

## **Submission to the Joint Committee on Human Rights inquiry into the implementation of the right to Independent Living for disabled people, as guaranteed by Article 19, UNCRPD**

### **Summary**

As highlighted by the Committee, Wales does not have a National Strategy on Independent Living, unlike England and Scotland. Consequently, there is no strategic approach to implementation of the right to Independent Living for disabled people in Wales.

To address this, Disability Wales (DW) is campaigning for a National Delivery Strategy on Independent Living in Wales. A petition in support of this is being considered by the National Assembly for Wales' Petitions Committee.

Choice and control over public services is widely recognised as an important building block of Independent Living. In recognition of this, the Welsh Government has stated its commitment to the Direct Payments Scheme and to developing Citizen Centred Services in social care.

However, DW believes that more needs to be done to secure disabled people's right to Independent Living, and that a National Delivery Strategy – addressing all aspects of Independent Living – is essential to achieving this.

The Wales Alliance for Citizen Directed Support (CDS), of which DW is a Council member, is supporting development of a Welsh approach to personalisation. However, CDS should not be taken forward in isolation from wider policy development but as an integral part of a National Delivery Strategy on Independent Living in Wales.

It may be necessary to develop new legislation to enforce implementation of the proposed National Delivery Strategy, and to secure the right to Independent Living for disabled people in Wales.

## **About Disability Wales**

Disability Wales (DW) is the national association of Disabled People's Organisations in Wales, striving to achieve rights, equality and independence for all disabled people.

We are an independent, not for profit organisation established in 1972 which is run and controlled by disabled people and their organisations. Our wider membership includes a range of other national and local disability organisations, trades unions and public and voluntary sector bodies.

DW's core role is to reflect the views of Disabled People's Organisations to government with the aim of informing and influencing policy.

We work primarily with the Welsh Government but also with government bodies at local, UK and European level. DW co-ordinates the Coalition on Charging Cymru which has campaigned for more than ten years for the abolition of community care charging.

We are involved with several other All Wales networks which take a strategic approach to development of Direct Payments. DW is also represented on the Council of the Wales Alliance for Citizen Directed Support.

DW's policy development is underpinned by the Social Model of Disability (SMD) which recognises that people are disabled more by poor design, inaccessible services and other people's attitudes than by their impairment or health condition. We are recognised as the lead organisation in Wales in promoting the understanding, adoption and implementation of the SMD. The Welsh Assembly Government adopted the SMD in 2002.

## **Background to Independent Living in Wales**

“Independent Living enables us as disabled people to achieve our own goals and live our own lives in the way that we choose for ourselves” (Disability Wales, 2010)

Independent Living has long been a central focus of DW's work. In 2008 the Welsh Assembly Government awarded funding to DW for the new role of Policy Officer (Independent Living).

In April 2010 to March 2011 DW ran a campaign for “Independent Living NOW!” The campaign principles received unanimous cross-party support in a debate in the National Assembly for Wales on 12 May 2010.

The campaign called for a National Strategy on Independent Living in Wales. A petition in support of a National Strategy was signed by over 700 people and is being considered by the National Assembly’s Petitions Committee.

In March 2011 DW published a Manifesto for Independent Living ahead of the May 2011 Assembly election. The Manifesto highlights six “Calls to Action” which disabled people in Wales have prioritised as key to making Independent Living a reality in Wales.

Whilst the Welsh Government have stated that their preferred approach to making change happen on the ground is to impose specific duties on public bodies under the new Equality Act 2010, DW’s view is that the priorities highlighted in the Manifesto, and others necessary for Independent Living, will not be achieved without a National Delivery Strategy for Independent Living.

Following the ‘Yes’ vote in the recent referendum on increased powers for the Welsh Assembly, DW is exploring the potential for reinforcing a National Delivery Strategy with new legislation to secure disabled people’s right to Independent Living.

## **Citizen Directed Support**

Provision of personalised, outcome focused social care and support services is vital to achieving Independent Living for many disabled people in Wales.

The Welsh Government has not followed the top down approach to personalisation, based on the In Control model, that has been adopted in England.

Instead, the Wales Alliance for Citizen Directed Support (WACDS), of which DW is a Council member, is developing a model that is more suited

to the Welsh context. This is based on three core principles: *choice and control, change and community*.

The model supports local innovation and provision of a range of options for service users, including Direct Payments and traditional service delivery for those who want it. The model also emphasises the importance of co-operative approaches to service provision, building social capital and community development using mechanisms such as Time Banking.

The Alliance includes disabled people, representative organisations, service providers and about half of the 22 Welsh local authorities.

Publication of the Welsh Government's paper on *Sustainable Social Services* (March 2011), which is broadly supportive of Citizen Centred Services, has opened up discussion on how to implement personalisation in Wales.

Although the Welsh Government continues to support development of the Direct Payments Scheme, take up has been very low. The All Wales Direct Payments Survey 2008-09 shows that of 71,377 children and adults receiving local authority funded services, only 2,440 (3.42%) received a Direct Payment.

Whilst continuing to support efforts to improve the take up of Direct Payments, and despite reservations about people being left with inadequate access to services if CDS is not implemented in line with the WACDS core principles, DW would like to see the transfer of control to disabled people extended further through implementation of CDS.

## **Citizen Directed Support and Independent Living**

DW supports the statement by Independent Living in Scotland (ILiS) that:

*“For independent living to be a reality, disabled people need access to certain basic rights. Self Directed Support (SDS) is one of these rights. For some disabled people it is an essential link in the chain of rights needed to ensure they are free to live their life in the way they choose, to be in control of it and to do this with dignity.*”

*To this end, controlling your own support...are not outcomes in themselves, but are part of a process which leads to the real outcome of Independent Living.”*

(ILiS Response to Draft Self Directed Support (SDS) Bill for Scotland, March 2011).

It is vital that this linkage between personalisation and the wider Independent Living agenda is recognised in the design and implementation of new systems of outcome focused, person centered care and support in Wales.

To this end, DW maintains that CDS should not be taken forward in isolation from wider policy development but as an integral part of a National Delivery Strategy on Independent Living in Wales.

## **Response to specific questions**

### ***The right to independent living***

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

Yes. Independent Living remains an effective framework for understanding and tackling the barriers that disabled people face which prevent them from having the same choices, opportunities and control of their lives as non-disabled people.

*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?*

As the JCHR note, in Wales there is no comparable policy to the Independent Living Strategy that has been implemented in England. DW continue to campaign for a National Delivery Strategy on Independent Living for Disabled People in Wales.

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

In developing a National Delivery Strategy on Independent Living the Welsh Government will need to consider whether new legislation is needed to secure the right to Independent Living for disabled people in Wales.

*If you consider changes to policies, practices or legislation in the UK are necessary, please explain.*

The Welsh Government has stated its commitment to improving public services, but without a coherent National Delivery Strategy on Independent Living – not only in social services but across all public services, and backed up by legislation if necessary – it is likely that disabled people in Wales will continue to experience poorer quality services than people in other parts of the UK.

### ***Impact of funding on the right to independent living***

*The decision, announced in the CSR, to remove the mobility component of Disability Living Allowance for all people living in residential care*

DW is concerned that the Coalition Government are still considering this proposal, despite strong evidence that it is flawed. DW is also deeply disappointed that the Coalition Government failed to take notice of the deep criticism of DLA reform which many disabled people and organisations voiced in the consultation.

### ***Changes to the Independent Living Fund***

DW is deeply concerned about the impact of ILF funding coming to an end on the 2000+ current recipients in Wales, as well as on potential future beneficiaries. ILF enables many disabled people to gain and maintain a decent quality of life. The ILF, as its website states, “is dedicated to delivering financial support to disabled people and advancing standards of independent living.” Loss of this funding will be devastating for many people. For example, in one case that we are aware of, a fiercely independent young man of 28 whose ILF

application was blocked by the introduction of new criteria, is forced to continue living at home with his parents. DW has raised these concerns with the Welsh Government and hopes to see the new Assembly finding ways to mitigate the effects of the ILF closure.

### *"The Big Society"*

The impact of cuts on the third sector in Wales is already becoming evident. For instance, DW was very disappointed to learn that Denbighshire Disability Forum was forced to close in April 2011 due to a cut to its local authority funding.

### *Restrictions on local authority funding, social care budgets and benefits reassessments*

DW is currently collecting case studies of people who have been affected by the "double whammy" of cuts to both public services and welfare benefits. A very bleak picture is emerging across Wales which, with the highest proportion of disabled people in the UK, is experiencing a disproportionate impact.

### *Increased focus on localisation and its potential impact on care provision, and specifically, on portability of care and mobility for disabled people*

DW welcomes the Welsh Government's commitment in *Sustainable Social Services* to developing portable assessments and national eligibility criteria for adult social care. It seems likely that time banking and the Welsh tradition of mutuality will be called upon to inspire new co-operative models of care and support

### *What impact does funding have on the ability of the UK to secure the right to independent living protected by Article 19 of the UN Disability Rights Convention?*

If consideration is given to the long term potential savings that can result from Independent Living (as evidenced in *The Costs and Benefits of Independent Living*, Office for Disability Issues, 2007), rather than to the initial set up costs of new services, then implementing Independent Living can make a positive contribution to the efficiencies and savings agenda.

*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 independent living?*

The pace and depth of public service and welfare benefits cuts that have been implemented by the Coalition Government is a serious threat to disabled people's right to Independent Living. In this regard, DW is supporting the disabled people's national day of action in London on 11 May 2011 in protest against the cuts.

### ***Participation and consultation***

*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?*

The Social Services Improvement Agency's 'Getting Engaged' project (<http://ow.ly/4vaSL>) identified a substantial number of participation and involvement notable practice examples in Wales.

However, DW regularly represents disabled people in a wide range of Welsh Government stakeholder groups and, generally speaking, at local authority level there is a woeful lack of meaningful engagement with disabled people and Disabled People's Organisations (DPOs).

The recently introduced Wales Specific Duties under the Equality Act 2010 require public bodies to engage with citizens on a pan-equality basis. DW wish to see the Welsh Government making a strong commitment to developing and supporting local and national DPOs to enable them to represent disabled people's views effectively and contribute productively to policy development.

*Are the current arrangements for involvement of disabled people in policy development and decision-making working?*

The Disability Equality Duty (DED) required public bodies to engage with disabled people. Despite inconsistent implementation across Wales, in some areas significant progress was achieved. Although the Wales Specific Duties under the Equality Act 2010 continue to require engagement with people who have "protected



characteristics”, DW is concerned that the ground gained by disabled people under the DED will be lost.

National Principles for Public Engagement in Wales have been developed: <http://ow.ly/4xw9w> Again, there needs to be a much stronger commitment to enabling disabled people’s involvement in policy development, decision making and budget decisions before any significant improvement can be achieved. This commitment would need to include provision of information in accessible formats and accessible meetings for all impairment groups.

### ***Monitoring the effective implementation of the Convention***

*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?*

The Government should use the National Principles for Public Engagement, referred to above, and proactively involve DPOs in gathering evidence that reflects disabled people’s views and experience.

*As part of the national monitoring mechanism, what steps should the EHRC, NIHRC and SHRC take to ensure that the Convention is implemented effectively?*

It is essential that the national reports present an objective and independent perspective, are widely publicised and are made freely available.

Consideration should be given to introducing new legislation to secure disabled people’s right to Independent Living.

DW would also like to draw the Committee’s attention to the sections on The Promotion of Independent Living, Choice and Control, and Cost Effectiveness (pp135-143) in *Community Care and the Law, Fourth Edition* (Clements L, and Thompson P, Legal Action Group 2007).