

A Review of the Independent Living Funds

What we think works well and what needs to change

By Melanie Henwood and Bob Hudson



Easyread version

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What is this report about?



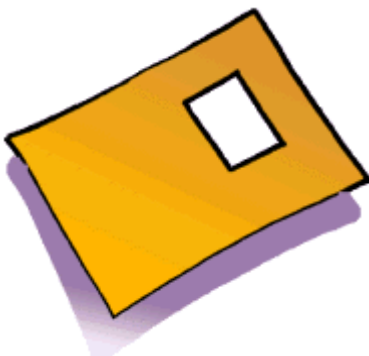
This is an easyread report is about a review that was done to see how well the Independent Living Funds work.



The Department for Work and Pensions asked for this work to be done.



It was done by 2 people from outside Government and the Independent Living Funds, called Melanie Henwood and Bob Hudson.



The full report is called a 'Review of the independent Living Funds' and can be seen at:



www.dwp.gov.uk

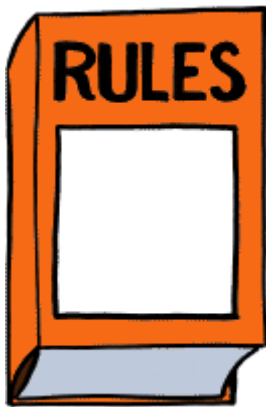
What are the Independent Living Funds?



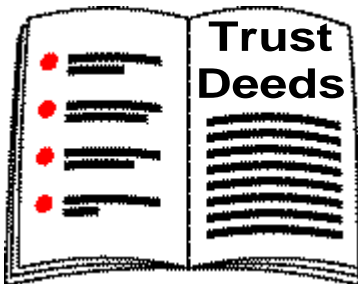
The Independent Living Funds give people money to help them live in their own homes and get the care and support they need.



The Independent Living Funds are managed by a group of people called trustees. They have to report to Ministers from the Department of Work and Pensions.



There are 2 different funds called the 'Extension Fund' and the 1993 Fund. They have different rules about who can use them.



The rules are written down in papers called Trust Deeds. A new set of Trust Deeds started in 2006. There is more information about these rules on page 58.

What is this review about?

This review looked at these questions:



- Should the Independent Living Fund carry on? If not what should there be instead?



- If the Independent Living Fund should carry on, then how should things be changed and how can they be made better?

We asked people what they thought in these ways:



- meeting with people who use services and their family carers



- we asked people who use the Independent Living Funds and organisations to send us their views



- we had interviews with Government and other organisations



We looked at what people said about good organisations and services and listened to what people said about the Independent Living Funds.



We have used this information to work out what changes we think need to be made to the Independent Living Funds and what should happen in the future.

The changes we think need to be made are called recommendations and we have written them in bold like this.

What is happening at the moment in social care?



A lot has changed since the Independent Living Fund was set up. There are a lot of changes going on in social care at the moment.



We think that it is important to look at these changes when thinking about how well the Independent Living Fund works and what it should be like in the future.



These things are happening at the moment:

- The way Government thinks about disabled people is changing.



Their 'Life Chances' report said that Government wants to make sure that all disabled people are treated fairly and equally by 2025.



- The Office for Disability Issues (ODI) has been set up to help Government Departments work together to make things better for disabled people.



- A lot of work is being done on independent living. This means people having choice and control over the way they live their lives and the support they get.



A review of independent living and how to make it happen is being done at the moment.



- A bill has been put forward about independent living. It is about making sure that people have choice and control in their lives. It is not a law yet though.



- The Government wrote a White Paper called 'Our Health, Our Care, Our Say'. It said that people who use services should be at the centre of public services.



They should have control over their support and get good care.



- Having a good and happy life is not just about health and social care.



We need to think about having enough money, strong and safe communities and making sure everyone is included.

Cash for care



Cash for care means giving people money or telling them how much money there is to spend on the care and support they need.

The Independent Living Fund was an early example of this.



The Government is now looking at different ways of giving people control over the way that money is spent on their care and support.

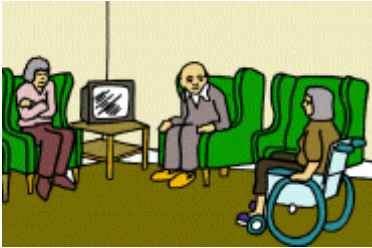


We need to think about how the Independent Living Fund fits into these cash for care projects:



Direct Payments

Direct Payments mean people who use services are given money to buy the care and support they need.



People cannot get Direct Payments if they live in a care home. Health money cannot be used for Direct Payments.



In some areas it is difficult for people to get Direct Payments and the numbers of people getting them are very different in different parts of the country.



In control

In control was set up to put people with learning disabilities and their families in control of their support and of deciding what they need.



It links with the Independent Living Funds and Direct Payments but is also about trying to change the way social care works.

In control was tested and has now been taken on by 60 local authorities.

Individual Budgets



These are like Direct Payments but allow people to bring together all the money for their care, which they get from different places, like the Independent Living Funds and Access to Work.



With Individual Budgets people know how much money there is to spend on their support. They can choose to have services or money to spend on support.



Individual Budgets are being tested across 13 local authorities in England.



The Government has said in reports that it supports Individual Budgets.

How well does the Independent Living Fund work?



We looked at what is important in a good organisation and listened to what people and organisations think about the Independent Living Fund.



Many people who wrote to us told us that the Independent Living Fund money makes a big difference to their lives. They said:

“I love this service.”



“Without the Independent Living Fund our lives would be terrible and stressful.”



“Without ILF lots of people wouldn’t be able to live at home.”



“For the first time for 39 years we have been able to enjoy a normal social life.”



This shows how important it is to these people to have the right support to help them to live in their own home and live the life they choose.



But we wanted to see if these good things come from the way the Independent Living Funds are set up and run.



We looked at these things, what people said about them and at what needs changing:

- Being fair and equal



- Being clear and open



- Being accessible



- Making sure people are in control



- Making sure people can choose how to spend their money on support



- Making a difference to people's lives

Being fair and equal



We looked to see if all the people who need help from the Independent Living Fund are getting it.



We know that not everyone who could get money asks for it or is given it.



Changes need to be made quickly to make sure that everyone is treated in a more equal way.

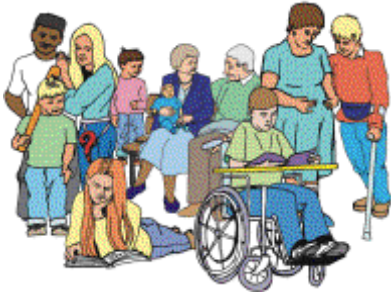


National organisation

The Independent Living Fund is run at a national level. This means that the rules are the same for everyone, wherever they live in the country.



People said that this is a good thing when they move to a different part of the country.



We found that in some areas more people use Independent Living Fund support than others.



In other places, people do not know about the Independent Living Fund or do not get the support they need to apply. Some people feel it is one of the 'best kept secrets'.

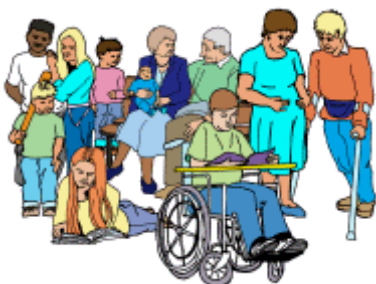


Some people said that it works better for people in England and not Scotland, Wales or Northern Ireland.



We think that the Independent Living Fund should tell people about what it does and about the support they can get.

It should work to make sure that the level of take up is the same in all local authorities all over the UK.



We also wanted to check if different groups of people get equal chances to get the support they need.

We found that there were problems for these groups:

Older people



People who are over 65 years old cannot apply for Independent Living Fund money. They can carry on getting support money if they already get it it.



Some people said it would cost too much to support older people and that if there is not enough money for everyone, then younger people should get the support.



Most people said that this is unfair and that it does not fit with Government's work on supporting older people and making sure that they are treated equally.



We think that it is unfair to leave older people out in this way. Departments should work together to look at how much it would cost to support people over 65 years old.

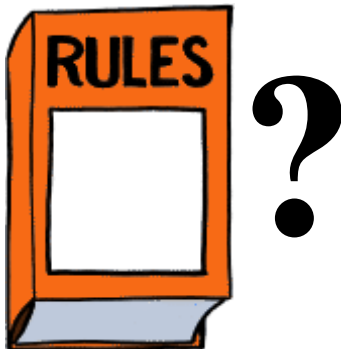


They need to tell people when they will start to support older people.



People who used to live in long-stay hospitals

People who live or have lived in long-stay hospitals have not been able to get support from the Independent Living Fund in the past.



This is now starting to change but many people said that the rules about who can get support are not clear.



This may be because in the past these people got support from the NHS but we do not think that this should be a reason to not support them now.



Departments should work together to look at how much it would cost to support people who live or have lived in long-stay hospitals.



They need to work out and tell people when they will start to support this group of people.

People with very high support needs



There is a limit to how much money can be paid by the Independent Living Fund and the local authority. The limit is £785 a week.



The NHS or other organisations can add money to this and there is no limit. Some people said that this helps them get extra money.



However, many people said that the limit is out of date and that it stops people with very high support needs from getting the support they need.



Departments should work together to look at how much it would cost to take off the limit on how much support money people can get.



They need to work out when they can start to support people with very high support needs who cannot apply for support at the moment.

People who are not on highest rate of Disability Living Allowance



People have to be on the highest rate Disability Allowance to apply for support money from the Independent Living Fund.



Many people said that this is not fair as some people on the middle rate still have high support needs during the day and need extra support money.



For example, these might be people with a learning disability, blind and partially sighted people and people with mental health needs.



Some people said that there is also a problem for people whose needs keep changing. They may not apply for support money as they might be worried about having it taken away later on.



We think that people who get middle rate Disability Living Allowance should be able to apply to the Independent Living Fund for support money.

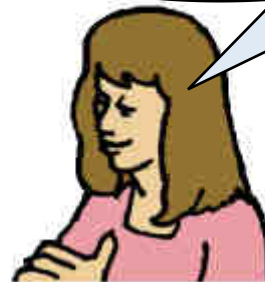
Partners and parents



The Independent Living Fund looks at the money a person has as well as the money their partner has. This can make things difficult.

One woman said

“It’s like saying that if you marry me it will cost you a fortune”



We think that a partner’s benefits and money should not affect the amount of Independent Living Fund money that people can get.



It is also difficult for disabled parents to get the support they need.



We think that disabled parents should be able to get support money to help them be parents and that any help that the local authority is giving them with this should count.

Other groups – People from Black and minority ethnic groups



Not many people from Black and Minority Ethnic groups ask for or get Independent Living Fund money.



The Independent Living Fund does not know about the ethnic background of a lot of people who already get support money.



We think that it is important for the Independent Living Fund to look at how it works with people from Black and Minority Ethnic groups and at how to make sure more people apply for support.

Other groups – Disabled students



Student loans are counted as money that could be used for care and this can make it difficult for disabled students.



We think that the Disabled Student's Grant and any student loan should not be counted as money that could be used for care when Independent Living Fund money is worked out.



It is also difficult for disabled parents to save and pay for their children to go to university or college.



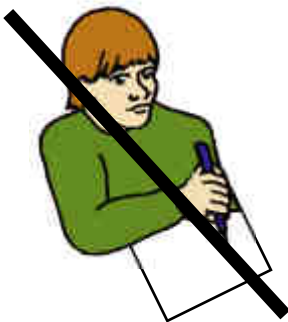
We think that the Independent Living Fund rules should change so that disabled parents can save and pay for their children to go to university or college without losing out on Independent Living Fund money.

6 Months

1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

Other groups – People who are dying

One of the rules says that people need to be expecting to live in the community for the next 6 months to be able to get support money.



This means that people who are dying can lose the support money they get or be stopped from applying.



We think that people who have less than 6 months to live should be able to apply for support money.

Being clear and open



We looked at whether people were clear about how much money they would get and how it had been decided.



We also looked at whether people felt they could ask about or complain about what had been decided.



People told us that the Independent Living Fund is often not clear and open.



They said they did not know how their money had been worked out or about the rules and the way the Independent Living Fund is run.

What happens when people apply?



When people apply for support money from the Independent Living Fund, a person comes to talk to them about their needs and about how much money they have. This person is called an assessor.



They write a report for the Independent Living Fund to say how much support the person needs and how much it will cost.



The Independent Living Fund looks at this report and at information from the local authority to decide how much money they will offer.



It is often difficult to understand how this is worked out.



This can all take a long time, which can have a big effect on people's lives.



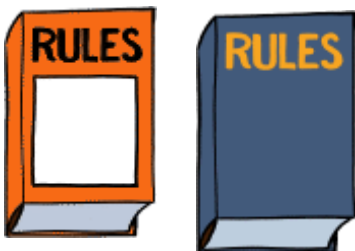
The Independent Living Fund has set itself a target of making decisions within 13 weeks of people applying. We think this is too long.



We think that the Independent Living Fund needs to look at making it easier for people to apply and should look at how it gives people who use services information.



It should set up ways of measuring how well it is doing so it gets better and quicker at getting back to clients.



People feel that the rules are different for each person. Some people who are linked with other disabled people and can share information were better able to get the support they needed.



Some people felt that there were problems when their needs changed.



The Independent Living Fund expects people to tell them but people said it can take a long time to get an assessor to come and talk to them about new or changed needs.



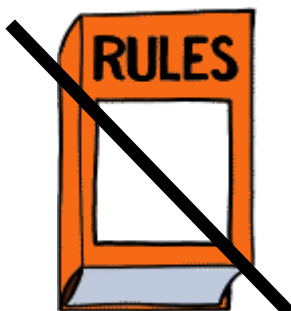
People said it was hard to know if they could complain or not.

People said that it was hard to know how to make complaints and who to.

Were Independent Living Fund staff helpful?



Many people said that assessors were friendly and helpful but that they did not have the power to agree with the person how much money they would get.



People said that assessors did not seem to follow fixed rules and that their decisions were not always the same.



Some people said they were not so happy with other Independent Living Fund workers and said that they were rude and unhelpful.



Some people said that they felt that the Independent Living Fund is always trying to keep its money safe and that the person using the service is the last person to be thought about.



We think that the Independent Living Fund needs to make clear how decisions are made about how much support money people will get.



This will give advisors and people who use services an idea of what will happen when they apply.



We also think that the Independent Living Fund needs to look at training for all staff in how to work with people who use the service.

Being accessible



We looked at how the Independent Living Fund is set up and the rules it works to.



We wanted to find out how easy the Independent Living Fund is for people to use and to see if there was anything that stopped people who would get support from applying.



We found that the way that the Independent Living Fund is set up and the different ways that local authorities and the Independent Living Fund work can make it difficult for people to use.



The rules

There are a lot of rules about who can get Independent Living Fund support money. The main ones are that the person must:



- live in the United Kingdom

16+



-66



- be older than 16 and younger than 66



- get the highest rate of Disability Living Allowance



- have savings less than £18,500

6 Months

1	2	3	4	5	6	7
8	9	10	11	12	13	14
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- expect to live independently for at least the next 6 months



- not live in a care home

£200



- get at least £200 worth of support each week from their local authority



- get Income Support



The person must meet all these rules. This means that if one thing changes, it will affect their Independent Living Fund support money. This can cause problems.



We think that the Independent Living Fund needs to look at making the rules about who can get Independent Living Fund support money simpler so that people do not have to meet all these rules at the same time.



For example, if a decision is being made about a person's Disability Living Allowance, the Independent Living Fund will sometimes stop paying support money until a decision has been made.



We think that the support money should carry on until a decision has been made.