

CONSULTATION QUESTIONS

Question 1

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

One of the most beneficial aspects of ILF for recipients and carers alike is that it enables people to stay in their own homes, and be as independent as possible, therefore they did not have to consider some types of care setting. Carers who use ILF to pay for their family member to be cared for agree that they are able to have more control over the choice of setting and that there is a consistency of care.

The fact that ILF funding is guaranteed is a major benefit as people can depend on the same level of funding coming in at a regular time. Being able to use funding to pay organisations such as Encompass (user led support in the Scottish Borders) to help with recruitment, handle payroll, etc, takes much of the pressure off individuals and carers and allows them to carefully select and employ the right people without having to deal with some of the difficult aspects associated with being an employer. It was generally felt that ILF works perfectly well as it is and people are happy with it.

What does not work so well is that the maximum amount of funding offered never increases, despite other cost of living increases. It is felt that more flexibility would be useful. Users and carers would like to be able to pay for things such as respite, day centre charges, equipment, travel costs, specialist clothing and travel costs and staff training where there are medical needs.

“We used ILF funding to help our daughter move into her own supported flat. She can interact with others and make simple choices. This has increased her independence and given us all a better life. ILF helped us to make an informed choice. At one point her life was so bleak, now she has new skills and greater independence” (family carer).

There was a strong sense that it will be crucial to maintain the different criterion and types of assessors as they are experienced and very supportive about ensuring independent living

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?

It is anticipated that, in most cases, ILF recipients will need the money for life to allow them to live independently.

The money should be used in the same way for others in the future, but with more flexibility as outlined in the response to Question 1. People should be able to request more funds when necessary, for example to cover costs if an unpaid carer is ill or in hospital. Help with transport or taxis to travel on every day business, and help with housework, should be covered by the Fund.

It should be available for people who have no care package at all. The criteria should be changed to allow them to be able to apply to the Fund, with consideration being given to their disability, including those with multiple conditions or mental ill health. People should be assessed by GPs who know the condition.

In general, ILF recipients and carers believe that ILF should remain separate and independent from mainstream care and support.

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?

There is no alternative. It should be used in the same way as it works well. It would be fairer if the provision is spread to cover more people.

Any 'freed up' money could be used. Recipients should not have to pay back unspent funds, and should be able to use them in other ways, with more flexibility as described previously, to enable independence and give people more control over their own lives.

Question 4

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

It is up to the Government to find innovative ways to increase the amount of money available, not service users and carers. The Government can always seem to find money for other things when required, such as offering aid in other countries, which users and carers cannot influence. Therefore it can find innovative ways to increase resources for people with disabilities in Scotland. Vulnerable people depend on the Government to look after them. ILF is working so do not change it, but put more money in the pot for more people with disabilities so that they can live independently for life. If possible, existing recipients could take a reduction of a small amount/percentage

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?

Users and carers had no real thoughts on this, other than increased flexibility as outlined previously, and cost of living increases. The priority is enabling people to live independently in their own homes where possible. Funding should be available for people who cannot get care packages. It should not be means tested nor should it have to fit with social work criteria.

Social work eligibility criteria in the Scottish Borders has been reduced – now only individuals assessed as having 'substantial' or 'critical' needs are eligible for any support, or funds, from social work services. ILF always offered an additional element to support people with additional needs with that little bit extra, beyond what SWS could ever offer – to live with independence and dignity.

There is a fear that changes could force people into residential care when they are no longer able to sustain their independence due to lack of funding.

Support should be available to people who would have been eligible for ILF funding before it closed – or those who were unaware of the existence of ILF and therefore did not apply even though they may have been eligible, which was a major inequity of the system.

There will need to be assurances that funding levels will be maintained for as long as needed. People who use ILF to enable them to work might become unemployed, while those who use it to employ carers may no longer be able to pay them – resulting in more people becoming unemployed.

Question 6

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

Option 4. New Partnership and/or Trust

This is the preferred option. There would be more potential to allow users and carers to be involved and make decisions. This is the common sense solution. It is stated in the consultation document that this option places disabled people and/or their representative organisations in charge of managing the Fund and this is seen as a major benefit by users and carers. It would be seen as completely independent from Government and local authority, and those people who were consulted stated that they are often more likely to trust an independent, third sector body.

Option 4 recognises the strength and expertise of the third sector and of the people it seeks to support. Whoever administers ILF should also be able to tell people what other support is available. An information and support service should form part of the new organisation.

The eligibility criteria for ILF is very different from social work's and ILF funding can be used for more than care, which may not continue should Option 1 be selected. If it goes to the local authority, there is a concern that ILF funding would just be added to the social work budget and not used for the purposes it was intended. This could lead to social work tightening their criteria.

ILF funding can be used for different purposes than the types of support provided by the local authority. This may not continue to be the case if the funding is transferred to local authorities. People use ILF funding to pay for housework and social outings, which would not be applicable under social work funding. There could be a danger that ILF funding would be used to complete a care package, and that people will be assessed using the local authority criteria, which is different from ILF. They may not continue to receive their current level of funding, leading to a reduction in care and support.

Not everyone has an assigned social worker, so have no current contact with the local authority and social work is not always aware of their current situation and needs. Social work departments may struggle to cope with the additional work and may not embrace the purpose of ILF, i.e. it enables disabled people to live independently. People may lose the option of employing their own carers and will have to accept the carers provided by the local authority. There is a perception that the local authority would select the cheapest carers rather than seek to ensure quality of care. There is the potential to lose continuity of care.

The administration of ILF funding, however it is done, should be monitored by a group of service users and carers. There should be a co-ordinated approach to ensuring that the voices of users and carers are heard between

now and 2015 and beyond.

It is recognised that the Scottish Government does not have experience in awarding cash payments to individuals directly in such a way, so this option was not felt to be appropriate for this reason and because of the disadvantages which have already been identified in the consultation documentation.

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.

There is a risk that some people with disabilities will be disadvantaged if they are not given the same opportunity to receive funding. This was an issue raised when the Fund was closed to new applicants, with people who could have benefitted from funding, and who met the criteria, being treated differently from those who applied and were successful.

Partners' income is not means tested but their pensions are. This is unfair as pensions replace earned income and should not affect an individual's right to receive ILF funding.