Closure of the Welsh Independent Living Grant: In the cause of equality of provision for disabled people?

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Background

Local authorities in Wales are rushing to meet the new September deadline, set by the Minister for Health, for the re-assessment of the 1,300 or more recipients of the Welsh Independent Living Grant (WILG).² In November 2016 the Welsh Government (following in the footsteps of the English Government) announced the closure of the WILG.

The transfer of care and support of all receipients to local authority provision has been contentious and has left many recipients anxious and fearful that their right to Independent Living wll be eroded by this decision. A strident campaign has been launched by recipients of the WILG (and the previous Independent Living Fund (ILF)) and their families and supporters under the campaign banner of #SWILG.³

Closure of the Wales Independent Living Grant

The Independent Living Fund (ILF) was established by the Department of Health and Social Security in 1988 as an independent trust to provide a weekly payment to a small number of severely disabled people who would have suffered very significant financial loss as a result of the abolition of supplementary benefits 'additional requirements' payments in that year.⁴ It is however thought that about one million disabled people experienced considerable losses as a result of the 1988 changes.⁵

The ILF existed in various forms until it was closed by the Department for Works and Pensions to new applications in December 2010,⁶ – at which time it was providing support to 46,000 people with complex needs to live in the in the community.⁷ At that time the UK Government argued that it was an unsustainable cost; that it perpetuated an unfair funding of services to disabled people; that distribution of ILF was inconsistent across the four nations and within the four nations; and that the advent of direct payments and individual budgets in England obviated the need for ILF.⁸ The ILF closed in June 2015 and the funding was devolved to English local authorities and the Scottish, Welsh and Northern Irish Governments.

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² HID letter to WILG recipient of extension of WILG deadline for reassessments until September 10.3.18.pdf

³ https://nathanleedavies.wordpress.com/save-wilg-campaign/

⁴ R Means and R Smith, *Community Care Policy and Practice*, Macmillan, 1994.

⁵ Walker, A and Walker L *Disability and Financial Need – The Failure of the Social Security System* in Dalley, G. (ed) Disability and Social Policy (Policy Studies Institute 1991) 2-56 at 34.

⁶ House of Commons Library: Briefing Paper Number 007787 28 February – The Closure of the Independent Living Fund(ILF).

⁷ Tom Porter and Tom Shakespeare, 'Imposed unknowns': a qualitative study into the impact of Independent Living Fund closure on users, Disability & Society Volume 31, 2016 - Issue 7.

⁸ Tom Porter and Tom Shakespeare, 'Imposed unknowns': a qualitative study into the impact of Independent Living Fund closure on users, Disability & Society Volume 31, 2016 - Issue 7, and see also House of Commons Library: Debate Pack Number CDP 2018-0004, 4 January 2018 – Changes to the Independent Living Fund.

The WILG was set up in 2015 following a consultation exercise and gave the Welsh Government a period of moratorium to decide on how to proceed⁹.

The options before the Minister were:

- the extension of current arrangements;
- an arrangement with a third party to continue to provide payments to recipients in Wales, and;
- to transfer the responsibility and funding to local authorities in Wales over a two-year transitional period so as to eventually provide support through normal social care provision.

In November 2016, it was announced that the WILG would close in March 2019 and that all recipients would be assessed by their Local Authority for care and support under the Social Services and Well-being (Wales) Act (SSWBA) 2014 by March 2018. The March deadline was extended to September 2018 to enable local authorities to complete their assessments of WILG recipients.

The #SaveWILG campaigning group led by Nathan Davies continue to fight a vigorous campaign to persuade Welsh Government to retain the WILG and grow the provision in a similar fashion to Scotland.¹¹

The Equality Impact Assessment (EIA)¹² carried out in advance of the closure decision in Wales conveys a Panglossian view,¹³ that is to say an overly optimistic view of what the 2014 Act will deliver following the closure of the WILG in 2019. It also fails to acknowledge and consider the potential adverse effect on individuals who may have significant changes to provision and how this will be addressed to ensure the recipients right to Independent Living.

The rational for the closure of the WILG is in keeping with the UK Government's arguments for the closure of the ILF. Welsh Government argues that:

- the continuation of the WILG will perpetuate a 'two tier' system of provision and that this is unfair on those who receive care and support solely through their local authority.
- the cost of maintaining a Welsh version of the Independent Living Fund is financially unsustainable as money devolved to Wales from the UK Government's closure does not have the capacity to respond to future need of recipients nor allow for the opening of the WILG to new applicants.
- the SSWBA 2014 and Direct Payment provision will enable and support independent living and that the need for a discrete fund is not required.¹⁴

Transition from the WILG to local authority provision: are there messages from England?

The analysis and studies of the impact of the closure on ILF in England are bound to give

⁹ Welsh Government –Consultation Summary –What happens when the Independent Living Fund closes? March 2015.

¹⁰ Welsh Government Written Statement –Future Support Arrangement for Former Independent Living Fund Recipients: Rebecca Evans Minister for Social Services and Public Health 3rd November 2016.

http://www.gov.scot/Topics/Health/Support-Social-Care/Independent-Living/ScottishIndependentLivingFund
 Paying for Care, Partnership and Cooperation Division, Social Services and Integration Directorate – Equality

Impact Assessment (October 2016) reviewed April 2018.

13 Stuart Bracking & Ors v Secretary of State for Work and Pensions [2013] EWCA Civ 1345 (06 November 2016) File Proceedings (1915) 1915 (1915)

²⁰¹³⁾ Elias LJ noted is agreement with the arguments that the EIA and documentation from the Consultation gave sufficient consideration to the impact of closure on recipients.

¹⁴ https://gov.wales/about/cabinet/cabinetstatements/2016-new/ilf/

concern to WILG recipients in Wales. The Shakespeare and Porter 2016 study, ¹⁵ which focused on the impact of the transition from ILF to local authority support, found high levels of concern and anxiety about Local Authority processes and provision during this period. The Department of Work and Pensions Post-Closure Review, ¹⁶ found both positive and negative experiences of the transition. Those who had retained their provision or had an increase in provision or a slight reduction reported satisfaction without any loss to their independence. For those who had experienced a significant reduction there was a loss of independence, greater restrictions to their independence and an increased reliance on unpaid carers. There was also a concomitant impact on the emotional and physical health of these participants.

An emerging theme from the research and reviews is the post-code lottery faced by previous recipients of ILF.¹⁷ The finding in Inclusion London's review confirmed this factor and found in addition inconsistent practice in relation to NHS Continuing Health Care (NHS CHC) referrals for funding and failings in the implementation of the Care Act 2014 which left services users without essential provision.¹⁸

Many disabled people who will be transiting from the WILG will be legally eligible for NHS CHC funding or at least NHS joint funding. In addition to the well-documented procedural hurdles they encounter in obtaining this support, in Wales a more troubling challenge exists. The Welsh Government has made it clear that it will not permit direct payments to be made for people eligible for NHS CHC¹⁹ (unlike in England such payments can be made²⁰). Many LHBs appear reluctant to facilitate direct payments via a trust arrangement (often referred to as an Independent User Trust (IUT)) even though the High Court has held this to be lawful (indeed necessary in certain situations).²¹ Anecdotally it is also reported that LHBs are placing obstacles in direct payments being made where there is a joint funding arrangement even though the Framework guidance makes it clear that where 'an individual has existing Direct Payment arrangements, these should continue wherever and for as long as possible within a tailored joint package of care'.²²

Concluding Comments

About 1,300 people will transfer from the WILG to local authority care and support under the SSWBA 2014 by March 2019. Many of the recipients and their carers are concerned that their right to Independent Living will be compromised as local authorities re-assess and establish their eligibility to services.

The <u>R (CWR) v Flintshire County Council</u> (2018) Case Note illustrates the challenges that a disabled person and his/her family can face in Wales as they seek to access care and support. This case note does however, highlight the statutory requirements for a comprehensive assessment of disabled people in need of care and support and their carers. It demonstrates too, that assessments undertaken in a cavalier manner can be challenged and local authorities held accountable for their assessment, determination of eligibility and

¹⁵ Tom Porter and Tom Shakespeare, 'Imposed unknowns': a qualitative study into the impact of Independent Living Fund closure on users, Disability & Society Volume 31, 2016 - Issue 7, and see also House of Commons Library: Debate Pack Number CDP 2018-0004, 4 January 2018 – Changes to the Independent Living Fund. ¹⁶ DWP (2017) Independent Living Fund Post Closure Review.

¹⁷ Greater Manchester Coalition of Disabled People, ILF – Postcode Lottery?, undated; see also Hard Government's failure to ring-fence ILF funding 'is leading to postcode lottery'", Disability News Service, 5 May 2016.

¹⁸ Inclusion London, One year on: Evaluating the impact of the closure of the Independent Living Fund.

¹⁹ The First Minister (Carwyn Jones) First Minister's Questions 25 March, 2014 – see National Assembly's Record of Proceedings.

²⁰ The NHS Act 2006 s12A and The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012 SI 2996 (as amended) Reg 32B.

²¹ Gunter v SW Staffordshire PCT [2005] EWHC 1894 (Admin) 26/08/05.

²² Continuing NHS Healthcare. The National Framework for Implementation in Wales (2014) para 4.46.

care provision. This may provide some reassurance to WILG recipients although it is perhaps questionable how many will have the energy, knowledge and courage to pursue this option.

While the term 'well-being' may be used in a perfunctory manner in discussion about social care, the definition in section 2 SSWBA 2014 is comprehensive and includes control over day to day life (s.2(4) (a)) and participation in work (s.2(4)(b)).

Clements notes²³ that section 6(3)(b) stresses 'the importance of promoting the adult's independence where possible' and argues that this is amplified and bolstered by para 56 of the Part 2 Code of Practice (General Function) which states that the well-being duty 'includes key aspects of independent living as expressed in the UN Convention on the Rights of Disabled People in particular Article 19 which recognizes the right of disabled people to 'full inclusion and participation in the community'; to choose where they live and with whom they live; and to have access to a range of community support services 'to support living and inclusion in the community, and to prevent isolation or segregation from the community'.²⁴ Assessment, eligibility determinations and decisions on how to meet need will need to be infused by these principles.

<u>R (JF) v. Merton LBC²⁵</u> highlighted the requirement for an assessment to have regard to the dimensions of well-being set out in statute.

A comprehensive overview of assessment, eligibility and meeting needs can be found at www.lukeclements.co.uk/wp-content/uploads/2017/11/Wales-SS-Well-being-Act-26.pdf page 9.

²³ Social Services and Well-being (Wales) Act 2014: an overview guide at page 3 accessible at http://www.lukeclements.co.uk/wp-content/uploads/2017/11/Wales-SS-Well-being-Act-26.pdf

²⁴ http://www.lukeclements.co.uk/wp-content/uploads/2017/11/Wales-SS-Well-being-Act-26.pdf#page3

²⁵ http://www.lukeclements.co.uk/wp-content/uploads/2017/09/2017-02-JR-Merton-Wales-doc.pdf