

What follows is the collated output from a face to face consultation event where LCiL and Inclusion Scotland staff elicited feedback on the future of the Independent Living Fund in Scotland from 15 disabled people and people with long term conditions, and one carer through small group discussions.

It is important to note that while people welcomed Scottish Government's intention to continue to fund those currently in receipt of ILF there was considerable discomfort, particularly among those who do receive ILF at the moment, about the unfairness of some people continuing to be eligible (because they were lucky enough to have been informed that the fund existed and then applied before it closed), and others being ineligible (because they did not know in time or had become disabled after the fund closed):

'it's an impossible question to ask and answer. Those who receive it can't envisage receiving less. But if we are to live in an equal society, should we have to lose some to give funding to others?'

'It's unfair as it is administered now. There are some who have ILF and there are some who don't. And it's not to do with need, but to do with timing. But at the same time, I'm not prepared to give up any part of my award.'

'The distribution of the fund is currently unfair as a lot of people did not know it existed until it was already gone. I was eligible for ILF, but was never made aware of it by my social worker.'

'People should not be asked to prioritise the money. It should be there for those who need it. Asking people who need money to live independently to decide amongst themselves how it should be distributed when this would lead to a shortfall somewhere for some people is an unfair thing to ask.'

'I'd love to see other people having it but I don't want to lose it'

'We feel we have to be selfish and say we want to stay the same'

CONSULTATION QUESTIONS

Question 1

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

Because of the discomfort mentioned above we did not specifically ask this question since people both in receipt and not in receipt of ILF were present at the event. We had made it clear that people would not be asked to disclose whether they received this funding or not.

However, some people were willing to talk about their experience and the two common themes were:

1. How much people appreciated seeing the same assessor over the years – this meant that the assessor understood their context and life situation, they were not asked to repeat their story over and over and were able to build a relationship with the person. This was contrasted with experiences with local authority social care assessment where there is often no consistency of workers.
2. That ILF assessment and review looked at what people wanted to do to lead an ordinary independent life, and was focussed on how that could be made possible. Again, this was contrasted with social care assessments and reviews which were often felt to be focussed on cutting costs wherever possible.

'ILF assessment was always a helpful and non-judgemental review'

People also talked about what ILF, as additional funding over and above a social care package, enabled them to do. Again there were two themes:

1. It provides overnight support, enabling people to stay in their own home rather than having to go into residential care:
'People do not get enough support through their direct payments. For example, sleepovers are not funded anymore and this should be a human rights issue. ILF has had to be used as a top up to this on many occasions.'

'quite frankly, I would die. I'm ventilated 24/7. I need the support. Although, I shouldn't really have to receive ILF. The LA or health should fund this type of care. To be less dramatic, I would have to go into residential care if I didn't have ILF.'

2. It provides the extra money that people need to live an ordinary life – money for social activity and for people to remain or become involved in their local community, which ‘critical and substantial’ social care provision from local authorities does not:

‘if I didn’t have my ILF I would be stuck in the house. I go to galleries, exhibitions, eat when I want’.

‘my life is meaningful because of ILF. I can have a normal relationship with my partner – go out for dinner at night and I don’t have to rush home to be put to bed at 9pm.’

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?

The majority of people felt that it should be used in the same way as now, for the reasons given in the response to question 1 above.

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?

People were keen to see ILF continue as now – it should continue to be a national fund, with one set of eligibility criteria and one administration system, as this prevents a ‘postcode lottery’ and makes moving from one local authority area to another easier.

Question 4

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

People made it very clear that any increase of money in the pot should not come from disabled people themselves.

They also want a more holistic approach to looking at disabled people’s lives and how support to live independently is perceived and funded. They felt that this would make it easier for more funds to be made available:

‘Employing people as support workers means that people have jobs and make a contribution to the economy. This should be seen as

having a positive impact on society. The service users can therefore be seen to be trainers and provide jobs rather than being a drain on the economy as they are sometimes seen as in the media and in the community. There needs to be a shift in society's perception as a whole i.e. it is a good thing when a disabled person can leave their house and go to work, they are giving back to society and the economy and so is their PA, they are not a drain on resources as some people perceive.'

'We need to present a different picture to the public, a positive picture to counteract the rubbish coming from ATOS, the government, etc. The outcomes of what ILF brings to people should be broadcast more. It is necessary to let people understand the role of social care better.'

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?

Again, people wanted to see funding targeted as it is at the moment – able to be used in a personalised way to support people to live independently by allowing them to buy the support they need for their own very individual circumstances. This is very highly valued about the way that ILF has been administered until now.

Question 6

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

There was unanimous agreement that the devolved fund should not be administered by local authorities.

There was considerable mistrust of local authorities and a fear that the money would become 'lost' in the overall local authority budget. People expressed particularly strong feelings on this point.

There was near unanimous agreement that the devolved fund should be administered by an independent body from within the voluntary sector and that the funding should be ring fenced so that it could not be combined (and therefore diluted or lost) within other budgets.

'it's essential that it's an organisation with disabled people on board'

'There should be a new independent body based on England's national ILF, and it should be ring fenced. It needs to be an organisation or trust made of all the different disabilities and all walks of life. It needs to continue assessing every two years. The new trust would employ ILF assessors.'

People also felt it important that the body should be an organisation with the right philosophy of independent living;
'whichever the option, we know it needs to start form the basis of 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.

Throughout the consultation event people talked about support as a right (see responses to earlier questions for quotes), and the whole system of supporting (and not supporting) disabled people to live ordinary, independent lives as a human rights issue.

They were clear that both the current situation (ie the ILF being closed to new applications) and the proposed new system where new applications could only be made as current recipients no longer require the funding are unfair:

'If we say that keeping ILF as it is does not discriminate against disabled people it is not quite true. All those not currently not getting the support to live independently are in a way discriminated against. But at the same time saying this is like shooting ourselves in the foot.'