating the NHS, July 2010

be able to take on such a role. The lack of corresponding commissioning support to promote and facilitate choice at an individual level cannot be mitigated by greater involvement at a strategic level, eg in Joint Strategic Needs Assessments. This is the chance for the individual to be involved directly and maximise independent living for themselves, their peers and the wider community.

3. What steps, if any, should the coalition Government, the Scottish Government or other public agencies take better to meet the obligations in Article 19 and to secure the right to independent living for all disabled people in the UK?

We need coordinated and consolidated action – including timelines and delivery mechanisms – to address and bridge the various gaps between policy and the reality of lived experience. This should be delivered through a (revised) Independent Living Strategy, which should take into consideration the following points.

It is particularly important that a holistic approach is taken to decision-making which affects disabled people, especially when one decision may impact upon another. For example, an individual may face the abolition of council-funded taxi cards which, if coupled with reduced or cut disability benefits and housing allowance, will greatly reduce their ability to achieve independent living. Yet, there is no consideration of the cumulative impact across such various funding streams which are sometimes ‘passported’, that is the individual needs to qualify for one stream in order to be considered for another.

The Government should do more to foster good relations across society, including promoting positive attitudes towards disabled people. Many of the barriers to achieving independent living, faced by disabled people, are exacerbated by others’ attitudes towards them.

Local authorities should support disabled people better to develop their own solutions and more effectively utilise public money. For example, disabled people could be empowered through schemes and measures that support people to pool their personal budgets. Such initiatives may lead to user-led mutuals, contributing to further social and economic capital. There will be a variety of creative solutions that will enable disabled people to get better outcomes from existing resources, particularly if existing commissioning processes (which favour larger providers) are dismantled in parallel.

New social care legislation (proposed by the Law Commission) and the Dilnot Review on long-term funding of social care should reflect the evident increase in unmet need as well as shared benefits from pooling risks. Unmet social care need will impact on the public’s purse in the form of premature increased need for referrals to health services³.

³ as evidenced by the ODI and Audit Commission

<http://odi.dwp.gov.uk/docs/res/il/better-outcomes-report.pdf>
<http://www.audit-commission.gov.uk/SiteCollectionDocuments/AuditCommissionReports/NationalStudies/financialimpactsofanageingpoplitreview.pdf>

The wider public should be informed and encouraged to think about how their own needs would be served in the future without an overbearing impact on their families and friends (who in an ageing society may not be as available as in previous decades).

Local accountability – eg for referendums on priority spending by councils – needs to be predicated on statutory duties with minimum guarantees for disabled people. Otherwise there will be too much pressure from a majority, lacking an understanding of the issues, not to support disabled people adequately. To facilitate this, ring-fenced budgets are helpful rather than counter-productive in ensuring that authorities spend dedicated money to secure independent living. Otherwise there does not appear to be any imperative or driver for them to deliver national policy, in particular in times of austerity measures.

Furthermore, disabled people need to be empowered to act for themselves, strengthening the benefits of involvement and reducing the need for others to speak on their behalf. Direct involvement with paid peer support should increasingly replace input from others, wherever appropriate - disabled people are usually the best experts in what they need.

4. What impact do funding, policy and budgetary decisions have on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to independent living?
 - the impact of (restricted) funding on the right to independent living (eg emergency budget; Comprehensive Spending Review; 2011 budget)
 - the decision to remove the mobility component of Disability Living Allowance for all people living in residential care
 - changes to the Independent Living Fund
 - the “Big Society”
 - restrictions on local authority funding, social care budgets and benefits reassessments
 - increased focus on localisation and its potential impact on care provision, and specifically, on portability of care and mobility for disabled people
5. How will recent policy and budgetary decisions impact on the ability of the UK to meet its obligation under Article 19 to protect the right of all persons to

Disabled people and society as a whole need to have certainty on statutory duties as minimum guarantees. This applies in particular if the Audit Commission will be abolished, public service agreements scrapped (despite evidence of targets having increased the proportion of socially excluded adults in settled accommodation, and employment, education or training) and CQC inspections stripped back.

We don't think that the 'Big Society' can flourish in an adversarial local context with disabled people not adequately supported to have their voice heard. A recent High

Court decision (Judge Walkers – judgement not yet available) has helpfully clarified that a council (Birmingham) cannot expect disabled people to identify the necessary spending priorities so that their support at substantial level could be maintained.

Innovation and creativity will emerge locally if proper incentives are set out, for example:

- A. There must be clear minimum statutory duties guaranteed to disabled people with a commitment to universal support wherever possible. This will reduce unnecessary tensions and help foster good relations.
- B. Local ULOs and smaller providers should be trained in setting out their ‘social return on investment’, and cost-benefit analyses need to be commissioned to help ULOs to compare their costs and benefits against council management and any other qualified willing provider.
- C. Service agreements, ‘payment by result’ and preferred provider lists need to be revamped to create a more level playing field between ULOs and ‘in-house’ or large third or private sector providers⁴. This should include provisions for light touch regulations and strong incentives for sub-contracting to micro providers.

We are particularly concerned about the impact of the following measures on individuals:

- A. Reduced formula grants affecting Adult Social Care, including through raised eligibility thresholds for support and increased charging⁵ (up to full cost recovery without cap as in Westminster⁶) place disabled people at the mercy of volunteers (provided that they are available in sufficient numbers). Some people report Having to stop social care support while their needs deteriorate. This will increase and accelerate the demand for health services that are currently free at the point of need.
- B. We are concerned that legal redress against public authorities will be even harder to achieve with the proposed restrictions to Legal Aid. Many disabled people do not have the resources or capacity to fight such cases without this support. This is not just a theoretical concern. The High Court has just ruled against Birmingham that tightening eligibility to critical needs only has been unlawful for ignoring provisions in the Disability Discrimination Act. The expected ‘saving’ by that council was £17.5m. Wirral has just confirmed a whistleblower’s concern of several people with learning disabilities having been charged

⁴ See NCIL consultation response ‘Supporting a Stronger Civil Society’ <http://www.ncil.org.uk/categoryid1.html>

⁵ ‘Charging into poverty’ by Coalition on Charging <http://www.disabilityalliance.org/chargingintopoverty.pdf>

⁶ Snapshot survey by Coalition on Charging, April 2011 <http://www.disabilityalliance.org/cohomecare.htm>.

£244.000 in contravention of the council's own charging policy.⁷ We are becoming increasingly aware that other authorities are introducing measures which should be contested in court, yet the increasing difficulty to access resources to do this challenges fundamental rights of access to justice.

- C. Austerity measures are already driving behaviours within local authorities that are contrary to independent living. For example, in the London Borough of Tower Hamlets they have unilaterally removed the self-directed assessment and resource allocation processes which underpin the personalisation agenda. The council suggests it is too expensive to maintain this approach. In fact, the local ULO believes this is simply because of poor implementation. This action has been taken without consultation. The same local authority is also reassessing people and including the availability of unpaid support to reduce the assessment of presenting needs, in order to reduce support packages. Independent living is taking a back seat to cost factors, reducing those disabled people to relying on the charity of others.
- D. While we welcome that the Disability Living Allowance (DLA) has been kept as a universal benefit, the cut of 20% is arbitrary, which places many months of uncertainty even on people with greater needs. The assessment for the new 'Personal Independence Payment' (PIP) has so far been excluded from consultation and also from parliamentary scrutiny (as has the 'review' of DLA for care home residents), and it has not been answered how disability-related expenditure will be covered for those people who will be denied PIP.
- E. Equally, the closure of the Independent Living Fund to new applicants is forcing those eligible to request support from cash-strapped and unprepared councils. We have had evidence on our helpline that councils have been unable to make up the shortfall. We have significant concerns that the same will apply to existing users of the ILF, upon its closure, and the resources will not be used by local authorities to support independent living.
- F. People can still not move from one council area to another – for instance to be closer to supportive networks of family and friends or to access education or take up jobs – without taking fundamental risks to how their needs are being cared for after their move (at stake are both assessment and corresponding support package).
- G. Subject to an appeal at the Supreme Court against Kensington & Chelsea, Ms MacDonald is required to wear urine pads over night purely to save costs for a carer despite her not being incontinent which in our view violates Ms

⁷ www.communitycare.co.uk/Articles/2011/04/18/116701/whistleblower-forced-to-quit-is-offered-job-back.htm

MacDonald's dignity. The judgment is now being used by many local authorities to justify cuts to care packages without proper reassessments⁸.

6. What steps should the Government take to meet its obligations under the Disability Rights Convention to involve disabled people in policy development and decision-making, including in budget decisions such as the Comprehensive Spending Review?
7. Are the current arrangements for involvement of disabled people in policy development and decision-making working?

The Government does reach out to the wider public but not necessarily particularly effectively with those who are affected most by reforms, as noted in response to question 2. This seems inadequate. The DLA reform has generated considerable anxiety amongst disabled people and the DWP consultation received over 5,500 responses. However it is unclear if and how this large level of involvement – including the direct input from disabled people and their representative organisations – has affected government plans; the DWP consultation response makes no mention of any changes (however small) to government plans in this area. Furthermore, the speed of proposed changes and reforms and the cuts to the ODI make it difficult to ensure appropriate level of input from disabled people (who are often not paid for this). The ODI or Equality 2025 should be better utilized as vehicles for intra-government representation for crucial decisions – and especially issues affecting only disabled people (eg time-limiting ESA).

Involvement and greater choice and control of disabled people are paramount to counteract the detrimental impact of reforms, eg reduced quality and continuity of care arising from the abolition of targets in health and social care. The more involved an individual is in their care and support and in practical tasks such as budget-setting, the greater the positive impact on health outcomes as reported by the Department of Health⁹. Aside from personal health gains, individual involvement then also reduces the burden on the taxpayer by delaying referrals to NHS Continuing Care. The Right to Control and envisaged right to a personal (health) budget correspond with positive examples of continuous and meaningful involvement.

For the time being, these compelling issues do not appear to have been recognised or implemented, not least due to the absence of incentives for long-term investment across health and social care. On the contrary, Hammersmith and Fulham carried out a consultation – only when forced to – according to the letter of the law rather than the spirit of the law. We had hoped that the specific duties under the Equality Act will reinforce the benefits of involvement. The level of involvement achieved under the previous duty was insufficient to deliver independent living. We are unconvinced that the

⁸ <http://www.communitycare.co.uk/Articles/2011/04/05/116623/controversial-court-judgement-used-to-justify-care-cuts.htm>

⁹ White Paper Equity and excellence: Liberating the NHS, July 2010

Equality Act duties will replicate or enhance the level of involvement achieved and risk undermining the obligations of the Convention.

8. What steps should Government take to ensure that disabled people's views are taken into account when drafting their reports to the UN under the UNCRPD?
9. As part of the national monitoring mechanism, what steps should the EHRC, NIHRC and SHRC take to ensure that the Convention is implemented effectively?

The Government needs to involve disabled people to determine meaningful outcomes and appropriate indicators of the UK's performance in securing the right to independent living. It is important that we do not exclusively rely on the UN reporting procedure as it can take years for the UN Disability Committee to consider the UK Government and shadow reports. In order to keep the momentum going, the Government should commit to an independent living strategy, backed-up by a range of domestic reports which would strengthen the UK's credibility towards the UN. To this end, findings at local levels should be linked back to changes at the national policy level and vice versa.

Any such input needs to be funded and research commissioned, for instance on the tensions between choice and control and cutting back on the welfare state. Research designs need to be robust. Finally, these reports need to identify action points and disabled people must be given a fair chance to keep momentum towards these action points.

About the Disability Rights Partnership

Our organisations are led by disabled people. Between us we represent over 500 local and national organisations.

The National Centre for Independent Living (NCIL): is a national support, advice and consultancy organisation that aims to enable disabled people to be equal citizens with choice, control, rights and full economic, social and cultural lives.

See: www.ncil.org.uk

Disability Alliance: is a UK charity and aims to break the link between poverty and disability. We have over 250 members and 36 years of benefits and welfare experience.

See: www.disabilityalliance.org

Radar: The Royal Association for Disability Rights (Radar) is a pan-disability organisation led by people with lived experience of disability or health conditions. Radar's vision is a just and equal society whose strength is human difference. Radar's mission is to enable individuals, networks and policy-makers to do things differently – and better.

See: www.radar.org.uk