



## National Carer Organisations response to the Scottish Government consultation on the future use of resources devolved following the UK Government's decision to close the Independent Living Fund

The national carer organisations consulting with carers and carers' centres across Scotland to find out their views about the future of the independent living fund once funds are devolved to Scotland.

The majority of respondents (90%) were carers, with 45% caring for someone currently in receipt of funding from the Independent Living Fund. Of these, 40% were Group 1 recipients and 60% Group 2 recipients. Of those carers who were caring for someone who was not in receipt of ILF funding, half would have qualified if the Fund had not been closed to new recipients in 2010.

The following response draws upon these responses and provides a range of their comments on the consultation questions.

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

Carers were very clear about the benefits of the current ILF system and what had worked well for them, the people they care for and, where they did not receive ILF, for other carers and their families.

Carers emphasised the most significant benefit of the ILF was that it gave the ability to choose the most appropriate support and to have control and flexibility over that support. This includes, for a small proportion of Group 1 users<sup>1</sup>, a choice on whether or not they are formally involved with local authority social work departments to arrange this support.

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<sup>1</sup> 216 at 31 March 2012: The Future of the Independent Living Fund, Analysis of the ILF Caseload, DWP (2012)

Carers emphasised that this had improved the quality of the life of the person they cared for and provided security and peace of mind, knowing that the funding was lifelong. They were also positive about the help available from ILF staff and the quality of information and support available.

“It worked extremely well for our daughter. It has given her good quality of life and to us, her parents, peace of mind, that if we needed more help in difficult times we could rearrange the care to put more care into place when needed. It gave us flexibility and we could buy a good and appropriate care for our daughter. We bought care in emergency situations at a short notice from carers we know. Invaluable necessity. In our situation, it all worked well for us. The system is a bit rigid --restricted usage of the funds. Losing ILF would be devastating for our daughter and us as a family. We could no longer care for her at home. Leaving home would be a much more expensive option for her and she would lose her independence. Her quality of life would deteriorate.”

*“Financial support there without too much interference from providers. Payments consistent and on time.”*

“The ability to be able to choose which care provider best suited my brother’s needs worked well; the professionalism of the ILF staff was really important and appreciated.”

*“The help in employing personal assistant is a great help as well as giving a level of independence to the recipient. It is a means of giving some time back to carers.”*

There were few comments about what had worked less well. Those who did mentioned financial criteria, inflexibility in how funding could be used and the provision of information. For example, one carer said that ILF was *“more inclined to be ready to adapt to application of funding to changing care needs but failed on its approach to income based criteria. e.g. partner’s pensions classed as capital therefore suspending the funding because of finance rather than need.”* Another noted that there *“are too many conditions pertaining to how the money can be used”* and *“the fact that some Local Authorities did not tell severely disabled people who could have qualified about it was anything but good.”*

**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?**

Carers made a range of suggestions on this issue without any clear consensus. Many felt that it should be allocated based upon the same criteria as those currently in receipt. However, additional suggestions including bridging gaps in funding, to respond to urgent needs or to be shared at a lower level amongst new users, for example, to up-rate awards in line with inflation.

"Many people my brother included, have had the support they receive from local authority reduced since Personalisation, maybe people affected by LA cuts could apply to ILF for some funding to bridge the gap, from monies no longer required from individuals."

*"I feel it's required to help with care costs that are badly lacking in the care in the community In fact WHAT CARE It's a disgrace families have to pick up the pieces and they end up in debt and struggling to make ends meet. This is a disgrace."*

"Saying yes but cannot see how someone using ILF would no longer need it. Can only look my own situation and the only way my daughter would no longer need it would be if she was no longer here. It is very sad that this Fund has been closed; it allowed disabled people an element of control over their lives. The money from one current user should be shared between several users, albeit giving a lower level of support but still for their choice of care."

*"Yes, more people should benefit from ILF we should also remember, that funds did not increase with inflation and in SOME CASES are the same as 10 years ago. To pay decent wages existing users should also benefit from money which becomes available from people who do not needed anymore."*

"Some individuals might need more funding if their condition deteriorates."

*"Because every day somebody new may find themselves in a situation where they need support either because they've developed a disability through an accident or from serving in armed services. Some people may have partners or other family who help to care them then for some reason find they no longer have that support if their carer dies suddenly."*

"The ILF fund should always be targeted at people with the greatest disability and need in our society. I think the criteria could be expanded to all adults but the aim should remain the same."

### **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?**

Again, responses from carers were mixed with no clear consensus apart from ensuring that those who currently received support continued to do so. Additional suggestions including offering some support to those who would have qualified for ILF funding if the Fund had not been closed, carer support and to provide extra support to current or new recipients which could exceed what current local authority criteria offers.

*“As sadly the ILF has been closed to new entrants, then perhaps it should be reduced to current recipients and the money saved spent on those presently excluded.”*

*“New needs based criteria that exceed LA eligibility criteria.” “To ensure that people’s urgent daily needs are recognised and, to a degree, met”*

*“A fund created to enable applications to be assessed on their needs for extra support.”*

*“It needs to go the families of the adults especially the carers” “Must be secured for caring and carers support.”*

*“To capitalise another Fund using a similar model as ILF and continue to support those currently in receipt of ILF.”*

*“Allocated in such a way that existing and new service users benefit from payments to help continue or improve their way of life”*

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

Carers made few suggestions about how the pot could be increased. They did however suggest that support to carers could increase independence and/or enable carers to continue caring.

*“...allowing family carers to choose which respite suits them, not earmarking respite money for set models of respite, thus giving them a degree of choice and enabling them to continue caring.”*

However, the majority of respondents were adamant on one issue, that funding should not be administered via local authorities

*“Do not give funding via Local Councils as they have very high administration costs and therefore extract vital funding from the point of most need”*

*“Sorry but the only innovative idea I can think of is under no circumstances should this funding be given to local authorities to have discretion over funding. Drawbacks would be admin costs would spiral and those most in need would not necessarily receive what they needed to enjoy independence.”*

*“Please don't put funds into the hands of local authorities; many carers are worried about it being absorbed into council funds and not being used to support those who need it to live independently.”*

“People like flexibility and choice. They want to be independent as much as possible. Give people the funds they need and they will spend it in a way they choose to live a life like everybody else. Local Authority contribution towards an independent life via direct payments is not enough. It’s a bare minimum for having maybe 1.5 days of activities/week. Keep the ILF funds separate from Local Authorities, because none of the ILF users will see any of it again after 2015. It will be diluted in other things. As the money becomes available from people who do not need any more, it should be given to people who would be eligible under ILF criteria and those who applied for funds, but did not get it since ILF closed for new applicants in 2010.”

*“Make sure the funding doesn’t go to local council because I’ve been told it won’t be ring-fenced for care it could be used for other services”*

**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?**

Carers were clear that ILF actively enable people to live more independent lives. Respondents suggested a range of approaches, dependent on the complexity of needs of individuals, which may support independent living including work placements, assistance in home and the ability to employ personal assistants. Most respondents emphasised the ability to reduce isolation and enable disabled people to be part of their own communities and enjoy hobbies, activities and time with their peers. Flexibility is extremely important.

*“Use the funds to support persons to live to full potential. Help fund attendance at resource centres, work placements, social activities.”*

“Due to ILF my 42 year old brother can live independently of me for part of the week, allowing him to spend time with support workers who are male and a similar age to him doing activities that he enjoys doing as "one of the guys". This is really important for his emotional and social wellbeing.”

*“There are two quite separate groups. 1. Those people who with help can live their lives with a level of independence. Their independence can be facilitated by such means as having a personal assistant. 2. Those people who are not able to live independently in any area of their lives whose very existence depends on others, particularly their carers. A fund like ILF can help those folk to have some life without the direct input from their carers or from the local authority provision. It should be used to promote social inclusion, be it work or other activities suited to the individual.”*

“My daughter gets funding to have a day out with support and to attend clubs with support.”

*“Best when added to LA funding to enhance integration into the community and promote independent living without agency supervision”*

*“Flexibility in employing carers of our choice, who have similar interests to the person they caring for. Flexibility in emergency situations, flexibility when and what the cared person wants to do. My daughter can live at home with parents who are organising the care. We get breaks when it is suitable to us, we can plan ahead and we decide who is helping us. As we (parents) are growing older we shall need more care for our daughter and flexibility and ILF funds are very important. It has worked well and gave our daughter a good quality of life. Only additional help from ILF allowed us to have some kind of life ourselves (as parents). In short--we have organised and provided a good quality of life with ILF funds which our daughter deserves. Without ILF our daughter would sit at home most of the week days/weekends doing nothing. Boredom makes her sleep and there is a considerable increase in epileptic seizures. Being occupied and having life outside her home is essential in her wellbeing. Without ILF it will not be possible. At the moment our daughter has independent programme and trough-out the week and enjoys life of her choice with her chosen carers. We are able to employ many carers who are an invaluable help to us as a family and particularly to our daughter.”*

*“My husband gets out with an agency carer who helps him go fishing, hydrotherapy and the cinema. My husband uses half of his DLA care money to contribute otherwise he would be like a prisoner in his own house.”*

*“Funding for people to give home-care support because a lot of disabled people cannot manage the same things to the same level able bodied can.”*

*“I have no example But the current system is not working for my son I feel more community's in community's are required or family's be given the money to build or buy a home to help look after their disabled adult child My son isolated in the community”*

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

Respondents were very clear that they believed that allocating monies to local authorities was not the way forward. The majority of respondents (95%) felt that Option 1 was the least attractive and this reflects their responses to all questions, focusing on the ability to have the maximum amount of choice, control and flexibility over the support that can be arranged through ILF funding. Moreover, this may be a clear reflection of many of the issues they face in accessing the support the person they care for needs through local authorities.

**Option 4** was the preferred option for more than half (56%), with 22% favouring Option 2 and 17% Option 3.

**Question 7: 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.**

None of the respondents noted examples around equality around the current proposals, but mentioned issues around access to support and services for people with specific disabilities, for example, mental ill health and mobility issues. It was, however, noted that there is currently inequality between those who receive ILF funding and those who do not.

“Personally I feel that closing the fund to new entrants whilst maintaining the same level of funding to existing users is discrimination against the more recently disabled people.”

Respondents did however highlight the need for decisions to be person centred and consistent and based upon ensuring that disabled people and carers have choice and control over the support they receive.

“That is one of the reasons that I think criteria should be looked at again. I think ILF has to be targeted at those with high dependency needs but should be more accessible to all people across communities. People may need support to access such a fund so that should be built into the new structure.”

*“By giving everyone the opportunity to access everyday activities. When they want and with whom they want is really important. Just because you have a disability doesn't mean life stops at 5pm on a Friday and begins again at 9am on a Monday, Freedom of choice is essential, and I believe the right of everyone.”*

Finally, respondents noted the real problems they face at the moment in accessing services and support and their belief that service reductions are *“creating an environment of social isolation.”*

## **Conclusion**

Throughout our consultation with carers, the national carer organisations have consistently heard welcome of the Scottish Government’s commitment to protect those who are currently receiving funding via the Independent Living Fund. The national carer organisations welcome this commitment.

Furthermore, we endorse carers' views that funding should not be disseminated to local authorities as, without ring fencing and with the current budgetary pressures faced by local authorities, there remains a very real risk that the support upon which disabled people and their families have come to rely upon could be diluted.

We know anecdotally that families have been asked to plan and review support in case of their ILF funding coming to an end, but have found this difficult as it is dependent on the unknown and local authorities have been reluctant to plan in this way. We believe, therefore, it is important to decide a way forward for this funding as soon as possible to end uncertainty for people receiving ILF and their carers.

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Coalition of Carers in Scotland  
Crossroads Caring Scotland  
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Shared Care Scotland  
Scottish Young Carers Services Alliance