

Co-Production Event Discussion Summary

Online, 12 February 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

- If the threshold is too low people will get smaller amounts of money and not as much benefit from it, but the Local Authority are also reducing funding. People have less in their care package so if it is £600 lots of people won't be able to get access.
- Local Authority do look at the ILF funding when they are setting their amount. They can see how much people get and then they reduce their contribution. If they didn't have to provide statutory care needs people might lose it altogether.
- It should be raised from £340 but not maybe as much as £600. It must be protected so that the Local Authority are not able to use it for things that should be covered in the care package.
- Thresholds are different for different local authorities. It does not seem like the same rules apply everywhere.

- £900 is the amount that people are at risk of residential care. This should be an amount to think about when it comes to thresholds.
- Should think about lowering the threshold because Self Directed Support (SDS) budgets being cut and people have less money from Social Work now than ever.
- Hard to decide on an amount. If it's too high then lots of people may not get access because of Local Authority cuts.
- No threshold but instead ILF should provide all direct payments.
- This should not be about a threshold. We need to think about the level of disability and people that are not getting any support. People who need care 24 hours a day will get the support they need but there are lots who don't have any support.

Maximum Award

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

Discussion Responses

- Fairer to re-open to more people by having a maximum award but the current maximum award is out of date because everything costs more than it did in 2015.
- Maybe we need a slight increase. Keeping it similar will make sure more people will get help. It could be around £550.

- Costs more for support staff now and people will end up with less hours as a result. Money won't go as far so the maximum award needs to be a bit more.
- Worried that social services will cut back and hours are being cut down. We need to take account of what a person needs and ILF has a role to play in getting social care packages back up to the level they were at before.
- People who don't have social work support will be missed if this is about a threshold sum as they don't have a budget.
- Lots of people with complex needs rely on unpaid carers and don't have the level of Social Work support they need. They would still have unmet needs if the decision is based on the threshold sum. More flexibility is needed around the threshold sum.

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

- This award is for people who have had a disability all their lives. People should have had support for a disability before they were 64 years old.

- People should be able to apply after the age of 64 because of issues that have come about due to getting older.
- Understand the need for an age limit. Without this the fund will be spread too thinly. Other support is available after 65 years old and before 16 years old.
- Age limit should be 16 years and over and should be a lifetime award.
- Should start from 18 years old for as long as you need it. No cut off.

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

- The way ILF do this now is working. No need to change it.

- Need to think about what happens when Award Managers get older. It can be good to include a third-party agency or support organisation but this is an individual choice.
- There needs to be an Award Manager. If not how would it work? Don't want to make it more complicated than it needs to be.
- Good idea to have payroll services in place with support from an agency as takes away a lot of the stress and anxiety from the financial side of things.
- Recipients should be at the heart of this process and should be as involved as possible. Sometimes it is good to have other parties involved like Centres for Inclusive Living to promote independence and make it possible to take risks.
- Social Work should not take on the Award Manager role. Better that this is handled by someone who know the recipient very well.
- Recipient should manage their own award wherever possible.
- More support and advice is needed for Award Managers to help them with this role.
- Maybe recipients and Award Managers could buddy up with other recipients and Award Managers to learn from them.

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

- Charging – available income contribution (currently £43 deducted at base with no double charging and can be waived in certain circumstances).
- If paying a small charge means more people get access to ILF then it's fair the budget from the Government to ILF is still limited so we need to make it last.
- It is too complicated to work out what charges people need to pay between ILF and the Local Authority. Would be better to have no charge.
- Feels like a charge for being disabled. But if ILF don't charge the charge would be transferred to the Local Authority.
- If there was no charge it would allow for that money to be spent on what recipients need.
- Some local authorities have different charges. Feel like people may be worse off if they are being charged by the local authority.
- There should not be a charge for independent living.

- If there has to be a charge it should be clear how the money is used to keep ILF going 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

- Capital sums for getting Personal Independence Payment (PIP) are much lower. Don't really understand how this amount was decided.
- There should not be a capital limit.
- Could be many different reasons why people end up with savings. They should not be punished for this.
- Those who are in a very good financial position for example millionaires should not get access to ILF.

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

- People could see why it might be important to have good relationships between ILF and the Local Authority, and agreed that this sounds good, but in some areas, it seems like this would be difficult and lots of time is wasted trying to get Social Work to come to reviews.
- Some people explained it has been a very long time since they have seen anyone from Social Work because they only have enough workers to try and fix the big problems. They are 'fighting fires.'
- Some people think it would be better if could run without having to involve Social Work.
- Other people said it can be a good thing the recipient if ILF, Social Work and the recipient can come together for reviews. ILF Assessors can help to make sure Social Work money is used for the right things, like personal care.

- People said it is very important for the person who is cared for to always be at reviews, and ILF and Social Work can work together to make sure they do the best they can for the recipient.
- One person said that some Social Work departments don't have enough people and they are always trying to 'catch up'. People should be able to go ahead with ILF reviews without Social Work involvement, this is a good thing because the review is all about the person and people get the time, they need to do this properly.
- Some people said the reviews should happen more often than every two years.

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 should be the main funder. ILF should be a top up to the amount that each local council agrees to pay.
- ILF should stay separate to Local Authority funding. It should be flexible and down to the person themselves to choose how to use ILF funds because it is about their needs.
- Local Authorities are cutting funds. ILF funding may be the only thing keeping someone out of residential care.

- Personal care is a statutory responsibility for Social Work and must stay this way. ILF money is not for personal care. It is for independent living outcomes.
- Different Local Authorities fund different types of personal care. This means some people have to use ILF money to pay for PAs to take them to medical appointments or cook for them This should all be covered in personal care but with Local Authority cuts it is not.
- ILF Assessors can look at the whole package of support make sure that Social Work remains the main funder.
- Additionality is important for unpaid carers. Money can be used for no residential respite so that unpaid carers can get a break.

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

- Flexibility is important because people's needs change. This allows people to use the money for things like respite so that the family unit can cope.
- We should not create barriers around how to use the funding. It should be used for the biggest benefit of the individual.

- Needs change so flexibility is needed. Sometimes families find themselves in a crisis and respite is needed quickly so being able to use ILF money flexibly is very important.
- We need to be able to be creative with ILF funds and it would be good to see examples and case studies on how other recipients have used their award.
- Being able to socialise and do things in the community is very important and having the flexibility to use ILF funds is something people really need.
- Looking after people's wellbeing. Having the right support can stop other problems from becoming bigger and make sure people stay healthy and happy.
- ILF is about enabling people to reach their potential and try new things.

Who Should Get Money First?

ILF Scotland wants to make sure that the people with the most needs can get the money they need when the fund opens again.

Some of these people might:

- have to go live in a residential home
- have to move away from their family
- be lonely because of their disability
- find it hard to ask for help or make friends
- need help doing things in the community

- not get money from the local council for all of their needs

Discussion Responses

- Everyone should have a chance to apply. People's needs change. If you say who should get the money now then some recipients will be at the top of the list but two years from now it could be different because there may be different needs.
- The fund should be used to take away barriers so whoever faces the most barriers in their lives should be the top of the list.
- If families are at the risk of breaking down because Carers can't cope these people should be high on the list. People can keep going if they get a bit of respite. As Carers get older it gets worse so we need to think about supporting these people.
- If Carers can't cope the family breaks down and the recipient could go into residential care. The flexibility of ILF means people can try to make sure this doesn't happen. Described as a 'life saver'. That's the only way to put it.
- People who don't get Self Directed Support (SDS) need to be high on the list because they only get basic care needs met by social work and the rest of the time they are alone.
- Should think about people with complex psychological disabilities. These are 'hidden' disabilities but still very life limiting and these are people who have lots of unmet needs.
- Include people who are lonely and cannot get out into the community.

- People with complex disabilities should be high on the list. Social Work will know who these people are.
- Older people who are at risk of residential care should be on the list.