

A Consultation on the future use of resources devolved following the UK Government's decision to close the Independent Living Fund (August-November 2013)



RESPONDENT INFORMATION FORM

Please Note this form **must** be returned with your response to ensure that we handle your response appropriately

1. Name/Organisation

Organisation Name

Down's Syndrome Scotland

Title Mr Ms Mrs Miss Dr Please tick as appropriate

Surname

Le Noan

Forename

Rachel

2. Postal Address

158-160 Balgreen Road

Edinburgh

Postcode EH11 3AU

Phone 01313137452

Email

Rachel@dsscotland.org.uk

3. Permissions - I am responding as...

Individual

/

Group/Organisation

Please tick as appropriate

(a) Do you agree to your response being made available to the public (in Scottish Government library and/or on the Scottish Government web site)?

Please tick as appropriate

Yes No

(c) The name and address of your organisation **will be** made available to the public (in the Scottish Government library and/or on the Scottish Government web site).

(b) Where confidentiality is not requested, we will make your responses available to the public on the following basis

Please tick ONE of the following boxes

Are you content for your **response** to be made available?

Please tick as appropriate

Yes **No**

Yes, make my response, name and address all available

or

Yes, make my response available, but not my name and address

or

Yes, make my response and name available, but not my address

(d) We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Please tick as appropriate

Yes

No

CONSULTATION QUESTIONS

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 Local Authorities does not. Therefore, disabled people and their directly accountable organisations call upon the Scottish Government to:

Replicate existing ILF policies - eligibility criteria, accountability mechanisms, portability, flexibility and staffing expertise in Scotland.

Administer the funding nationally, through an independent trust.

Based on the Joint Statement above, Down's Syndrome Scotland would also like to call upon the Scottish Government to:

Protect existing users – Down's Syndrome Scotland would consider IFL to be good practice and this should be expanded rather than removed from those who receive it.

Meet new demand - Money that becomes available through attrition should be guaranteed to go back to the Scottish Government. In the longer term, new money should address the needs of adults with disabilities which will have to be prioritised.

Question 1

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

What has worked well:

The current ILF does significantly help people with disabilities by improving their quality of life and giving them real independence. It also represents a major benefit for current recipients since it allows them to engage socially. Social interactions are essential for all of us and it is crucial that people with Down's syndrome are given real opportunities to build new friendships or interact with people within their community on a regular basis.

Other positive aspects of the ILF are that it relies on independent assessments and that the money is paid directly to the service user (97p in every £1 goes directly to the recipient). As pointed out by the Learning Disability Alliance Scotland (LDAS), recipients are also able to recruit members of their family thanks to this fund. This is important too since families usually know best about how to meet the recipients' specific needs.

The issue of 'portability' is also a crucial factor in the successful implementation of the ILF; service users are not bound to stay in one specific area but can instead move from one local authority to another without losing any support.

Finally it is also worth pointing out the low administrative costs of running the ILF.

Issues of concern:

One should be aware of the different groups of users currently receiving the ILF, with Group 1 for which a contribution from local authorities was not part of the ILF eligibility criteria, and Group 2 who needed a minimum local authority contribution of £200 per week until 2008 (which was increased to £320 in 2008 and then to £340 in 2010) in order to be eligible.

This highlights the issue of an existing two-tier system not only between ILF users and people with the same needs who do not receive ILF (first because of the implementation of higher eligibility criteria, then because of the closure of the ILF to new applicants in 2010), but also within the group of ILF recipients itself.

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?

To our knowledge, there seem to be no guarantee as of yet that money coming from attrition and underspend would be transferred to the Scottish Government. In that case, it seems fair to argue that the transfer of the ILF money to the Scottish Government could only be for a short period of time

and should be used to guarantee that current ILF recipients continue to receive appropriate funding.

On the other hand, if money becomes available through attrition, then Down's Syndrome Scotland would like the Scottish Government to establish a fund similar to the ILF. We do recognise however the existence of a two-tier support system for people with disabilities, including people with Down's syndrome, and the need to address this issue. For this reason we acknowledge the need for cases to be reviewed on an individual basis. For some users, this may result in reductions in their current funding; nonetheless, together with attrition and underspend, money available from some re-assessments could then be used to provide support for new users.

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?

The principles of the ILF work towards the Scottish Government's aim of a healthier, fairer and wealthier Scotland. As a result, we believe that the available resource should be spent to ensure that independent living, accountability, independence from local authorities and portability remain key priorities in arranging support for people with Down's syndrome.

The Keys to Life strategy published last June clearly emphasises the importance of focusing on Independent Living to improve the quality of life for people with learning disabilities. The new policy also recommends that day opportunities are developed that are person-centred, assets-based and values driven for people with learning disabilities. A new Scottish fund could therefore have some of its principles based on the recommendations outlined in *The Keys to Life* and the budget allocated for implementing them.

With regard to payments, the Scottish Government argues that a new fund could not guarantee any award 'for life' as the ILF currently does. In addition, we would suggest that a new fund should not be used for short-term payments which are not in line with the ILF's principles. Importantly, the money available should be used to enhance the individual's social aspect of life, enabling him or her to socialise outside his/her home and take part in various activities/events. Local authorities only provide basic support packages as noted by Self Directed Support Scotland (SDSS), therefore any new resource should be used towards complementing the support provided at local level. As for eligibility, we support LDAS's view that individuals receiving the higher rate of DLA or PIP should remain a priority.

Moreover it has also been argued that a new fund could be used to mitigate the impact of the changes to the benefits system which will badly affect people with learning disabilities. We are however of the view that the issue of the Welfare Reform should be considered separately. Indeed the rights of disabled people to independent living should not be curtailed because of the

need to compensate for the financial impact of another reform. Down's Syndrome Scotland is aware of and share concerns with other disabled peoples' organisations about changes to the benefits system. Mitigating the impact of the reform by using resources meant for independent living needs could only worsen the quality of life of people with Down's syndrome who would then have their benefits reduced and would also be prevented from engaging with their community.

Question 4

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

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?

We believe that support provided to people with Down's syndrome should always be based on a person-centred approach. It is therefore difficult to pinpoint a single area which is likely to have the biggest impact on supporting independent living. Such process can only be carried out on an individual basis.

Nevertheless, Down's Syndrome Scotland understands the need to use the evidence of outcomes to evaluate the relevance of the funding. Thus we are of the view that money made available could be tied to specific agreed outcomes which would then allow for funding to be appropriately monitored and assessed on an individual basis.

Question 6

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

Firstly we would argue that Option 2 would not be reliable since the Scottish Government has indeed little experience in dealing with disability assessments and awarding funding on an individual basis.

Then, **we strongly disagree with Option1**. Although we recognise that £50m might represent a small amount of money to manage, we are of the view that, however small the amount, these monies should not be given to local authorities to manage. According to the consultation document, Option 1 might lead to equality of service provision within a Local Authority area and individuals would benefit from Local Authority expertise in terms of assessment. This might be accurate for some areas but, in our experience, it is unlikely to be the case across all 32 local authorities. Our Family Support Service Officers have seen excellent practice in some local

authorities, but their experience has also shown that significant discrepancies remain regarding services provided to disabled people locally. Moreover portability is a key strength of the ILF and this would not be guaranteed by having local authorities managing a new fund.

Moreover, even though devolving the monies to local authorities might be an easier option, a simple transfer does not mean that this option will benefit people with Down's syndrome and the Scottish Government most. The issue of eligibility criteria and the absence of a reliable and transparent monitoring/accountability process currently constitute serious concerns in the way services are being delivered at local level. Any new system will need to take these issues into consideration and we believe that Option 1 would not fully address these. The principles behind the ILF should remain at the core of the Scottish Government's new sustainable fund and be pursued, albeit in a different format.

Devolving the management of the new fund to local authorities could only deteriorate the current situation faced by many service users of a 'postcode lottery' in terms of access to services locally. Regarding Option 1 we would therefore argue that the listed disadvantages significantly outweigh the potential advantages and it is likely to be the least favourable option for people with Down's syndrome.

The strength of the ILF resides in the fact that the service user is placed at the heart of the funding process from the initial assessment to managing the funds. This allows recipients to live independently and engage with their community as they wish, thus enabling them to fulfil their most basic rights. In order to guarantee the rights of people with Down's syndrome, we therefore believe that Option 3 or Option 4 would be the most appropriate for managing the new fund. We would support the most cost effective option between these two with the view to minimise as much as possible the cost of delivery of services. We also welcome the suggestion in Option 4 that the fund could be administered by a third-sector organisation. In our view, this would more likely constitute a guarantee that the rights and interests of people with Down's syndrome will be effectively respected and protected throughout Scotland due to the predominantly social values driven nature of the third sector.

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.

Down's Syndrome Scotland is the only charity dedicated to specifically working to improve the lives of people with Down's syndrome in the country. We work to help them achieve their full potential by providing information, services and support to them, their families, carers and professionals.

Although the situation of people with Down's syndrome has significantly improved over the past few years, much work still has to be done to ensure they are treated as equally as any other citizen in Scottish society.

Through *The Same As You*, and now *The Keys to Life*, the Scottish Government is committed to improve the quality of life for people with learning disabilities and has recognised the need to enhance their human rights. Access to independent living constitutes one of these rights which ought to be protected and supported by the Scottish Government.

The UN Convention on the Rights of Persons with Disabilities recognises 'the equal right of all persons with disabilities to live in the community, with choices equal to others' and states that state parties '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' (Art.19). In order to become fully included in their community, people with Down's syndrome may require extra financial support to arrange for specific services to be delivered to meet their needs. The principles governing the ILF aim to facilitate this and these principles should therefore remain at the core of the Scottish Government's strategy to establish a new sustainable fund.