



Consortium for the Regional Support for Women in Disadvantaged and Rural Areas

Response to: Consultation on the Future Support of Independent Living Fund Users in Northern Ireland

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Women's Regional Consortium: Working to Support Women in Rural Communities and Disadvantaged Urban Areas

1. Introduction

1.1 This response has been undertaken collaboratively by the members of the Consortium for the Regional Support for Women in Disadvantaged and Rural Areas, which is funded by the Department for Social Development in Northern Ireland and the Department of Agriculture and Rural Development in Northern Ireland.

1.2 The Women's Regional Consortium consists of seven established women's sector organisations that are committed to working in partnership with each other, government, statutory organisations and women's organisations, centres and groups working in disadvantaged and rural areas, to ensure that organisations working for women are given the best possible support in the work they do in tackling disadvantage and social exclusion.¹ The seven groups are as follows:

- Training for Women Network (TWN) – Project Lead
- Women's Resource and Development Agency (WRDA)
- Women's Support Network (WSN)
- Northern Ireland's Rural Women's Network (NIRWN)
- Women's TEC
- Women's Centre Derry (WCD)
- Foyle Women's Information Network (FWIN)

1.3 The Consortium will be the established link and strategic partner between government and statutory agencies and women in disadvantaged and rural areas, including all groups, centres and organisations delivering essential frontline services, advice and support. The Consortium will ensure that there is a continuous two way flow of information between government and the sector. It will ensure that organisations/centres and groups are made aware of

¹ Sections 1.2-1.3 represent the official description of the Consortium's work, as agreed and authored by its seven partner organisations.

consultations, government planning and policy implementation. In turn, the Consortium will ascertain the views, needs and aspirations of women in disadvantaged and rural areas and take these views forward to influence policy development and future government planning, which will ultimately result in the empowerment of local women in disadvantaged and rurally isolated communities.

1.4 This response is informed by women's views and perspectives articulated at consultation engagement events organised during October 2014 by FWIN and WSN. Appendix 1 provides further detail on this engagement.

2. General comments

2.1 The Women's Regional Consortium appreciates the opportunity to respond to the 'Consultation on the future support of Independent Living Fund (ILF) users in Northern Ireland', as issued by the Department of Health, Social Services and Public Safety for Northern Ireland (hereafter, DHSSPSNI).²

2.2 Within the wider policy debate on the subject at hand, the notion of 'independent living' may be broadly characterised in terms of people with severe disabilities having 'choice, control and freedom to determine where and with whom they live'.³ As research affirms, such persons can be among the most vulnerable and excluded population cohorts in the United Kingdom.⁴ Yet research also indicates that, in as much as it has reportedly proven 'dramatically effective'⁵ in facilitating independent living for some of these people thus making a 'reality of community care',⁶ the ILF has had a transformative effect on recipients' everyday lives.

² DHSSPSNI, 'Consultation on the future support of Independent Living Fund users in Northern Ireland', DHSSPSNI: Belfast, 2014.

³ B. Byrne *et. al.*, 'UNCRPD: shortfalls in public policy and programme delivery in Northern Ireland relative to the articles of the UNCRPD, summary report', ECNI: Belfast, 2014, p.10.

⁴ On this, see Disability Rights Commission, 'Equal treatment: closing the gap', DRC: London, 2006.

⁵ D. Black, 'The Independent Living Fund: helping to make a reality of community care', *British Medical Journal*, Vol. 298, 1989, p.1540.

⁶ *Ibid*, loc. cit.

For this reason, commentators have expressed dismay at the Department of Work and Pension's decision to close the ILF, forecasting negative outcomes in community care and individual wellbeing should independent living support reduce or cease altogether post-closure.⁷ The United Kingdom government's own equality impact assessment of this decision lends some credence to this position, projecting that the closure '*is likely to have an adverse effect*' on recipients in the English case.⁸ And, in the Northern Ireland case, stakeholder groups have forecast similar negative outcomes: '[recipients] will struggle to maintain their current levels of independence should ILF support be reduced or withdrawn'.⁹

From this perspective, the Consortium welcomes DHSSPSNI's commitment to ensure that 'disabled people ... who are most in need of ... care and support are not disadvantaged' by the closure.¹⁰ That said, in a context of extended austerity characterised by intensified competition for already scarce public resources, between comparably compelling priorities across different kinds of vulnerable cohorts (i.e. disabled cohorts *and others*), we have misgivings about the Executive's potential to properly fulfil that commitment. We remain especially concerned about the implications that a post-ILF environment might hold for the well being of disabled women.

These misgivings are informed by concerns over the following issues: likely future constraints on the Executive's capacity to mitigate the effect of the closure of ILF; the impact of the closure on the relationship between vulnerability to social exclusion, health inequalities and severe disability; the absence from the document of a clear definition of what independent living constitutes, such as could appropriately frame the commitment to mitigation; and, the need to cultivate a substantive human rights perspective on the matters in question in order to properly capture what is at stake in this debate.

⁷ See, for example, J. Campbell, 'Without the Independent Living Fund, it's a bad time to be disabled', *The Guardian*, 31 March 2014.

⁸ DWP, 'Closure of the Independent Living Fund', DWP: London, 2014, p.13.

⁹ DHSSPSNI, *op. cit.*, p.9.

¹⁰ *Ibid.*, p.5.

Participant discussion in the engagement events underlined these concerns and raised associated issues, as will be shown in the remainder of the paper.

3. Specific comments

Extended austerity and mitigation of ILF closure

3.1 This section outlines Consortium concern at the relationship between the forecast of extended austerity and potential constraints on the Executive's commitment to mitigate the effects of the ILF closure.

The consultation document notes that the decision to close the ILF was met by ministerial 'disappointment' at DHSSPSNI over imputed 'damage' to the 'very ethos of caring'.¹¹ The document then proceeds to outline the department's commitment to 'do all it [can]' to 'mitigate the effect' of that decision on existing ILF recipients in Northern Ireland.¹² Yet, at the same time, the document places that commitment squarely in the context of austerity-driven limitations, i.e. 'current and likely future constraints on public spending'.¹³ In other words, it acknowledges the austerity-constrained/responsive nature of any such mitigation. That acknowledgement raises the important question of how the anticipated context of extended austerity might restrict realisation of this mitigation commitment.

Research affirms that extended austerity across Europe 'is contributing to inequality that will make economic weakness *longer-lived*, and needlessly contributes to the suffering of the jobless and the poor *for many years*'.¹⁴ Longer-lived economic weakness of this kind may be associated with the prolongation of fiscal constraints. And, the latter may, in turn, be associated with the extension of retrenchments in social expenditure. In combination, these associations may further intensify competition for already scarce public resources among comparably compelling priorities across different kinds of vulnerable cohorts (i.e. disabled cohorts *and others*).

¹¹ *Ibid.*, p.5.

¹² *Ibid.* loc.cit.

¹³ *Ibid.*, p.12.

¹⁴ J. Stiglitz, quoted in Oxfam, 'Oxfam briefing paper summary: a cautionary tale - the true cost of austerity and inequality in Europe', Oxfam: London, 2013, p.2.

It, of course, remains to be seen precisely how, and to what extent, such a projected eventuality might potentially impact the Executive's commitment to mitigation in respect of ILF. Clearly, if, as noted, the commitment is austerity-constrained/responsive and austerity is extended, then it conceivably could have *some* impact. And, this projection is, in itself, troubling.

In sum, while the Consortium certainly welcomes the departmental ambition of attempted mitigation, in so far as any such mitigation will be austerity-responsive, we remain concerned at the capacity of the Executive to realise that ambition in a context of extended austerity, characterised by prolonged intensified competition for already scarce public funding between comparably compelling priorities.

The Consortium recommends that the Executive, in taking due account of likely austerity-driven fiscal constraints on its capacity to mitigate any effects of the ILF closure, prioritise continuity in care support packages for the lifetime of current recipients.

Social exclusion, health inequalities and severe disability

3.2 The Consortium is concerned at uncertainty over how the consultation proposals might potentially impact the relationship between severe disability, vulnerability to social exclusion and health inequalities.

The relationship at hand is well established in the literature. For example, research affirms that 'becoming disabled' entails a significant risk factor in financial hardship and vulnerability to social exclusion given its impact on individuals' participation in employment and civil society: 'disabled people are disproportionately likely to be out of work, on low incomes and unable to participate in social activities'.¹⁵

¹⁵ T. Burchardt, 'Being and becoming: social exclusion and the onset of disability', JRF: London, 2003, p.5.

The ILF has reportedly helped mitigate that risk, enabling increased participation across different dimensions of the public sphere, including both the labour market and associational life. As one recipient has neatly put it:

[ILF has allowed recipients] to learn, work, volunteer, play and live in a way that has met our needs and allowed us to be full and active members of the society we live in ... we want to live in, and be part of, our communities.¹⁶

It has consequently been predicted that decreased participation in the public sphere could result for recipients were care packages to shrink in a post-ILF environment. That prediction envisages a transition from independent living in the community as 'a beacon of good practice' to 'a poorly funded [care] regime rooted in 'clean and feed' provision', such as would leave severely disabled people 'in the shadows'.¹⁷

Research also indicates that the level of exclusion following disablement can increase depending on the severity of the disability, so that the severely disabled are more vulnerable to exclusion.¹⁸ The kind of disability in question can also impact vulnerability. For example, individuals with learning disabilities can be disproportionately affected by health inequalities, i.e. 'more likely to experience major illnesses, to develop them younger and die of them sooner' than individuals without such disabilities.¹⁹ In addition, research suggests that protection against vulnerability to exclusion among disabled cohorts is innately income-dependent and that, consequently, at the level of policy, the provision of 'stable and adequate income' is '*the most fundamental* form of protection against such vulnerability.'²⁰

On this view, any post-ILF monetary reductions resulting in less than 'stable and adequate' provision would place affected individuals at increased risk of exclusion, compounding pre-existing vulnerability to exclusion related to health inequalities. Focus group participants highlighted this risk, citing both

¹⁶ Campbell, op. cit.

¹⁷ Ibid.

¹⁸ Burchardt, op. cit.

¹⁹ DRC, op. cit., p.1.

²⁰ T. Burchardt, Being and becoming: social exclusion and the onset of disability, CASE report 21, London School of Economics: London, 2003, p.67.

anecdotal and firsthand accounts of the relationship between income-associated vulnerability and health inequalities among disabled individuals in need of at-home care support. This included the reporting of different kinds of vulnerabilities related to mental ill-health.

Participants were especially troubled at the potential implications for women's wellbeing of any such post-ILF income reduction, should it result in recipients scaling back expenditure on 'essential items', such as food and utilities, in order to maintain pre-existing care levels. This projected scenario was associated with the danger of exacerbated ill-health and, in consequence, increased hospitalisation. The latter was held as particularly troubling in light of reported difficulties in the resettlement of disabled people from long-stay hospitals in the Northern Ireland case. Recent research supports this claim-making, identifying 'ongoing delays' in such resettlement.²¹

The substantive point here is this: against this backdrop of vulnerability, marginalisation and health inequalities, there is a compelling social justice case to be made for continuity of provision levels *for the lifetime of current ILF recipients*. Participants in the engagement events underscored this case, overwhelmingly supporting those consultation options *that appeared to* best approximate continuity of provision – namely, options 2, 4 and 5, while simultaneously rejecting those that did not.²² The latter, of course, includes not only option 1 of 'do[ing] nothing', which government has itself already ruled out as 'unacceptable', but also option 3, which the document states might mean 'some ILF users may experience a reduction in their overall support packages'.²³ Motivated thus, participants appealed for government to monitor and take proper account of *all* of the implications of the ILF's closure,

²¹ B. Byrne *et. al.*, 'UNCRPD: shortfalls in public policy and programme delivery in Northern Ireland relative to the articles of the UNCRPD, final report', ECNI: Belfast, p.108.

²² That said, I say 'appeared to' precisely because some participants held that there was insufficient logistical/operational/financial information in the consultation document, on the precise nature of ILF and the implications of proposed successor options, to allow them to take a properly (i.e. fully) informed view on option selection. In the absence of such clarificatory information, the content of the document was characterised as 'confusing' and 'ambiguous'.

²³ DHSSPSNI, *op. cit.*, p.11.

to include both direct variants (i.e. any loss of income), as well as any indirect variants (i.e. the knock-on effects of any such loss).

As it considers how best to proceed in a post-ILF context and evaluates the different options outlined in the document, the Executive should seek to carefully address the question of how each option might potentially impact the relationship between vulnerability to social exclusion, health inequalities and severe disability.

Furthermore, to ensure more meaningful and effective decision-making and delivery on this front, that question should be considered on a fully integrated (cross-departmental) basis, ensuring requisite disaggregated data is collected to properly track and monitor any impact of decision-making on recipients' everyday lives, including any that might follow from reductions in overall support were option 3 implemented.

Human rights perspective

3.3 Cultivating a substantive human rights perspective on this debate would allow the Executive to properly capture and take account of the wider social justice issues at stake. Yet the consultation document makes only fleeting reference to human rights requirements (i.e. the content of the European Convention on Human Rights), while failing to mention other, more directly relevant, requirements (namely, the content of the United Nations Convention on the Rights of People with Disabilities; hereafter, UNCRPD),²⁴ which specifically provide for the dignity and independence of disabled people. This omission is troubling for various reasons, most obviously because article 19 of the UNCRPD pertains to *the right to 'living independently and being included in the community'*.²⁵

The importance of cultivating a robust human rights perspective on this debate was recently underscored by research from the Equality Commission for Northern Ireland (hereafter, ECNI), which examined the implementation of

²⁴ B. Byrne *et. al.*, 'Final report', *op. cit.*, p.108.

²⁵ *Ibid.*, *loc. cit.*, p.19.

UNCRPD requirements in public policy and programme delivery in the Northern Ireland case.²⁶ Focussing specifically on how policy and programme outputs have failed to meet these requirements, the ECNI paper identified ‘substantive shortfalls’ with respect to the implementation of article 19 and other associated rights, concluding that:

disabled people in Northern Ireland experience barriers to living independently and being included in the community... [including] a lack of choice, control and freedom to determine where and with whom they live.²⁷

To compound matters, in large part, explanation for these shortfalls in independent living delivery was attributed to ‘problems with a lack of joint working’, especially between DHSSPSNI and DSD, which ‘*limit the potential for many people with disabilities to live independently*’.²⁸ This observation is particularly worrying given that ILF oversight in Northern Ireland is currently the responsibility of DSD, while responsibility for future support of ILF users will transfer to DHSSPSNI as of July 2015.

Participants at the consultation engagement reinforced this call to overlay a substantive human rights perspective on the debate, arguing that the right to independent living should be properly recognised and protected by the Executive as the touchstone of this policy review. So, for example, in respect of support for severely disabled women in a post-ILF environment, it was held that ‘these women should be given [the] right to remain in their own homes ... they must still have their independence’. The projected danger entailed the disrespect of this right post-ILF, whereby individuals might be forced into some kind of residential care.

Implicated here is the document’s failure to include a clear definition of independent living. As noted, the latter may be broadly captured in terms of disabled people having ‘choice, control and freedom to determine where and with whom [and how] they live’.²⁹ In the absence of such a definition, it is

²⁶ Ibid.

²⁷ Ibid., p.108.

²⁸ Ibid., pp.107-8.

²⁹ Ibid., loc. cit.

never entirely clear in the document what precisely the Executive intends mitigating against following the closure of the ILF. The inclusion of such a definition would have ensured that the commitment was unambiguously framed and spelt out in terms of *mitigation against any loss of individuals' capacity to 'live their lives the way they want to live'*.³⁰ In turn, such a transparent commitment could have helped address some of the concerns participants had over the potential implications of closure.

From this perspective, in addition to developing a robust human rights perspective on this debate, the Executive should also seek to remedially address and enhance its cross-departmental approach to delivery on independent living, taking due account of all implications in respect of same across all pertinent interacting policies and strategies, including, for example, 'Transforming your care' and the gender equality strategy.

Rural perspective

3.4 The consultation document notes that the proffered post-ILF options have been rural proofed, concluding that 'there does not appear to be any potential for an adverse differential impact on [ILF recipients in] rural areas'.³¹ Some participants objected to this conclusion.

The thrust of their argument was this: that should support reduce as of July 2015, a differential rural impact could result given pre-existing infrastructural constraints on rurally isolated cohorts' capability to live independently, such as critical shortfalls in transport and service support. The aforementioned ECNI research on the implementation of UNCRPD requirements in public policy and programme delivery captured these constraints. For example, the project identified accessibility in transport, including access to health services, as a prerequisite of independent living that is currently under-delivered rurally.³² The nature of the nexus at hand was neatly summarised in stakeholder

³⁰ OFMDFM, 'Annex to the report of the promoting social inclusion working group on disability', OFMDFM: Belfast, 2009, p.131.

³¹ DHSSPSNI, op. cit., p.16.

³² Byrne *et. al.*, 'Final report', p.133.

comment for the project thus: 'living [independently] in the community requires services in the community *and so far this has not happened* [rurally]'.³³

From this perspective, in addition to opposing any reductions in support for recipients, participants called for strategic remedial action from government to address the aforementioned infrastructural shortfalls that place rurally isolated disabled cohorts at additional risk of exclusion. It was also suggested that rural barriers to independent living could be better addressed were improvements made to frontline health and social care delivery, for example, in respect of general practitioner, social worker and carer contact.

The Consortium would urge the Executive to revisit and carefully re-examine the question of how the ILF closure might potentially impact pre-existing rural barriers to independent living, particularly in transport and service infrastructure, should recipient support reduce in 2015.

4. Conclusion

As noted, severely disabled individuals can be amongst the most vulnerable and excluded population cohorts. Yet the ILF has reportedly helped remedially address these experiences of vulnerability and exclusion, innately benefiting recipients' everyday lives. This response has consequently outlined concerns over recipient welfare in a post-ILF environment, in particular, concerns over vulnerable women's health and well being.

The consultation document presents DHSSPSNI as alive to the '*potential* upset and distress likely to be caused' to such individuals were support to cease following the ILF closure.³⁴ But, as commentators have rightly observed, it is not just the prospect of support cessation that engenders such recipient distress, but also *the prospect of any kind of reduction such as would threaten the facilitation of independent living in any way and to any extent.*³⁵

³³ Ibid., p.107.

³⁴ DHSSPSNI, op. cit., p.12.

³⁵ Campbell, op. cit.

It has been argued that cultivating a substantive human rights perspective on this debate would allow the Executive to properly capture and take account of the wider justice issues at stake. Doing so would affirm the compelling social justice case for protecting existing ILF packages for the lifetime of recipients.

In a context of extended austerity, characterised by intensified competition between comparably compelling priorities for scarce public resources, there is an added urgency to maintain and overlay this perspective across all public policy and programme delivery and output, accurately assessing and tracking any adverse independent living impact.

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Appendix 1

Women's Regional Consortium: Engagement Events DHSSPSNI's 'Consultation on the future support of Independent Living Fund (ILF) users in Northern Ireland'

Engagement profiles: types, locations and dates

- WSN-facilitated focus group, WSN Belfast offices, 20 October 2014
- FWIN-facilitated semi-structured interviews (various locations in the north-west), 20-22 October 2014