



Consultation on Independent Living Fund in Scotland

This response is submitted by the Independent Living in Scotland project. We gratefully acknowledge the input of our allies, in particular Self-Directed Support Scotland, Glasgow Disability Alliance and Inclusion Scotland.

About the Independent Living in Scotland (ILiS) project

- The Independent Living in Scotland project aims to support disabled people in Scotland to have their voices heard and to build the disabled people's Independent Living Movement (ILM). It is funded by the Scottish Government Equality Unit to make the strategic interventions that will help to make independent living reality for disabled people in Scotland.
- It is hosted by Inclusion Scotland, a consortium of Disabled People's Organisations and steered by disabled people's organisations¹. DPO's are organisations led by and for disabled people. You can find out more about them in the ILiS publication "It's Our World Too", available at www.ilis.co.uk.
- The ILiS project is part of a wider Independent Living Programme. This is a partnership programme which seeks to mainstream the principles and practices of independent living within the general economic and social policy of Scotland. The shared "Vision for Independent Living" (<http://www.scotland.gov.uk/Publications/2013/04/8699>), sets out the Scottish Government, CoSLA, NHS Scotland and the Independent Living Movements shared aspirations for independent living in Scotland.
- For more information about independent living, see Annex.

Background to our response

- ILiS welcomes the opportunity to be consulted on the future of the Independent Living Fund in Scotland. We endorse the fuller response submitted by Self-Directed Support Scotland, which we contributed to.
- Via our host organisation, and partnership working with other Disabled People's Organisations, the ILiS response reflects the lived experience of disabled people and their aspirations and expectations.
- **We support, and would particularly draw the Government's attention to the Joint Statement previously co-produced by ILiS, Disabled People's Organisations and SDSS, which says:**

"The money available from the ILF supports disabled people to participate in society and lead an ordinary life in a way that funding for social care based on other criteria and

¹ The ILiS Executive Advisory Group is formed of the Convenors of SILC; Jim Elder-Woodward OBE, Inclusion Scotland and Scottish Disability Equality Forum.

delivered by LAs does not. Therefore, disabled people and their directly accountable organisations call upon the Scottish Government to:

- Protect existing users – you cannot empower one group of people by disempowering another already disempowered group
- Meet new demand, firstly, from the money that becomes available through attrition from the existing resource, and in the longer term, find new money to address this demand
- Replicate existing ILF policies; eligibility criteria, accountability mechanisms, portability, flexibility and staffing expertise in Scotland
- Administer the funding nationally, through an independent trust.”

ILiS response to consultation

Q1: What aspects of the current ILF worked well and what elements did not work so well:

- 1.1 The ILF provides support for disabled people over and above that support which would otherwise be provided by local authorities. We know that for those disabled people who receive ILF, this can support them to live in their own home and participate in the community. For some, the alternative is being forced to live in residential care, in breach of their human rights.
- 1.2 The ILF echoes the principles of independent living including by being independent and accountable to users, flexible, portable and based on eligibility that supports participation, equality and human rights, not just life and limb provision. We know from involvement work carried out by Self-Directed Support Scotland that disabled people had more favourable experiences with ILF than with local authorities.
- 1.3 We support SDSS’s assertion that the ILF is ‘an efficient, equitable and exemplar social care and support model.’
- 1.4 Recent changes to the ILF have not worked. Closing the fund to new recipients and raising eligibility criteria has an obvious negative impact on newly excluded disabled people.

Q2: Should the money that becomes available after existing ILF recipients no longer need it be used in the same way for others in the future? If so, why? If not, how else might the money is used?

- 2.1 Along with DPOs and their members, ILiS believes that the decision to close the ILF to new recipients was wrong and that it clearly creates more inequality and increases unmet need. This is particularly galling at the time when every household is facing austerity and disabled people are disproportionately affected by UK Welfare Reform and local authority cuts. We believe that, after protecting existing users, any money available (e.g. through attrition/change in circumstances of existing users/increases to the ILF) the fund should be reopened to new recipients on the same basis as it is currently available to current recipients.
- 2.2 ILiS is also aware that those disabled people who receive ILF are concerned that their support has not risen to take account of rising costs for several years. This creates several problems including, for example, that many disabled people have not been able to increase the pay to their Personal Assistants for some years, and may have to cut back on some of the things ILF is meant to support in order to make ends meet.
- 2.3 The money made available after existing ILF recipients no longer need it should be used to make funds available to disabled people, in a way that supports independent living. It should not be diverted away from disabled people or from the purposes of supporting independent living. In addition, new money is required to address current unmet need and inequality.

Q3: If the available resource is simply that which is transferred from the Treasury, how would you like to see it used if it was not to be a continuation of the existing approach?

- 3.1 Alongside DPOs, ILiS believes that the overwhelming priority is to maintain support for existing ILF recipients by continuing with those, funding packages as they currently are. We do not think it is acceptable to consider reducing the support for one disabled person in order to provide support to another.
- 3.2 As for Question 2 above, new money needs to be found. Inequality for all disabled people needs to be addressed urgently, and this will not be achieved by further disempowering some disabled people in an attempt to create equity across a wider group of disabled people. Equity across disabled people is an indefensible goal.

Q4: What innovative ways might there be for increasing the overall amount of money in the pot.

- 4.1 We support Inclusion Scotland's answer to this question, and do not agree with the assertion in the consultation paper that "the ILF is not sustainable in its current form ..." or "...that a 'Scottish ILF' would be equally unsustainable". We agree that this should be a priority which needs to be addressed at political level and that options are fully costed for comparison and to assess sustainability.
- 4.2 We also agree with Inclusion Scotland that this suggestion conflicts with the commitments shared by all the partners in the IL Programme and set out in the 'Shared Vision for Independent Living in Scotland'. (See above, About the ILiS Project).

Q5: With any available resource, where is the most effective area to target resources which can have the biggest impact on an individual's ability to live more independently?

- 5.1 See above answer to Question 3. ILiS, alongside DPOs, believes the first priority should be to support the current funding of existing users and thereafter to open the ILF to potential new recipients.
- 5.2 We believe that the ILF should continue on foundations of equality and independent living with reference to disabled people's own definitions of what this means (see the annex and 'Shared Vision of Independent Living' above).
- 5.3 Whatever solution is finally enacted, it is paramount that the ILF monies are ring-fenced, at the current levels. Without ring-fencing the funds and without retaining the current net value to the user we will fully expect to see the entrenchment of further inequalities for disabled people.

Q6: Once funding has been devolved to the Scottish Government, which option do you think will be most appropriate for Scotland?

- 6.1 ILiS, alongside DPOs, supports Option 4 as set out in the consultation paper. This option indicates the foundation of, a new independent trust in Scotland. We believe this option will offer the best safeguards for existing users whilst potential supporting new from funds made available from attrition or new sources.

- 6.2 One of the strengths of the current system is that it is equitable and portable across Scotland, unfettered by Local Authority boundaries. We agree with others that this option is the only option that can enable this to continue.
- 6.3 We also agree with others assertions that this option is the most likely to reproduce current valuable ILF policies on eligibility, accountability and transparency at the same time as being potentially the most cost effective option.
- 6.4 In particular, a national body will be most capable of involving disabled people in the design, development, delivery and monitoring of the ILF in Scotland. Involvement of disabled people, on an equal partnership basis, should be a foundation of whichever Option is taken forward. ILiS produced guidance on co-production for disabled people and their partners which has been endorsed by the Cabinet Secretary. We recommend 'All together now' as a good starting place for building and sustaining positive partnerships.²
- 6.5 The Local Authority option (1) which locates the funds with 32 Local Authorities, raises several concerns including that, even with ring-fencing for current recipients, local authorities will subsume ILF funds into their existing social care budgets meaning that non-ILF support gets cut and replaced with ILF support with the end result being less support overall. This clearly will have a detrimental effect on choice, control, dignity and freedom and human rights and equality. It is also possible that local authorities would absorb resources released through "attrition" with other social care budgets, rather than being released for potential new recipients. We also agree with others, that this option will further entrench, rather than address, existing post-code lotteries.
- 6.6 ILiS is aware that for many disabled people, their experience of Local Authority social care is not a positive one. Care packages are being cut and charges increased. This brings into question whether disabled people, as applicants, users and partners (see above) can have faith in a system administered by Local Authorities.

Q7: Equality Impact Assessment

- 6.7 ILiS agrees with others that the Scottish Government should take human rights based approach to supporting disabled people. The Independent Living Fund helps to promote equality by support independent living for disabled people.

² <http://www.ilis.co.uk/get-active/publications/co-production-toolkit>

- 6.8 We recognise that the recent closure of the ILF to new potential recipients has increased the difficulties that those people face in participating in society and living an ordinary life. We believe that the ILF needs new sources of funding in Scotland.
- 6.9 We agree with Inclusion Scotland that a Scottish independent and accountable ILF trust body, which involves disabled people as equal partners is best and would help to ensure that the Scottish Government addresses its equality duties and human rights obligations.

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Annex

About independent living

- **Independent Living means** “disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself, or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life.” This is the definition developed by disabled people and adopted by the ILIS project.
- For many disabled people, this practical assistance and support (such as access to the environment, advocacy, personal assistance, income, and equal opportunities for employment), underpinned by the core principles of independent living, freedom, choice, dignity and control is essential for them to exercise their rights and duties of citizenship, via full and equal participation.
- Without it the right support many disabled people cannot enjoy the human rights they are entitled to³ (as set out in the Human Rights Act and the European Convention of Human Rights); live free from discrimination and harassment (as promoted by the Equality Act 2010); nor contribute to a wealthier and fairer, healthier, safer and stronger, smarter and greener Scotland⁴.
- The role independent living plays in promoting and protecting the human rights of disabled people is recognised and underpinned by international human rights and equalities obligations to which the UK and Scotland are party to; including the recognition that all of the rights outlined in the ECHR and Human Rights legislation belong to disabled people, and that these are further strengthened and contextualised by the rights set out in the UNCRPD.
- Independent living promotes an up-to-date understanding of disability and disability equality that can support policy and practise to protect the human rights of disabled people. It achieves this by recognising the essential role of “material support” in ensuring disabled people can “participate in society and lead an ordinary life”.

³ ILiS; “ILiS Response to the JCHR Inquiry into the Implementation of Article 19 of the UNCRPD”, 2011

⁴ ILiS; “Response to the SDS Strategy in Scotland”, 2010