

The **Self Directed Support Scotland** response to the Scottish Government consultation on the **future use** of resources following the UK Government's decision to close the **Independent Living Fund**

About Self Directed Support Scotland

Self Directed Support Scotland (SDSS) is a national membership organisation which actively promotes Independent Living by supporting, working with, and championing the aims of self-directed support Disabled People's Organisations.

SDSS develops resources, material and training for their member organisations and regularly delivers presentations which show that the social model is at the heart of self-directed support and independent living. SDSS also works with local authorities, voluntary sector organisations, NHS health boards, universities and colleges to influence and guide the implementation of the Social Model within their own policies and programmes.

Tha Taic Fèin-Treòraichte Alba (SDSS) na charthannas a tha a' brosnachadh chiorramach a bhith neo-eisimeileach le taic agus coobrachadh an com-pàirt le buidhnean chiorramach.

Tha sinn ag obair le ciorramaich a' toirt dhaibh cuideachadh gus buidhnean a chruthachadh a bhios fo an stiùir fèin.

Our website: www.sdsscotland.org.uk

Introduction

Self Directed Support Scotland (SDSS) was established in 2003 to promote independent living through self-directed support in Scotland.

Over the last 10 years Scotland has made significant advances towards social care and support that is directed by individuals in a coproduced environment. Securing fairer social care and support for disabled people has always been a priority concern for SDSS and our member organisations.

The closure of the Independent Living Fund (ILF), by the UK Government, posed significant issues for Scotland. In our response to the UK Government's consultation in September 2012, we believed there was no case for reform or closure of the fund. Disabled people tell us, the ILF was the forerunner to self-directed support - directed by individuals, it works better than social care and support from local authorities – and should not be closed.

This response to the Scottish Government consultation: 'Scottish Government consultation on the future use of resources following the UK Government's decision to close the Independent Living Fund' (2013) sets out what we believe is a comprehensive and convincing case for continuing the ILF in Scotland.

This SDSS consultation response was written from the collective views of our member organisations and their service users, who are disabled people. SDSS carried out an extensive consultation exercise with our member organisations. We supported member organisations in their consultation events across Scotland with service users. At these events, the vast majority of disabled people expressed anxiety at the UK Government's decision to close the fund – along with the Welfare Reform Agenda. They said they look to the Scottish Government to continue to support independent living through ILF.

We hope this response proves useful in informing the deliberations of the Scottish Government.



Florence Garabedian
Chair



Jess Wade
Manager

Joint Statement from Disabled People's Organisations:

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 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

SDSS, [Independent Living in Scotland project](#) and [Inclusion Scotland](#) coproduced the above statement as an overall response from the Independent Living Movement in Scotland on the future of ILF in Scotland.

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

Our response:

1. Although our member organisations regret the closure of the fund to new recipients, they believe **all** components of ILF in its current form, work well for service users.

What worked:

2. The fund is run as an independent trust. ILF is **accountable** to its service users **through design**. ILF was the forerunner to self-directed support – assessments and packages were co-produced. Service users stated to member organisations that experiences of ILF were more positive than experiences with local authorities:
 - a. same care manager over a long period
 - b. portability of support package - anywhere
 - c. nationally accountable standards in:
 - i. eligibility criteria
 - ii. standards for staff and;
 - iii. fair and transparent policies and procedures
3. Member organisations believe without major reform of social care and support delivery through local authorities **the advances in independent living** - delivered through ILF - **will be lost**. They also tell us these advances **cannot be replicated by local authority delivery (Option 1)**.
4. We believe the ILF is an efficient, equitable and exemplar social care and support model. DPOs tell us the resource should continue and be opened up with new resources allocated to it in Scotland. They also tell us that this is in contrast to the social care and support provision offered by local authorities.

What has not worked:

5. Raising the eligibility threshold and then closing the ILF to new recipients. This is now being aggravated by the disproportionate impact of the welfare reform agenda and the response to it has had a negative impact on disabled people.

6. In the same way that disabled people are not responsible for this situation they shouldn't be the ones having to address this at the cost of their own support.

ILF recipient:

"Without ILF, my local authority will not support me to work... I work in another Council area. Will I need to leave my work? I can't move because there isn't any accessible housing... how is this progress, I want to work... I want to have a life. Why me?"

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?

Our Response:

7. Member organisations tell us new recipients should be able to get ILF. Evidence from member organisations demonstrates, the decision by the UK Government to close the ILF to new recipients created unmet need. The fund closure has created inequalities for disabled people excluded from applying for ILF support. Local authorities only provide support packages with basic support¹. In addition, DPOs tell us, the UK Government's targeting of disabled people in the welfare reform agenda will create further poverty². However, **the money to fund support for new people and to address the unmet need and resulting inequality, should come from attrition from the existing resource, or from new money.**
8. This new resource should not come from taking money from existing recipients, who should continue to have their funding protected. Therefore, we do not agree fund recipients should be reassessed in order to redistribute the funding equality. Recognising '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 Scottish Government should examine ways of protecting existing funding and to add sources of new money.

¹ <http://www.scope.org.uk/news/other-care-crisis> and <http://www.inclusionscotland.org/documents/FiveAsks.doc>

² <http://www.inclusionscotland.org/news/story.asp?id=4181>

Service User:

“My support package from the local authority is basic. It gets me up in the morning. But doesn’t get me out of the house to see friends... it’s not a life... I think ILF would have supported me to do so much more.”

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?

Our Response:

9. If the transfer of resources between the UK and Scottish Government only allows current resourcing to continue we agree with the Scottish Government that:
- 10. Existing ILF packages in Scotland must remain unchanged and protected.**
11. Our drive is for an equal society; where all of Scotland’s people can enjoy equally the human rights they have and participate, on an equal basis, in our society. ILF supports disabled people to do this. We believe it would be unfair to support disabled people by reducing support to another disabled person, rather than from the whole of society’s resources. **We do not believe you can achieve equality by seeking to support one disempowered group, at the expense of disempowering another.**
12. However, we recognise that simply transferring funds from the Treasury – without putting in additional resources from the Scottish Government – would not address further unmet need and will sustain and create further inequalities for disabled people.
- 13. We therefore call upon the Scottish Government to use the powers available to it to protect the funding for current ILF recipients and to use the opportunity to:**
 - a. Open up new resources to new need, on the basis of the ILF criteria
 - b. Reproduce the ILF model of administration, in Scotland

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

Our Response:

- 14. We believe that the existing ILF resourcing model is efficient – 97p in every £1 goes to the end user³. (See response to Question 6 to further improve this efficiency with Option 4)**
- 15. As DPOs we would be against changing the resourcing structures within the fund. This could empower one group of people, by disempowering another, already disempowered group (see response to question 3).**
- 16. For many disabled people, social care is crucial practical assistance that supports them to participate in society and lead an ordinary life. In this sense, social care is a crucial infrastructure for equality and should be supported and resourced as such.**

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 response:

Protecting existing recipients packages

- 17. Resources – existing ILF monies and any attrition and new funding – should be targeted to support existing (via the current ILF spend) and potential recipients to participate and be equal citizens in society.**
- 18. ILF resources should remain invested in care/support of disabled people, people with long term conditions and older people and continue to complement self-directed support (SDS) aims**
- 19. Although SDS should work towards enabling disabled people to live more independent lives, a combination of different key factors undermines this aim. This includes local authorities being under financial constraint as they are just beginning to understand the concept and implications of Independent Living and their relation to individual outcomes.**

³ <http://www.dwp.gov.uk/ilf/publications/corporate-publications/statistics/>

20. Our members believe the available resource linked to the former ILF should remain within social care aims. This resource should be directed towards supporting people to have equal participation in society, in the way it works for them. This is why developing criteria to shape the use of the fund, outside a social care/support purpose, would be against the individual outcome focused approach promoted within the current SDS agenda. Therefore, we are not comfortable with using these funds to areas (e.g. support towards employment as suggest in consultation doc.) that should be invested in by other budgets.

We suggest the following principles be used to develop a successor system for the ILF resources in Scotland:

21. **Overarching principles of independent living, equality and human rights:** The principles of independent living, equality and human rights should steer what happens – this includes promoting, protecting and supporting the full participation for all disabled people as equal citizens (not just survival), in society.
22. **Freedom:** users of community care are free to live their life in the way that they choose, without barriers to this freedom caused by care and support systems e.g. no flexibility around times/people/tasks etc.
23. **Choice:** users of community care can choose how to live their life, what they do with it and who they involve in it.
24. **Dignity:** everyone is entitled to dignity in their own life and others respect this dignity – from the point of accessing support to the delivery of it.
25. **Control:** people can and should control their own lives, including what they do, who with, and when they do it.
26. **Participation:** disabled people have a right to participate in society and in decisions which affect their human rights.
27. **Accountability:** those responsible for the respect, protection and fulfilment of human rights are accountable to rights holders.
28. **Non-discrimination and equality:** Community care is crucial for the equality and human rights of disabled people. Without it, many disabled

people cannot; live free from discrimination and harassment as the Equality Act 2010 promotes, enjoy the human rights they are entitled to⁴ on an equal basis to others – as set out in the Human Rights Act and the European Convention on the Rights of People with Disabilities.

- 29. Legality:** decision makers must make an explicit link with human rights legal standards in all processes and outcome measurements.
- 30. Stability:** disabled people do not live in fear about losing their support or about the cost of that support. This includes; decisions and practice around funding levels, assessment, eligibility and review processes as well as being able to continue to ‘buy’ a consistently high service – either as ‘good employers’ or to retain a preferred agency/provider.
- 31. Better outcomes for individuals:** rules and processes, including assessments and eligibility criteria, work for the individual and their best interests. The outcomes for disabled people and other users of community care, in terms of better health and well being, should be at the centre of both the legislation and the way that it is implemented.
- 32. Portability:** Disabled people and other users of community care have clear entitlements to it, regardless of where they live. Disabled people, know that they can move freely, for whatever reason, across Scotland and that their support package can come with them.
- 33. 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 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, without having to re-negotiate their funding.
4. It is provided after a co-produced assessment with the end user and

⁴ ILiS; “ILiS Response to the JCHR Inquiry into the Implementation of Article 19 of the UNCRPD”, 2011

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

ILF recipient:

“I don't think you should take money from me to pay for someone else. ILF packages should be based on outcomes.”

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

Our Response:

Efficiency in current ILF system

34. Member organisations tell us and we agree - the existing ILF system is extremely efficient. The model works for the recipients. It is economical for Government^{5 6}. Ninety seven pence in every pound is given to recipients⁷. This efficiency cannot be replicated within a local authority (Option 1). Service users say the existing ILF model should be replicated in Scotland.

⁵ <http://www.dwp.gov.uk/docs/business-plan-201112-image-free.pdf>

⁶ <http://dpac.uk.net/2013/02/defend-independent-living-save-the-independent-living-fund/>

⁷ <http://dpac.uk.net/2013/02/defend-independent-living-save-the-independent-living-fund/>

35. ILF supports disabled people to participate in society to lead an ordinary life in a way that funding for social care based on other criteria and delivered by local authority does not. Therefore, disabled people and their directly accountable organisations call upon the Scottish Government to:

- a. Protect existing users – you cannot empower one group of people by disempowering another already disempowered group
- b. 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
- c. Replicate existing ILF policies; eligibility criteria, accountability mechanisms, portability, flexibility and staffing expertise in Scotland

We believe that the only way to continue the flexibility, portability, continuity and human rights focus, offered by the current system, is to administer the funds using Option 4 (A new Trust). This is in particular contrast to administering the funds via Option 1 (Local Authority).

Local Authority involvement (Option 1 concerns)

- 36.** Member organisations tell us local authority support is minimal and does not cover the support needs offered by ILF. The Scottish Government have stated they intend to ring fence funding for existing recipients. There is no such intention for the self-directed support funding (from local authorities).
- 37.** There is a concern that with Option 1, local authorities will consider ILF funds to be part of their social care budget, and will seek to “align” it with existing resources. This might result in other support currently provided to ILF recipients, for example SDS, being reduced. We call upon the Scottish Government to address this issue.
- 38.** The lack of portability of support packages (between Council areas) prevents disabled people from freedom to live where they choose. They say that eligibility policy and assessments are unfair, unaccountable and varied throughout Scotland. There is no effective independent review of local authority social work decisions⁸, policies or oversight and any effective redress. This is in opposition to the existing good practice

⁸ http://ajtc.justice.gov.uk/docs/decisions_with_no_appeal_web_final.pdf

standards in ILF. With Option 1, and the addition of ILF funding to local authorities, all of this will be lost.

39. We are also concerned that delegating **any** fund management to local authorities (Option 1) would undermine any strategic targeted focus of the resources.
40. The Convention of Scottish Local Authorities (COSLA) believes it will cost local authorities £1 million per annum to administer the ILF resources in Scotland post 2015. We believe this is a gross over estimate of the actually cost of administering the fund.
41. The current ILF is nationally administered; this model ensures 97p in every £1 goes to the recipients. Therefore we believe COSLAs assumption of costs is too high, and would not deliver best use of Scottish Government resources. Given the economic management and increased budgetary constraints of local authorities, we do not believe Option 1 would be a sustainable use of funding, for the benefit of service users.
42. The experience of our member organisations and that of SDSS shows that, to administer a support organisation, working for 3500 individuals (equivalent to the current ILF recipients in Scotland) the total budget would not exceed £650k per annum.
43. We believe Option 4, a new Trust, would require less staff than an existing support organisation in Scotland, therefore the overall cost to the Scottish Government may even be lower than our estimation of £650K on the basis of the support organisation model.
44. We also believe further initial costs can be reduced, if the Scottish Government; secures the use of the existing IT system used by the ILF in England and utilises the experience of DPOs and support organisations.

Welfare reform agenda and unmet need

45. Targeting resources at existing recipients will help in part; to mitigate the effect welfare reform agenda has on disabled people. This will facilitate continued independent living for existing users only. However, the unmet need for potential recipients will continue to grow. This situation is not ideal or fair. The imposed welfare reform agenda by UK Government and accumulative inequalities will need to be addressed by the Scottish Government. That is why we urge Scottish Government to consider how it will address unmet need – without ‘robbing Peter to pay Paul’ and taking funding from people with existing support packages.

46. We believe Option 4 will address unmet need, by targeting the funds where it is needed the most – to support individuals - with independent living.
47. As a result we favour the 4th option **administer the funding nationally, through an independent trust aiming at the same efficient fund management as the ILF.**
48. We believe this is the best use of Scottish Government resources:
- a. Targeting the resources where they are needed most – to fund recipients – independent living
 - b. Trust accountable directly to Scottish Ministers/Government
 - c. Administration of the fund would not exceed £650k per annum
 - d. Further reductions in costs if IT systems are retained and experience of support organisations is utilised
 - e. Offer portability to recipients
 - f. Offer continuity in service provision
 - g. Fair and accountable policies coproduced with DPOs
 - h. Credibility and acceptance of a Trust - through coproduction with disabled people

ILF recipient:

“ILF works for me, they understand me and I know my ILF worker. My ILF package works... I can't say the same about the local authority. They don't know me... I have no idea who my current case manager is...”

49. If a new independent trust was created - SDSS would be prepared to work with others to ensure it has the right governance and structure - to support recipients towards independent living.

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.

Our Response:

50. Our drive for is for an equal society. All of Scotland's citizens should enjoy equally the human rights they have and participate, on an equal basis, in our society. For disabled people, many of them may need

practical assistance and support – to achieve this - for some this includes the ILF. We welcome therefore, that the Scottish Government has duties to promote the equality of disabled people, set out in the Equality Act 2010.

51. It is widely understood for disabled people to have equal opportunity, 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.
52. Taking this approach to the future resources – and indeed social care more widely – will serve to make disabled people more equal to other disabled people. Simply redistributing the ILF resource among existing users and potential new users, to achieve equitable distribution misses this nuance⁹. However, it will not serve to address the inequalities between disabled people and non-disabled people.
53. Member organisations tell us, without the fund and the support it buys; inequality and poverty for disabled people will continue to rise.
54. Our members also tell us and we agree – the Scottish Government should continue the fund as an independent trust and more money should be injected into it. The resource can then be opened to new need/demand. This would mitigate further consequences instigated by the UK Government’s welfare agenda in Scotland.

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⁹ Wiebke Kuklys; "Amartya Sen's Capability Approach: Theoretical Insights and Empirical Applications," Springer, Berlin 2005