

# **Dundee Carers Centre Direct Payments Support Service ILF Consultation Report**

## **Consultation Event - 24 October 2013 at Central Baptist Church, Dundee**

Following a successful bid to the Scottish Government for funding to host a consultation event, we invited people living in Dundee and Angus who use our Direct Payments Support Service to come along and take this opportunity to have their say in the future of ILF in Scotland. We also asked both Dundee City Council and Angus Council to send out the same invitations to their Service Users who had ILF funding and they agreed. All the invitations included a paper copy of the Scottish Government's easy read version of the ILF consultation paper along with a link to the full consultation paper.

A total of 45 people attended the event, of which 29 were service users and unpaid carers. In the limited amount of time available we chose what we believed to be the most pertinent questions from the Scottish Government's ILF consultation paper (following advice from Scottish Government). Each is addressed in turn within this report.

People were divided into 3 groups to deliberate the questions with a facilitator and note taker at each table.

Facilitators were;

Jack Blaik, Former ILF Contact Officer with Edinburgh City Council

James Blair, SDSS Policy (Personalisation & SDS) Co-Ordinator

Vanessa Dallas-Ross, Direct Payments Co-ordinator, Dundee Carers Centre

Chris Raftery, ILF Policy Manager, Scottish Government, set the scene for the day and was Key Note Listener throughout the sessions. He also summarised at the end of the day.

Tim Mineard, Deputy Manager of Dundee Carers Centre chaired the event.

The following is an account of people's responses to the questions put to the groups. We did not record the views or opinions of professionals present, only those of the service users and unpaid carers, all of whom had the opportunity to express their views to each question. Each bullet point represents a quotation from individuals. The exception to this is the bullet points in question 6 where note takers summarised the views and opinions of the

groups.

### **Question 1**

#### **What parts of the current Independent Living Fund worked well and what parts did not work well?**

We asked people to complete and return this question before the Consultation Day. It was sent out with the invitation on the reverse of the booking form and a freepost envelope was provided.

#### **What worked well:-**

- Being able to have a one to one care worker for social outings. Also to have same within my shared house.
- Being able to use money to have hours that suits my son's needs.
- It has been great for our son to gain independence as a result of receiving the money in order to pay care workers to take him out and about.
- ILF has worked very well. It allows me to fund care workers so that I could stay in my own home while my children were still at school.
- When properly set up with adequate funding and monies used properly, the current scheme has worked well.
- Allowing self choice in planning. Having social time out with my home of my own choice.
- It helps me to get the support that I need to go to different activities that I enjoy.
- Allowing the disabled person the independence to plan their own life and have the funds to hire their own personal assistants ensuring they have the care and support they need.
- Yes, it worked well.
- ILF money is good as it allows users the freedom to choose what they want to do, be more independent
- Enabled my daughter to become increasingly independent from parents and gain life skills to enable her to now look at living in her own home.
- A caring understanding (Personal Assistant) with good timekeeping and manners.
- One to one care. Tailored to need and individual requirement. The certain knowledge that a well-matched Personal Assistant was working with me to achieve comfort, safety and health needs at all times.
- All of it!

#### **What parts did not work so well:-**

- All of it seemed okay to us
- Cannot think of any
- Have no complaints about ILF
- Due to hourly rates imposed by service care providers and because the ILF fund was frozen, hours available were reduced. At the same time,

personal contributions were increased.

- When my condition deteriorated, ILF was swallowed up as additional personal care and support was not provided by Social Work Department. When care workers were needed for outings or clinic appointments ILF again was used.
- Finding ourselves at this time of change and uncertainty for the future come 2015.
- Paperwork involved.
- Dealing with employment issues with Personal Assistants.
- Alignment of payments from ILF to ourselves and bills from care workers.

**Summary –** A majority of respondents commented on how well the fund has worked for them. Indeed, a few commented that they could not think of any part of the fund that has not worked well.

## Question 2

### **When people no longer receive ILF, how should the money then be spent? Should it be spent in the same way?**

- People who are new to be assessed should be offered the money
- People currently receiving ILF should be protected and funds currently receiving not amended
- Any money left over should be put back in the ILF pot
- If hourly rates go up by certain providers, existing clients should be able to receive extra to compensate this
- Money to go back in the pot (ILF)
- Should be offered to next person on the waiting list
- Current users' money reduced so others can benefit
- Users currently receiving should be protected
- Fund to be topped up to pay everyone
- Some money is better than nothing would rather see everyone getting something, as it has made such a huge difference to son
- A short term solution would not be good as would be more difficult to administer and be more complicated
- People can adjust to having less
- If someone doesn't require the money anymore it should be put back in the pot and used for new applicants – not for any other government fund
- Majority want to keep the system as it is
- Leave it the same way it is being spent now
- Any money left over should be put back in for new applicants
- Next person in the ILF applicants queue should get it
- Protect what current users are receiving

- Short term would not be good, a disability is long term so should ILF. A one off grant should be issued for short term needs if needed
- Someone from the government should spend a day with ILF users to experience what it is like

**Summary** – It was agreed that this was a “very difficult” question to ask of people. There was a clear split with some people feeling strongly that current ILF recipients’ funding should be protected and remain the same while others felt that it could be distributed more widely. Generally, people stated that as the money becomes available, it should be put back into the “ILF pot” for others to pursue.

### Question 3

#### If ILF is not going to continue, how would you like to see the money used?

- Concerned that the funding would get swallowed up if the LA gets it and it may end up being spent on other things.
- We like the freedom with ILF and would like more flexibility.
- If the LA gets the funding, I wouldn't be happy as they have different criteria to meet. This doesn't treat people as human beings and people shouldn't be treated like a product in a factory.
- Like having an independent assessor for ILF, she was helpful and reassuring and didn't feel that the budget was the main focus, unlike having a Direct Payment or LA input, where budget **was** the main focus.
- We have never had to complain about ILF, however anything to do with LA, we have always had to complain.
- If current users are not going to get it, it will not affect us.
- Would like it to stay the same – if it's not broke don't fix it.
- It should be based on individual's needs. Some people only have basic needs met by LA as their care packages are too large. It costs too much to meet social outcomes. Other service users may have a small amount of practical needs therefore social outcomes can be met.
- I don't want money to go to LA!
- We as unpaid carers are saving the government billions. We shouldn't have to make these harsh choices.
- Forms are too difficult and you have to be a forthright intelligent person in order to get what you need.
- Changes in ILF may result in mental health problems for both the supported person and unpaid carer, who already have a lot of pressure on them.
- Is this a question for us? This is a Government priority and it is an unfair question to ask us.

- It's transformed our lives and we want that for others.
- The money shouldn't go back into the big Government pot.
- There is too much of a margin between what the service providers get and the wages they pay their workers. A national cap on what agencies could charge would help. The agencies put the prices up so now we have to contribute more ourselves.
- It's been so beneficial for us, we cannot answer the question.

**Summary –** Some people here had concerns about the money going to LAs. The general feeling was that it works well and should therefore remain the same but in Scotland. An interesting comment was made about the benefits of an independent ILF assessor.

#### **Question 4**

#### **Can you think of any innovative ways to help increase the money that there is to give disabled people support?**

- Look after carers which would help reduce the amount used on NHS
- NHS/Social Care partnership coming up, bringing these 2 together will save money
- Increase taxes – Council Tax and/or Income Tax. Scottish Government has the power to vary income tax by 3%. This would need public support, but people would need to consider the benefits. Society should contribute when they are well so people can benefit when they are not so well.
- Speak to big businesses, banks
- Take all the ILF money and stick it on the lottery!
- Share of some of the big pensions
- Local Authorities could cut the rate they pay providers but this may reduce the quality of care provided.
- Create a new lottery specifically to supplement Social Care or get funding from the existing lottery
- Make existing services as good as they can be, although this may cost service user more.
- Pooled resources may be a good idea, but do not agree with volunteer Personal Assistants.
- Encourage the uptake of Direct Payments, although this option can be challenging for some individuals. There are Direct Payments Support Services that can help.

**Summary -** A variety of responses here. The specifics being; increase taxes, involve big businesses and lottery funding.

## **Question 5**

**How can we use the resources available to help people live more independent lives? What is the most important thing that we need to do to help people live more independent lives?**

- We like using it as it is at the moment as it is targeted to individuals
- It tops up LA input as there is not enough to cover what is needed
- LA promote ILF but don't know much about it
- ILF filled the gaps
- ILF keep LA funders in line with independent criteria
- Would like independent funding streams maintained
- Should be targeted to individuals depending on their outcomes and needs assessments for social needs, respite, support in the workplace or at college
- Should be outcome based
- Should be agreed with an independent assessor
- Need to keep the funding independent from LA contribution as combination of funding streams important as LA can only provide minimum amount of funding
- Like things to stay the same
- Unpaid Carers have their own health problems, are ageing and cannot continue to provide the same level of support as before. They need increasing funding to take the pressure off themselves, protect their health and well being and that of other family members.

What areas are important?

- Depends on the individual -  
socialising, swimming, cinema
- Being able to do social activities independently from parents
- Socialising with peers
- Individual support
- Support at home, assisting with all needs, personal care, respite for unpaid carers
- Independence and social life most important
- LA would need to take responsibility for whole care package, socialising is low need in SW terms and LA budget may not be able to meet social needs
- Worried that they may end up in residential care without the same level of funding and ILF support.
- ILF should be managed differently with less restrictions and flexibility to meet social and inspirational needs and taking into account the quality of life of the unpaid carer as well as the service user.

- Need for support for unpaid carers to enable them to cope with their caring role. Preventative funding which may reduce the need for increased funding in the future.
- Respite
- Ability to use family members as Personal Assistants is an advantage, especially for sleepovers, so you can have peace of mind and sleep better. Family members have to give up work to be employed so should be able to get paid for this.
- Having choice about what you do and being independent.
- Enablement following a hospital stay, but this should be dependent on criteria and assessment.
- Important that it's not taken away from existing service users, as people will have less opportunity to do the things they want to. A reduction would be better than losing it completely.
- Some people struggled before they received ILF funding and do not want to be in that position again.
- Support to go on holiday as well as support in and out of the home.
- Priorities of any new fund should stay the same as existing ILF.

**Summary –** A general feeling that the status quo is good. People were of the opinion that outcome based assessments are important to them. Other important factors include; living at home, social life, respite, support to go on holiday, ability to employ family members and being able to make choices.

## Question 6

**When Scottish Government are given funding, what model do you think will be best for Scotland?**

### Group1

#### Option 1 - Local Authority

- No one likes this option, in case money got divided into something else.
- Only advantage to this is that double working would stop
- With same place dealing with a lot of benefits for 1 user might look like too much

#### Option 2 - Scottish Government

- Don't think they will want to do this
- Don't think they have the experience
- They are not used to giving people money

#### Option 3 - An existing agency

- No one liked this option

Option 4 - A new partnership or trust

- Fit in well with other services
- User led, carers, disabled people

A fifth option was mentioned – A new Local Body

From the 9 service users and unpaid carers in this group, all nine people choose option 4

## **Group 2**

Option 1 - Local Authority

- All agreed they did not want LA
- All agreed that it would reduce double work – one worker/one process

Option 2 - Scottish Government

- Is something to consider, but would this be efficient?

Option 3 - An existing agency

- no interest about this option

Option 4 - A New Partnership or Trust

- definite preference for all in group
- felt it was difficult to comment as there were no hard facts to consult on
- concerns about getting the money/ keeping the money and worried that it's not frittered away by those who will manage it.

From the 11 service users and unpaid carers in this group, two want it to continue in the same manner and nine chose Option 4.

## **Group 3**

Option 1 - Local Authority

- Concerns money may filter into other things and criteria could be changed
- LA Care Managers know their Service Users best, have good relationship with Care Manager and happy with assessment process
- May be an option if Scottish Government set a framework for LA to manage ILF funding.
- Service users are not involved enough in LA decision making

Option 2 Scottish Government

- It could be fairer if distributed on a national rather than local level

Option 3- An existing agency

- No one knew of any suitable organisations who could take this on

Option 4 - A new partnership or trust

- need to involve people with expertise
- disability movement in Scotland
- involve and include disabled people

From the 8 service users and unpaid carers in this group, two chose Option 1, one chose Option 2 and five chose Option 4.

**Summary** - The vast majority of people voted for Option 4 – A New Partnership or Trust to manage the Independent Living Fund in Scotland.

Option 1 received 2 votes

Option 2 received 1 vote

Option 3 received 0 votes

Option 4 received 23 votes

(note – some participants had left the consultation event at this stage)