

Co-Production Event Discussion Summary

Aberdeen, 17 January 2024

First Group Discussion

Minimum Qualifying Amount (Threshold Sum)

The **Threshold Sum** means the amount of money that a disabled person must get from their local council to get Independent Living Fund money too.

Discussion Responses

- This should not be about a fixed amount, it should be about the support a person needs, how complex their needs are, and the amount of family support they have. All of these things have an impact.
- £600 is high. It would be better to have a lower limit and for more people to get access to ILF or start with a lower limit and then increase it if they need to.
- It has to be fair and accessible to the largest number of people.
- We are worried about using this limit to decide who has the most unmet needs. ILF should be looking to support the people who have the most needs and face the biggest barriers. Other organisations can help and tell them about people who have the most unmet needs like:

Centres for Inclusive Living, Alliance, Self Directed Support Scotland and National Involvement Network (NIN).

- If we set the limit in one place some will be disappointed. If we set it too low there may not be the money to fund enough people.
- Need to think about people who already have ILF. It needs to be fair and have the same rules for everyone.
- It could be worked out in relation to how much people get from Social Work for example £888 is the COSLA benchmark (very few exceptions to that for people who are living in the community). 75% of that would be £570.72 that's better than picking a nominal fee. This could be changed each year if needed.

Maximum Award

The **Maximum Award** is the biggest amount of money the Independent Living Fund can give to someone each week.

Discussion Responses

- Not sure this should be a fixed amount for everyone, because everyone has different support needs.
- There are lots of things to think about. People in rural areas might need more money because they don't have as much choice of things to do in the community. It costs more for support staff and they have to travel further to get to places where there are things to do.

- Food and energy and support staff all cost more so the Maximum Award should be more as well.
- It should be about matching people's needs and making sure the fund can help as many disabled people as possible.
- £475 is enough and the Local Authority has to remain the main funder.
- Some will need care more including overnight. These people should get more from the fund.
- Living in rural communities everything cost more and there are other limits to what people can do because of the weather. It is important to think about giving people in these areas more to cover the extra cost.
- Too much money from the budget is spent on travelling for people in remote areas. They should be able to get more money to help with this.

Age

In this document, **Age** means how old you need to be to get money from the Independent Living Fund.

When the fund was open to applications you needed to be between 16 years old and 64 years old.

Discussion Responses

- There shouldn't be no upper age limit.

- 64 is meaningless as it is no longer the retirement age.
- There has to be scope for the system to consider people who become disabled beyond 64 years old.
- 16 to 66 would be a starting point, but the upper age limit will have to go up with time as people keep living longer.
- Because the fund has been closed to new applicants for a years, some people who could have applied for an award if fund was currently open might have missed their chance because of the upper age limit.
- 16 years old and above seems right and maybe this can be looked at again in the future. There is currently more funding available to children than there is to adults.
- In some cases, ILF could give money to people under 16 if they can't get support form other funds.

Second Group Discussion

Award Management

Everyone who gets money from Independent Living Fund Scotland must have an **Award Manager**.

Award Managers can be:

- the person getting the funding

- someone who has some control to support the person – like a Financial Guardian, for example
- someone else – like a family member
- Social Work staff

Discussion Responses

- It is good if the recipient is able to manage the award. They may need support and guidance.
- Parent or family member could also be a good award manager.
- Care providers or voluntary organisations could also take on this role to support the recipient.
- Parents working in partnership with third party organisations (Real Life Options are a charity) to who can manage awards.
- Families can be good but can sometimes make decisions in the place of the disabled person – the disabled person's views must always come first.
- Social workers would not be the best people to Manage Awards. They are too busy.
- Being an award manager is a lot of pressure. Parents and carers need help with this.
- If there are changes to support staff it can take a long time to find someone new. The money can build up if this happens and it is stressful for the person managing the award.

- Should be possible to use these funds for specialist training for support staff for example epilepsy training.
- Can't pay support worker holidays they only get paid when they come.
- Using a company to manage the pay for support workers is a good way to take away some of the stress.
- The award manager must know the user. Can't be a Duty Social Worker who has never met the person.
- ILF can pay the cost of working with an agency. This means the Award Manager do not have to do as much.

Charging for ILF (Available Income Contribution)

This means an amount of money that a disabled person pays towards their support – on top of the money the Independent Living Fund pays.

At the moment it is £43 per week.

Discussion Responses

- Should stop charging for ILF because it complicates things and it is difficult for people to understand along with the charges from Local Authorities.
- People have to pay a lot in charges just now for other things in life. They should not pay for ILF.

- The charge might put people off from applying.
- Scottish Government is going to stop charging for care then why not just stop it now for.
- Need to think of existing recipients and fairness. So there might have to be a charge to start with and it could be stopped in the future.

Capital Threshold

This means the amount of money someone has in things like:

- savings
- investments
- second houses
- land

At the moment the Independent Living Fund capital threshold is £32,750.

This means that if someone has or gets this amount of money, they cannot get Independent Living Fund money.

Discussion Responses

- Having a capital threshold won't make a big difference to the amount of people who apply for ILF.
- Other benefits are already means-tested, so the ILF doesn't need to be.
- People should be allowed to save.

- The capital threshold, if there needs to be one, should be as high as possible.
- People should be able to get legal advice or financial advice about this.

Third Group Discussion

Relationships with Local Authorities

At the moment both local councils and the Independent Living Fund give money together to disabled people.

Independent Living Fund aims to visit each disabled person once every few years to check everything is going well.

A social work staff member from the local council should go along too. And the person themselves should be asked what they think.

Discussion Responses

- It depends which Local Authority as there are big differences between different local authorities.
- Joint reviews are a good thing if the social worker knows the person and the review is well planned with lots of notice.
- Having Social Work involved might cause delays. ILF should have other options to do reviews without social Work or speak to them on the phone if they cannot come to a review.

- Local Authority needs to pay for the care needs and ILF is for quality of life. It would be nice if the Local Authority did not know how much ILF has given the person. They will try to reduce how much they give.
- Joint review system is not working. Some money has gone back to Local Authorities which should have gone to ILF and some money has gone back to ILF that should have gone to the Local Authority. It is messy.
- If payments from the Local Authority and ILF could be made at the same time this would make it much easier for people to keep track of things.

ILF and Statutory Funding (Additionality)

Independent Living Fund money was not meant to be the main funding for disabled people.

It should be topping up the amount that each local council agree to pay.

Discussion Responses

- Social Work must pay for personal care. This is their responsibility.
- ILF should truly be additional for everything that is not personal care.
- Want to keep ILF completely separate from Social Work funds.
- Re-opening should not be about filling in the gaps where Social Work have stopped funding this. ILF is about more than that. It should be about people living a good life.

Use of ILF Funding

The extra money that Independent Living Fund gives helps people to choose things that are important to them to help them live more independently.

Discussion Responses

- Transport is a major cost in rural areas. People have to use ILF for this.
- A simple Easy Read guide would be useful to help people understand what the money can be spent on.
- The award should be used for things that help people feel included in society.
- Voluntary organisations could help a lot with planning how to use the money.
- A video showing people the process would be helpful. This might include existing recipients sharing what they have used their ILF Award for.
- New recipients meeting existing recipients would be helpful.
- Use funds to pay for holidays including the extra cost of taking support staff along.
- There should be flexibility in how the funds are used as long as it allows the recipient to try new experiences and take risks. Disabled

people's lives can be very small especially after covid so we should use the fund to make their worlds bigger.

- Use funds to pay for non residential respite.
- Use funds to buy CEA Card (card scheme for disabled cinema guest). This means Carers can go free with a disabled person to every cinema in Scotland.