

**Equality Commission for NI Response to the Department of Health,
Social Services and Public Safety (DHSSPS)
Consultation on the future support of Independent Living Fund
(ILF) Users in Northern Ireland November 2014**

1. The Equality Commission welcomes the opportunity to respond to the consultation on the 'Future Support' of Independent Living Fund (ILF) users in Northern Ireland. In setting out our response to this consultation, the Commission takes into account the following:
 - Relevant equality law;
 - The UN Convention on the Rights of Persons with Disabilities (CRPD);
 - The views of ILF users.

Summary

2. The Commission notes that the underlying theme of all of the options presented in the consultation paper is the eventual closure of the ILF. All of the options indicate that any future model concerned with the delivery of independent living resources is time bound, focused exclusively on the support requirements of existing ILF users only, rather than those individuals who may also benefit from this type of fund now, and in the future.
3. The options presented in the paper will either preserve existing inequalities associated with the existing model, or exacerbate these existing inequalities by withdrawing support to existing ILF users.
4. Given the Equality Commission's role, together with the Northern Ireland Human Rights Commission, as part of the Independent Mechanism for Northern Ireland tasked with promoting, protecting and monitoring implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in Northern

Ireland we cannot endorse any of the options outlined in the consultation paper. This is because we believe that the eventual closure of the ILF, without any clear indication of the arrangements to succeed the scheme, will impact adversely on the rights of persons with disabilities under Article 19 of the CRPD ‘Living independently and being included in the community’¹.

5. We note the comments by the Joint Committee for Human Rights that, in their view, welfare reform, changes to eligibility criteria for adult social care and the closure of the Independent Living Fund (ILF) ‘risk interacting in a particularly harmful way for disabled people. Some disabled people risk losing Disability Living Allowance (DLA)...whilst not getting support from the ILF, all of which may force them to return to residential care’.²
6. The Commission, therefore, does not endorse any of the options as outlined in the consultation paper. Specifically, we:
 - do not endorse **option 1, ‘to do nothing’** on the basis that this would allow the Fund to close in June 2015, having very adverse consequences for existing ILF users, as all payments to current users would stop at the above date undermining the equality and human rights of all concerned, such as CRPD Article 19 ‘Living independently and being included in the community’;
 - do not endorse **option 2, the formation of a successor body similar to the ILF**, concerned only with the support needs of existing users as opposed to including others who would qualify for the Fund;

¹ States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

² Joint Committee for Human Rights: ‘Implementation of the Right of Disabled People to Independent Living’, paragraph 161, Twenty Third Report, 6 February 2012.

<http://www.publications.parliament.uk/pa/jt201012/jtselect/jtrights/257/25708.htm>

- do not endorse **option 3, the transfer of funding and responsibility to the Health Trusts**, on the basis that firstly there is no guarantee that existing users will receive the same quality of care and support, following revised health care assessments. Secondly potential users eligible for ILF support now and in the future would likely remain excluded from this type of support, thereby perpetuating an existing inequality between existing ILF users and those would otherwise be eligible for support³;
 - do not endorse **option 4 the transfer of existing funds and responsibility to health care Trusts, with preserved rights for existing users**, on the basis that the inequality between existing users and potential users who are otherwise eligible for the Fund would continue to exist;
 - do not endorse **option 5 the transfer of existing funding to the Health and Social Care Board with preserved rights for existing users to provide a regional centralised service** on the basis that the inequality between existing users and potential users who are otherwise eligible for the Fund would continue to exist.
4. One option the Department may wish to consider is to go beyond the limitations of the current options presented in the consultation paper and extend the ILF to other potential applicants who would meet the current eligibility criteria to receive support from the existing ILF Fund, as and when places become available.
 5. Adopting such an approach would address the existing inequality between existing ILF users and others who would otherwise be eligible to access support from the Fund, as well as further fulfil the State obligations under the CRPD, including in particular the

³Murphy, Eleanor (March 2013): Northern Ireland Assembly Research and Information Service Briefing Paper 'Independent Living Fund' March 2013, highlights that according to Disability Action a pan-disability Northern Ireland wide charity, "Since the ILF closed to new users in 2010 disabled people in Northern Ireland who would have previously been eligible for ILF have been limited by the restricted budgets on offer from the Health and Social Care Trusts and have missed out on opportunities for improving quality of life." See paragraph 4, bullet point page 5, available at: http://www.niassembly.gov.uk/Documents/RalSe/Publications/2013/social_dev/4413.pdf

rights of disabled persons rights set out in **Article 19, ‘Living independently and being included in the community’**.

6. This option is also entirely consistent and in keeping with disability equality legislation in particular sections 49a and 49b of the Disability Discrimination Act 1995, as amended by the Disability Discrimination (NI) Order 2006, specifically the public sector disability equality duty, commonly referred to as the ‘disability duties’.⁴ Any measure which enables disabled people to live more independently at home and to participate in community life in a manner of their choosing is likely to result in a better quality of life for disabled people and effectively realise the duties to ‘promote positive attitudes towards disabled people and encourage their participation in public life.
7. Furthermore, this option would reflect the views and aspirations of ILF users⁵ in Northern Ireland who have expressed their preference for the establishment of a regional ILF model which extends the existing Fund to new users (the approach taken by the Scottish Government).⁶
8. Irrespective of which model is adopted following this consultation exercise, any measures taken should not be retrogressive in nature and undermine the current quality of support received by ILF users. We would urge the Department to make a decision on the future of the ILF at the earliest opportunity, taking full account of user’s views and concerns, in order to reduce their uncertainty about the current situation.

⁴ Equality Commission for Northern Ireland (March 2007): A Guide for Public Authorities - Promoting positive attitudes towards disabled people and encouraging the participation of disabled people in public life. Available at: <http://www.equalityni.org/ECNI/media/ECNI/Publications/Employers%20and%20Service%20Providers/DisabilitydutiesGuideforPAs2007.pdf>

⁵ Centre for Independent Living Northern Ireland (November 2014): There was a consensus among ILF users that Northern Ireland should adopt a regional model for the ILF similar to the approach taken in Scotland. Further information available at: <http://www.cilbelfast.org/content/update-latest-ilf-saga>

⁶ As noted in paragraph 17 page 8 of the consultation paper the Scottish Government intends to create an ILF to safeguard support for existing ILF users while further investing an additional 5.5 million pounds to re-open ILF to new users.

Specific Comments

Rationale for Closure of the Fund

9. The Department may wish to consider that within current budget restraints, resources presently being allocated to the existing ILF model be invested to develop a similar successor model to provide support for existing users as well as allow applications to the Fund as and when places become available, in order to mitigate the risk of exponential escalation of costs.

Mainstreaming Service Provision

10. With respect to the question of mainstreaming the Fund within the overall health and social care budget, the Commission is mindful of the views of service users that their preferred option is an independent regional model to ensure that resources to any future independent living arrangements are not subsumed by the overall health and social care budget, or reduced because of the economic situation referenced in the consultation paper.⁷ The provision of a regional model for the ILF would enable service users and other stakeholders to better assess the management of the budget, providing greater transparency and accountability.

The Views of ILF Users

11. The Northern Ireland Independent Living User Group have identified as a key priority the need to ensure the continued financial support to current ILF users and those eligible but not currently benefiting from the ILF current administrative arrangements.⁸ We are aware that ILF users met with the Northern Ireland Assembly All Party Working Group on 11 November 2014 and expressed a strong preference for a locally administered ILF, similar to that planned for Scotland.⁹ The

⁷ Department of Health Social Services and Public Safety (Consultation on the Future Support of ILF Users in Northern Ireland, paragraph 29, page 12)

⁸ The Independent Living Fund User Group Briefing Paper defines the ILF User Group Northern Ireland as consisting of ILF users, carers, family members and representative groups. The group was established by people who took part in the consultation event in Belfast, August 2012, about the Future of ILF and is user led. The group has met once since the consultation event and has set out their key priority which is: **“To ensure the continued financial support provided for current ILF users and those eligible but not currently benefiting from the Fund.”** Further information available at

<http://www.cilbelfast.org/sites/default/files/NI%20ILF%20User%20Group%20Briefing%20Paper.pdf>

⁹ Centre for Independent Living Northern Ireland: Update on the latest Developments on the Northern Ireland Living Fund, November 2014, available at <http://www.cilbelfast.org/content/update-latest-ilf-saga>

Commission considers that any outcome of this consultation exercise should reflect the views and aspirations of those directly affected by the decision on the medium and long-term future of delivering independent living opportunities for those disabled people with intensive complex support requirements.

UN Convention on the Rights of Persons with Disabilities

12. In considering the future of the ILF and the potential consequence on existing and potential users of the fund, the Department should take into account its commitments under the CRPD. The Convention provides an important human rights framework to guide the Department in the development of any future measures or programmes related to independent living opportunities for disabled people in Northern Ireland.
13. We draw the Department's attention to the preamble to CRPD which recognises the need to promote the rights of all people with disabilities, including those who require more intensive support.¹⁰ Further, article 3, 'General principles', also makes clear the importance of persons with disabilities being given the opportunity to exercise their individual autonomy and independence, including the freedom to make their own choices.¹¹
14. Indeed ILF users have advised that "for many users the ILF represents the difference between being able to choose to live at home, supported by their families or having to go into permanent residential care."¹²
15. Both the preamble to the Convention and article 4(3) 'General obligations'¹³ make clear that disabled people should have the opportunity to be involved in decision making processes about policies and programmes which directly affect them.¹⁴ The preference of ILF users should be considered in this context.
16. It should also be noted that Article 19, 'Living independently and being included in the community', requires the state to 'ensure

¹⁰ The UN Convention on the Rights of Persons with Disabilities, preamble (j)

¹¹ The UN Convention on the Rights of Persons with Disabilities, Article 3 - general principles (a)

¹² Op Cit, Centre for Independent Living November 2014

¹³ Article 4(3) CRPD states that in the development and implementation of legislation, policies and programmes and in other decision making processes concerning issues related to persons with disabilities states parties shall consult with and actively involve persons with disabilities.

¹⁴ CRPD, preamble (o)

that persons with disabilities should have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others in any particular living arrangement'.¹⁵ Further, it requires that persons with disabilities should have access to a range of in-home residential and other community services necessary to support living and inclusion in the community and to prevent isolation and segregation from the community.¹⁶

17. It is apparent that the ILF provides users with flexibility of choice as to how they live their lives and reflects the intent and purpose of the above article. Just as important an independent ILF successor model for both existing users and future users reflects the real choice of disabled people affected by the forthcoming decision on the ILF.¹⁷

Disability Strategy

18. The Department should also bear in mind the commitments made by the Northern Ireland Executive within the Disability Strategy, specifically strategic priority 8, to 'increase the level of choice, control and freedom that people with disabilities have in their daily lives'.¹⁸ The continuation of the ILF in whatever form will address this priority, provided it takes account of existing and potential users.

Resources

19. The CRPD also draws attention to the issue of resources in terms of realising all of the rights set out in the Convention and this includes the right to independent living.

¹⁵ Article 19(a) the right to independent living, CRPD.

¹⁶ Article 19(b) the right to independent living, CRPD.

¹⁷ Mencap (November 2014): All Party Group meets to discuss Independent Living Fund. ILF users met with the Employment and Learning Northern Ireland Assembly Committee and advised those present that "for many users the ILF represents the difference between being able to choose to live at home, supported by their families, or having to go into permanent residential care." The ILF users recommended that the Northern Ireland Executive develop a regional ILF similar to the approach taken in Scotland. Further information available at: <https://www.mencap.org.uk/news/article/all-party-group-meets-discuss-independent-living-fund>

¹⁸ Office of the First and Deputy First Minister (March 2013): *A Strategy to Improve the Lives of Disabled People 2012 – 2015*, penultimate paragraph, page 18. Available at: www.ofmdfmi.gov.uk/disability-strategy-2012-2015-revised-010313.doc

20. Within Article 4.2, 'General obligations', with regard to economic, social and cultural rights, the Convention directs public authorities and state funded agencies to take measures to the maximum of available resources, with a view to achieving progressively the full realisation of these rights, (such as those enumerated in Article 19), without prejudice to those obligations contained in the Convention.
21. This obligation is also articulated within the International Covenant for Economic Social and Cultural Rights (ICESCR) and the United Nations Convention on the Rights of the Child (UNCRC).
22. The UN Committee on Economic, Social and Cultural Rights has stated that:

“Any deliberate retrogressive measures ... would require the most careful consideration and would need to be fully justified by reference to the totality of the rights provided for in the Covenant and in the context of the full use of the maximum available resources”¹⁹.
23. It is likely that the allocation of resources currently made available to the Independent Living Funding will reflect on the perceived level of commitment by the state in general and by the Department in particular to their obligations under the Convention. Further economic restrictions placed on disabled people in areas such as Independent Living restrict meaningful choice as to how disabled people with high complex support requirements live their lives. It is of critical importance that any realignment of independent living resources which directly or indirectly affects disabled people must not lead to any retrogression of disabled person's rights as established in the Convention.

Conclusion

24. The Commission would encourage the Department to give consideration to the long-term future of the ILF in the interests of both existing and potential users who meet the current eligibility criteria of the existing ILF model. In doing so we would strongly

¹⁹ CESCR General Comments No. 3, *The Nature of States Parties' Obligations* (Fifth session, 1990), U.N. Doc. E/1991/23, para 9.

recommend the Department's final decision fully reflect the views of ILF users and be implemented in a timely manner to address the concerns users have about the future of the fund.

25. In making the decisions about the future resourcing of Independent Living options, The Commission urges the Department to take full account of the Convention, in particular the preamble to the Convention, Article 4 'General obligations' and Article 19 the 'Living independently and being included in the community'.

Annex 1: The Equality Commission for Northern Ireland

1. The Equality Commission for Northern Ireland (the Commission) is an independent public body established under the Northern Ireland Act 1998. The Commission is responsible for implementing the legislation on fair employment, sex discrimination and equal pay, race relations, sexual orientation, disability and age.

2. The Commission's remit also includes overseeing the statutory duties on public authorities to promote equality of opportunity and good relations under Section 75 of the Northern Ireland Act 1998 (Section 75) and to promote positive attitudes towards disabled people and encourage participation by disabled people in public life under the Disability Discrimination Act 1995.

3. The Commission's general duties include:

- working towards the elimination of discrimination;
- promoting equality of opportunity and encouraging good practice;
- promoting positive / affirmative action
- promoting good relations between people of different racial groups;
- overseeing the implementation and effectiveness of the statutory duty on relevant public authorities;
- keeping the legislation under review;
- promoting good relations between people of different religious belief and / or political opinion.

The Commission, with the Northern Ireland Human Rights Commission, has been designated under the United Nations Convention on the rights of Persons with Disabilities (UNCRPD) as the independent mechanism tasked with promoting, protecting and monitoring implementation of UNCRPD in Northern Ireland.

Addendum to Equality Commission for Northern Ireland response to the consultation by the DHSSPS on the Future Support of Independent Living Fund (ILF) Users in Northern Ireland

Section 75 and Equality Scheme Commitments

DHSSPS equality considerations to date

Section 4 of the consultation document is entitled '*Human Rights, Equality and Rural Proofing Implications*'. The Commission notes that within this section the Department has committed to carry out an equality impact assessment (EQIA). However the document does not indicate when this EQIA is to be carried out.

The Commission has also been advised by the Department that no screening has been completed because this was a *discussion paper*, inviting comment on possible ways forward and does not seek comments on a policy decision as no policy decision has yet been made.

The Commission also notes that on Page 17 of this section of the consultation document, a variation of the screening questions (referred to as '*equality impact assessment questions*') is set out and consultees are asked to respond.

Commission advice

With regard to the Departments obligations in relation to Section 75 of the Northern Ireland Act (1998) and it's equality scheme commitments, the Commission advises the following:

- This consultation document would appear to fall within the definition of a policy as outlined in the Department's Equality Scheme and therefore should have been screened at the earliest opportunity in the policy development process.

- The Commission is disappointed that the policy development and current consultation would appear to have proceeded to this point, without screening undertaken.
- The Commission is aware that the Department has carried out a range of engagements with stakeholders, such as a stakeholder event and ILF Advisory Group, during 2013. Information and evidence arising from those engagements could have been utilised in a screening assessment of the potential equality impacts of the policy options.
- In the absence of screening by the Department on potential equality impacts, this consultation effectively shifts the onus from the Department to consultees, to identify the equality implications of each option.
- The Commission notes that the Department has committed to undertaking an EQIA of this policy. Although there is this commitment:
 - The Commission notes that the Minister intends to announce the final decision on the way forward in early 2015, utilising the information gathered from this current consultation. It is unclear therefore how the Department can effectively give due regard consideration, using the tool of EQIA, within the proposed timelines;
 - It would have been more effective to consult on an EQIA at the same time as the policy consultation;
 - The potential equality implications, for each policy option (5 options in this policy consultation), should be set out in the EQIA for consultees to consider;
 - Consideration of alternative policies and mitigation should be considered within the EQIA.

The Commission is happy to advise further on the Departments Section 75 responsibilities.

For further advice, please contact:

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