

Consultation response



Response to the Scottish Government consultation on the future use of resources following the UK Government's decision to close the Independent Living Fund

November 2013

LCiL is a user-led charity, working with disabled people to enable them to take control of their lives and live independently in the community. All our services respond to needs identified by disabled people and offer a range of practical and emotional support to promote their equal participation in all aspects of society.

This submission is LCIIL's response, as an organisation, and is different from the other response sent on behalf of a group of disabled people, people with long term conditions and older people who gathered to consider the consultation document. For more information about LCIIL visit our website: www.lothiancil.org.uk

Introduction

As the first Centre for Inclusive Living to have been created in Scotland (1991), LCIIL has a long experience of working with users of the Fund and the ILF itself. We have seen first-hand the significant impact that access to the Fund can achieve for individuals; how efficiently and flexibly it has been managed and, through close and regular contact with ILF assessors, we have been able to work alongside them effectively for the benefit of ILF recipients. **We do not want to lose these great achievements.**

As a user-led organisation we have a thorough understanding of the current high level of anxiety amongst users of ILF and share their disappointment at the former closure of the Fund to new recipients and the recent UK decision to close it. In common with many of our service users, we welcome the Scottish Government's 'intention that current recipients should not have their existing funding taken away unless their personal circumstances change and they become ineligible.' We are also aware that this is an 'intention' rather than a commitment for the reason that the Scottish Government doesn't have 100% control of the process.

We believe, however, that by allowing option 4 (a new partnership or Trust) to happen, the Scottish Government could enable the new agency to secure funding for current users and to use the funds towards enabling disabled people, people with long term conditions and older people, to live more independent lives, as efficiently and effectively as the current set up.

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1. Question 1 – What aspects of the current ILF worked well and what elements did not work so well

From our direct experience of working with the ILF and the regular comments of our service users we are aware of many positive aspects of the Fund:

- Genuinely aimed at Independent Living for disabled people, people with long term conditions and older people. By Independent living we mean all disabled people 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
- National and therefore 'passportable' across the whole country'
- Effectively based on the Social Model of Disability
- Flexible and individual outcomes-focused
- Is conducive to a human rights approach to health and social care
- Not bureaucratic
- Easy to talk to either as individuals or as support organisations
- Effective and good value for money in the way it is managed

Generally the model works extremely well and delivers on what it has been created for.

The setback of this is not so much due to the Fund itself but to the lack of commitment from the UK Government to invest in the human rights and welfare of people who are disabled by many societal barriers. The rise of the threshold followed by the more recent closure of the Fund has been a huge setback for the Fund. We, as a support organisation, witness every day the consequences of this as care/support packages are being reduced and people get the minimal bare support that enables them to survive, but not to live independent lives like other non-disabled individuals.

We also see how carers, including parents of young disabled people, who would have received support under the former arrangement, struggle (and too often fail) day in and day out to maintain family, social and professional relationships, becoming second-tier citizens in our communities. **In effect the closure of the Fund has been a huge setback to the human rights of disabled people and carers.**

We believe that, starting with the future of the ILF, the Scottish Government has a unique opportunity to address this and demonstrate its commitment to disabled people's human rights and demonstrate that they are still committed to Independent Living as stated in the jointly signed document with COSLA

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and the Independent Living Movement representatives 'The vision for Independent Living in Scotland'.

Question 2 – 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 be used?

Based on the Scottish Government's 'intention that current recipients should not have their existing funding taken away unless their personal circumstances change and they become ineligible,' we believe that any attrition funds should remain with disabled people and people with long term conditions, enabling them to live more independent lives and be able to seize opportunities available to non-disabled people. Opportunities which disabled people are all too often denied

Although we know that Independent Living cuts across all areas of lives we take the pragmatic view that attrition funds should remain invested in health and social care/support. This view is based on the recognition that the combination of tremendous changes in this field and of very severe budget cuts in care and in welfare, significantly undermine the potential benefits of the Self Directed Support strategy and the health and social care integration plans.

Question 3 – 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?

As explained earlier in this document, we genuinely believe that, if adequately funded, the ILF is an effective and sustainable model of support towards Independent Living. The issue for our organisation, service users and other disabled people is not that it should be used differently – the way it is used currently works for people and is excellent value for money – but that it should continue to be supported.

It is not for this paper to expand on the following finding, but it has been demonstrated - by many organisations worldwide, including Independent Living in Scotland (ILiS), Inclusion Scotland and others in this country - that supporting disabled people, people with long term conditions and older people to live independent lives, participating in society, including economically and socially as equal citizens is a profitable investment for society.

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If the available resource is simply that which is transferred from the Treasury we would like to see it used towards this aim and expanded.

Question 4 – What innovative ways might there be for increasing the overall amount of money in the pot?

We are aware that powerful stakeholders within health and social care, including budget-holders, approach any move towards increasing the overall amount in the pot in a very narrow-minded way, presenting their arguments selectively.

Merging ILF funds with the wider health and social care budgets or re-distributing it (along with the health and social care budgets) amongst a larger number of disabled people, people with long term conditions and older people will not increase the overall amount of money in the pot. It will just create a combined pot that has to support a greater amount of individuals than the two pots currently support separately.

Redistributing the same amount of money amongst a greater number of disabled people may increase the individual support of some but that will only be at the expense of other disabled people's support and their opportunities to live more independent lives.

We do believe that there are creative ways of increasing funds to support disabled people but they cannot be at the expense of people who have the right to be supported, collectively and individually. With other organisations within the Independent Living Movement, LCiL is committed to work with Scottish Government on this.

Aligning other health and social care budget holders to the effectiveness of the ILF in allocating and managing funds is one of the ways forward. The other way would simply not work.

Question 5 – 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?

Our 22 years' experience in the field, led by disabled people, tell us that access to adequate health and social care/support, although amongst other rights of disabled people, is the key condition to enable any individual to

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access other forms of support to live more independently. This is currently being greatly compromised, both in terms of the number of people being able to access the support (e.g. reducing eligibility criteria) and in terms of the level and quality of support (e.g. impact of various forms of resource allocation systems across the country).

We feel therefore that any resources connected to the current/future ILF Fund must be targeted there; in other words not target areas that should be funded by other budgets, e.g. education, employment. In a society where disabled people had, collectively and individually, enough support to take up their rights this wouldn't be the right approach, but in the current situation, whereby disabled people, people with long term conditions and older people are portrayed as budget burdens, unsustainable costs and barriers to economic growth, this should be the priority.

We share the position with other support organisations that the following principles be used to develop a successor system for the ILF in Scotland:

- Overarching principles of independent living, equality and human rights
- Freedom
- Choice
- Dignity
- Control
- Participation
- Accountability
- Non-discrimination and equality
- Legality
- Stability
- Better outcomes for individuals
- Portability

Most importantly we as a member of SDSS share the view that **Aspects of the 'current' ILF that are important for the future of the funding:**

1. The money remains ring fenced, protected within the Scottish Budget, to provide care and support and at the current level of 97p of every £1 spent reaches the end user.
2. It is delivered on a national eligibility criteria focussed on supporting and delivering independent living¹.

¹ <http://www.ilis.co.uk/independent-living>

3. It is portable and flexible. The national consistency of the application of ILF monies means that is not subject to a postcode lottery and has offered the portability of support that is crucial for disabled people to move around the country for employment, to be near family and so on, without having to re-negotiate their funding.
4. It is provided after a co-produced assessment with the end user and by someone who is not the budget holder; therefore, ensuring decisions to offer funding are based on need not on budget.
5. It is provided after a regular review to ensure individual needs are met appropriately.
6. It is provided as a direct payment. The ILF has shown a pioneering history and wealth of experience in delivering direct payments since the 1990's.
7. This method of support has supported choice, control, freedom and dignity in the lives of disabled people in a way that more traditional care and support has been unable to offer.
8. It is monitored in a way that supports accountability whilst being flexible and non-intrusive

Question 6 – Once funding has been devolved to the Scottish Government, which option do you think will be most appropriate for Scotland?

In line with the overwhelming number of disabled people we support and across the country, we believe that Option 4 is the most appropriate option for Scotland, not least because it is the only option that can deliver on the key aspects mentioned just above.

We see that the voice of disabled people, people with long term conditions, older people and their organisations are united on this. This is based on past and current direct experience of receiving (or not) care and support and of working with other organisations in the field.

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As an organisation operating within the voluntary sector for more than 20 years, we also know that there are a number of opportunities to do this effectively and in co-production for the benefit of disabled people, people with long term conditions and older people.

Question 7 – To assist with our partial Equality Impact Assessment in relation to the future development of a sustainable Fund to support disabled people in Scotland to live independently, please describe any equality issues (in relation to age, disability, sex, sexual orientation, gender re-assignment, race, religion or belief, pregnancy and maternity and marriage and civil partnership) that you feel may arise and suggest ways in which these could be addressed.

The ultimate aim of LCiL is towards building an equal society and we believe that ensuring that the ILF's achievements continue and are strengthened is key to this aim. We therefore welcome that the Scottish Government has duties to promote the equality of disabled people, set out in the Equality Act 2010.

With Self Directed Support Scotland (SDSS) we share the view that for disabled people to have equal opportunities, they should not always be treated the same. Sometimes disabled people need to be treated differently. Some disabled people need extra money to live; just so that they have an income somewhere close to that of their non-disabled peers (as recognized in the benefits system, e.g. enhanced payments for disabled people, on top of Universal Credit). This situation is explained by the Nobel Prize winner in economics, Professor Amartya Sen. He stated 'disabled people have two major economic 'handicaps.' The first is 'income handicap' which results in the majority of disabled people having less money than their non-disabled counterparts. The second is 'conversion handicap.' Here disabled people often need to spend more – or to have more spent on them – to achieve the same 'goods' or outcomes as their non-disabled peers.

This is one of the reasons why we feel that the ILF model should be adapted and strengthened in Scotland, including through Option 4.

This is even more important now that disabled people's human rights are being undermined by regressive UK policies.

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