

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?



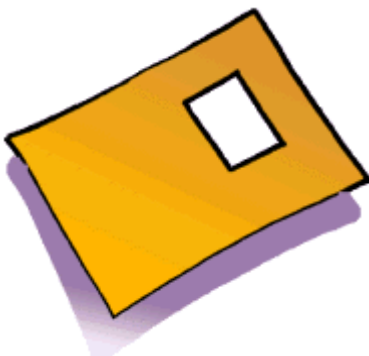
This is an easyread report is about a review that was done to see how well the Independent Living Funds work.



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

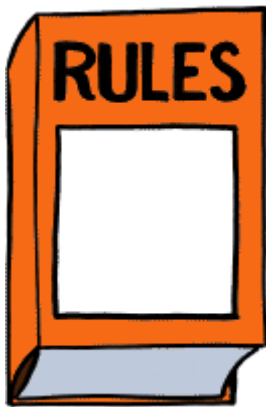
What are the Independent Living Funds?



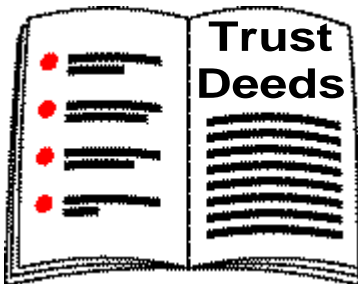
The Independent Living Funds give people money to help them live in their own homes and get the care and support they need.



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.

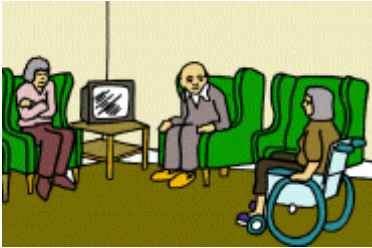


We need to think about how the Independent Living Fund fits into these cash for care projects:



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.

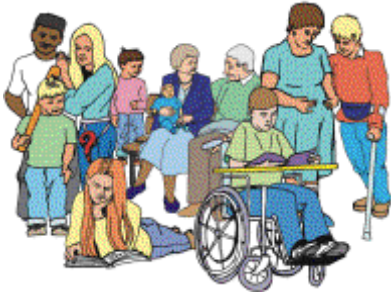


National organisation

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'.

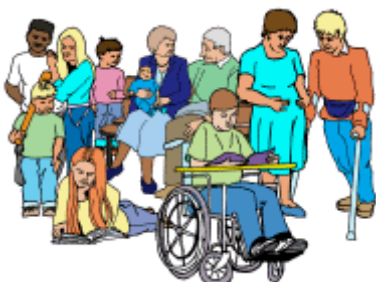


Some people said that it works better for people in England and not Scotland, Wales or Northern Ireland.



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.

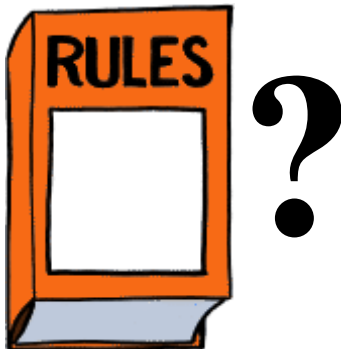


They need to tell people when they will start to support older people.



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.

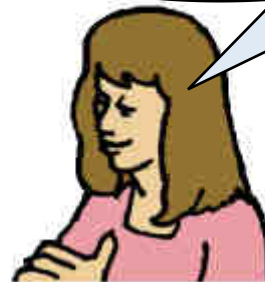
Partners and parents



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.



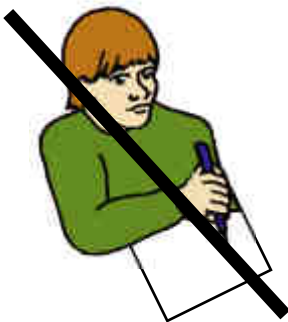
We think that the Independent Living Fund rules should change so that disabled parents can save and pay for their children to go to university or college without losing out on Independent Living Fund money.

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.



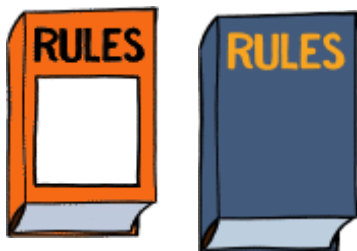
The Independent Living Fund has set itself a target of making decisions within 13 weeks of people applying. We think this is too long.



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.



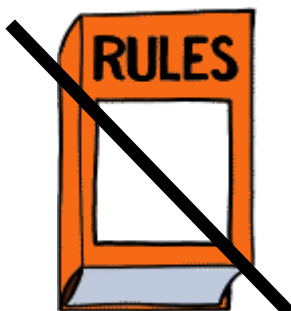
People said it was hard to know if they could complain or not.

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.

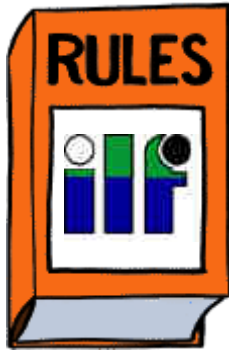


This will give advisors and people who use services an idea of what will happen when they apply.



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
15	16	17	18	19	20	21
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29	30	31				

- 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.

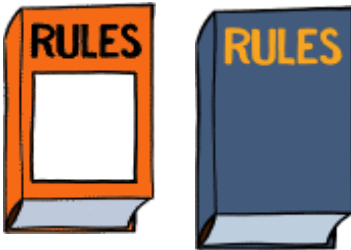


We think that the support money should carry on until a decision has been made.

Looking at how much money a person has to pay for their care



The Independent Living Fund and the local authority look at the money a person has to see how much they can pay for their own care. They do not do this together.



Sometimes people lose out because the Independent Living Fund asks the person to pay more money than their local authority did. Often the rules are different.



We think that by the end of 2008, the local authority and Independent Living Fund should look at the money a person has together.



At the moment, money that people earn from a job is not counted when the Independent Living Fund decides how much support money it can give but money from work pensions is counted.



We think that money from work pensions should not be counted.




It costs more and more to buy services and support each year.

But the money that people can have in savings or the Independent Living Fund money that they are paid does not get put up each year.



Local authorities have rules about the savings people who live in care homes can have. They put the amount up each year. Income support goes up each year as well.



We think that Independent Living Fund money and the savings that people can have should be put up each year in the same way.

£200



Support or services from the local authority

People have to be getting £200 worth of support or services before they can apply to the Independent Living Fund for support money.



Some people do not think this is enough because the Independent Living Fund is meant for people who need a lot of support.



Other people think that it is too much because some people are stuck in services that cost a lot or that they don't like because if they stop using them, they will lose Independent Living Fund support money.

£200



We think that the money that the local authority has to be paying should stay at £200.



The Independent Living Fund and local authorities need to look at who pays what when the person is getting over £575 worth of support a week.



Making the Independent Living Fund accessible

More and more organisations are working on the internet and using e-mail.



The Independent Living Fund website is not easy to use. It is hard to find the right information and the writing is small.



We think that the Independent Living Fund needs to make its website better and more accessible.



They need to ask people who use services what they think about the website and the changes that need to be made.



The Independent Living Fund has put its information in different formats like Braille, which is good. But people said that there are too many words in the information they give out.



We think that the Independent Living Fund needs to look at the information it gives out and ask lots of different people what they think about it.

They can then make their information better and meet people's needs.



Some people said that the form you need to fill in is difficult to understand.



Many people said that it took a long time for the Independent Living Fund to decide if it was going to give them support money and if so how much.



We think that the Independent Living Fund should aim to give people an answer within 8 weeks at most. If they cannot do this they should tell the person why.

Reviews and assessments



At the moment the Independent Living Fund looks at whether a person's needs have changed every 2 years, unless the person asks them to do this sooner.



We think the Independent Living Fund should look at whether a person's needs have changed every year and more often if needed.



We think that the Independent Living Fund and local authority should work together to look at people's needs. People should be able to fill in simple forms on the internet.

Making sure people are in control



The Government wants disabled people to have choice and control over their lives and the support they get.



They have been looking at



- life planning



- user-led organisations run by disabled people



- people making the decisions for themselves about what care and support they need. This is called self-assessment



- telling people as soon as possible how much money they will have for their support. This will mean setting up a way of doing this that different organisations can use.



We looked at how well the Independent Living Fund works with these ideas and found that there are some problems.



The way it works will need to change to make sure that people are put in control and given the support they need.

Life planning



Giving people cash for care is a good way of starting to put them in control. Often people need support to manage their money and plan their support. This is part of life planning.



The Independent Living Fund gives people some money so they can get help with papers and with managing their money. Many people said that it was not enough money.



People said that the Independent Living Fund needs to give people support to be managers.



People on Direct Payments often get some help to manage their support. If they are just on Independent Living Fund money they do not get this and people said that this was not fair.



People said that they only got money to pay their staff holiday pay and National Insurance if they asked for it, even though these are things that all employers must pay.

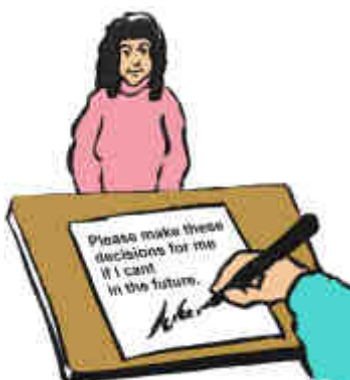


We think that the Independent Living Fund should work on a plan for helping people with life planning. They should work with local authorities and other organisations on this.

User-led organisations run by disabled people



The Government said in its 'Life Chances' report that it will support a user-led organisation to be set up in each area by 2010. These organisations will be like 'Centres for Independent Living'.



The Independent Living Fund and the National Centre for Independent Living have already agreed to work together but we think more needs to be done.



We think that the Independent Living Fund should support this work to set up or build up organisations run by people who use services.



They should work with local authorities on this so people who get Independent Living Fund money and Direct Payments get the same level of support.



Assessments

An assessment is where someone looks at the support and care a person needs.



People said that they have to go through lots of assessments and tell different organisations what their needs are.



We think that the Independent Living Fund should work with others to make sure that people do not have to tell lots of different organisations what their needs are.

We think this should happen by 2008.



One way of making sure that people do not have to go through lots of assessments is to ask them to make the decisions for themselves about what care and support they need.

This is called a self-assessment.



People may need support to do this. In Control and Individual Budget test projects are looking at self-assessment.



We think that the Independent Living Fund needs to work on telling people about self-assessment and take part in the projects that are looking at how well self-assessment works.



They should look at how the work of assessors would fit in with self-assessment.

A simple way of telling people how much money they will have for support



For people to be in control they need to find out quickly how much money there is to pay for their support. They also need to know how this has been decided.



Work is being done on finding simple ways to work out how much support money people will get. The work is looking at people's lives, their levels of need and who they live with. This is called Individual Budgets.



We think that the Independent Living Fund should look at the work being done to see what problems there might be with fitting in with this way of working and how they could be solved.



The Independent Living Fund must work to become part of Individual Budgets by 2009/10.



We think that the Government should be setting up this way of working across the country. This work will affect the Independent Living Fund and local authorities.

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



Part of having control is about being able to choose how to spend money on support in a way that makes most sense in our lives.



We looked at whether the Independent Living Fund was set up in a way that helps people to do this.



The Independent Living Fund has to work to a set of rules but it can also give people more control if it wants to. We found that it does not always do this.



Keeping records of how money is spent

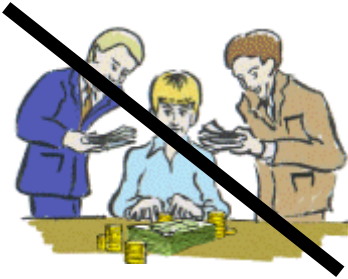
People who get support money have to show how it is spent. They may also have to do this in a different way for other money they get, for example through Individual Budgets or Direct Payments.



This can be difficult and confusing for people and put them off asking for support money.



We think that the Independent Living Fund and other organisations should make sure that people only have to keep records in just one way.



Some people, mostly staff in local authorities, said that the Independent Living Fund did not do enough checks on how money was spent.



We think it is good that the Independent Living Fund is going to do a test project to visit people after 6 months to check if they are ok with managing their money.



We think that the Independent Living Fund should carry on doing checks in the same way, but they should do more to find and support people who find it difficult to manage their support money.

What Independent Living Fund money can be used for



We heard that Independent Living Fund money helps many people to 'live a life' rather than just survive.



But we found that some of the rules about what money could be spent on limited people's choices.

People told us about these issues:



- Money can only be used to pay for help at home and personal care.



We think that people should also be able to spend support money on other things which give them control and choice in their lives, such as things they do in their spare time and taking part in the community.



- People said that they need some money to pay for support to help them to take on and manage staff.

Some people said that they need a bit of extra money at the start to get set up.



We think that the Independent Living Fund should pay these costs and look into giving people a bit more money so they can get the support and advice they need at the start.



- At the moment, people cannot keep any money they do not use from month to month. This can make things difficult for people whose needs change often.



We think that people should be allowed to keep money that is not spent, so they can build up a bit of money for the times they need more support.



We think that the Independent Living Fund should at least match the Direct Payments rules.



- Independent Living Fund money is paid every 4 weeks for the 4 weeks before. This can make things difficult for people who do not have much money to start with.

We think that the Independent Living Fund should give people money for the 4 weeks to come instead. They should make this change as soon as they can.



- Waiting for decisions to be made about how much money people will be given can make things very difficult for people who might lose their carers or their home.

We think support money should be paid from the time that the Independent Living Fund gets a filled in form.

They should pay back support money for any time that the person has to wait.



- There are sometimes problems when people go into hospital.



There are rules about how long Independent Living Fund money and Disability Living Allowance can be paid for while the person is in hospital.



Support workers can be really important when people are in hospital to help them communicate.



We think that the Department for Work and Pensions and Independent Living Fund should be able to support people who really need their support when they are in hospital.



We know that Independent Living Fund cannot go on paying support money for ever but the rules are too strict at the moment.



- Family members who live with the person cannot be paid to support them. Many people were not happy about this.



Some people said that the Independent Living Fund money meant that they did not always have to get help from friends and family.



We think that in general, Independent Living Fund money should not be paid to family members living in the same house. Trustees should be able to change this if really needed.

Making a difference to people's lives



Independent Living is about people living in the way they want to. It is about making a difference to people's lives and making sure they are in control.



We looked at whether the Independent Living Fund works in this way. We found that the Independent Living Fund is behind and old-fashioned in some ways.



People said that the Independent Living Fund thought about support rather than the difference that is made to people's lives.



Some people said that they did not feel that the Independent Living Fund workers understand what independent living is and that this needs to change.



We think that the Independent Living Fund needs to understand what Independent Living really means for people if it is going to work well.

How well the Independent Living Fund works with Government and others?



The Independent Living Fund has always had to work with other organisations. We looked at how well it works with:



- Local authorities
- Individual budgets
- The NHS

Local authorities



Local authorities have to make sure that people get social care services. The link between them and the Independent Living Fund is important.



A lot of people said that local authorities and the Independent Living Fund do not always work well together.



The Independent Living Fund has done some work on this and tried to make sure that each local authority knows who they can contact at the Independent Living Fund.



We think that the Independent Living Fund should carry on making better links with local authorities.



They should look at how they can work with local authorities and their social workers.



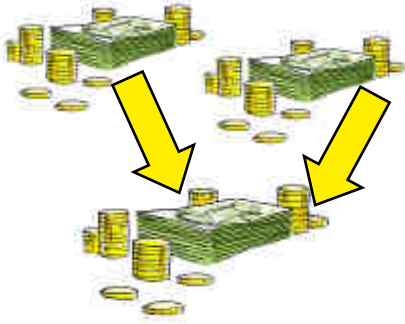
A few people said that Independent Living Fund money could be given to local authorities to give out like other money for services and support.



A lot of people were worried that the money would then get spent on other things.



We think that Independent Living Fund money should not be given to local authorities to give out.



Individual Budgets

Individual Budgets bring together all the money for a person's care, which they get from different places. They choose how to spend the money on support.



Independent Living Fund money is being used in the test projects. People are worried that there will be problems because at the moment Independent Living Fund money cannot be used to buy some types of support.



The Independent Living Fund has asked if it can allow people to spend their support money in different ways.



We think that it should try to fit in with the Individual Budget projects as much as it can.

This means that when the rules change it can allow people to spend money in the way that makes most sense for their support.



The NHS – Health Service

Health care and social care have often been seen as very different things. Getting the right support is the issue for many people, whether it is paid for by health or social services.



Who pays can affect the money people get for support. At the moment health money cannot be paid to people as cash for care.



The Independent Living Fund will not count health money when it decides if it can give a person support money.



This means that if a person's support is paid for health and not social services, they may lose out on Independent Living Fund money.



The Independent Living Fund has asked for the Department of Health to tell them how health money fits in with Individual Budgets.



We think that the Department of Health should look again at how health money fits with Individual Budgets.



We think that Independent Living Fund users who start to get support paid for by the NHS and health should not lose their support money because of this.

How open is the Independent Living Fund as an organisation?



We looked whether the Independent Living Fund is open about the way it works and the decisions it makes.



People expect to be involved in deciding how an organisation is run but we found that a lot of people did not know how the Independent Living Fund works.



We wanted to see how it finds out what people who use services think and how it uses this information to meet their needs.

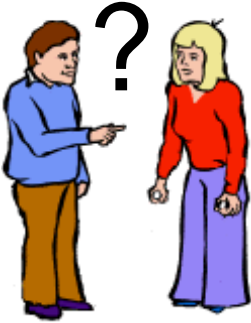


We found that the Independent Living Fund wants to get better at working with people who use services but that they still have a long way to go.

The people who manage the Independent Living Fund



The Independent Living Fund is run by a group of people called trustees. Many people did not know about them even though they have a lot of power.



As soon as we talked about the trustees, people wanted to know who they were and how they were chosen.



People said that they do not get the chance to meet the trustees or ask them questions.



We think that people who get Independent Living Fund support money should be given the chance to do this.



The trustees hold private meetings and there are no notes about them on the internet.

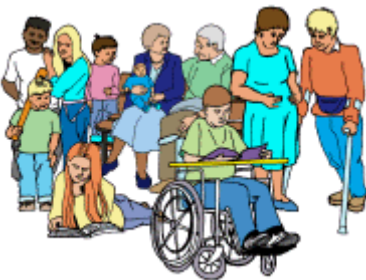


We think that the trustees should hold their meetings in public and that people should be able to see meeting notes.



Working with people who use services

Working with people who use services is an important part of putting people in control.



The Independent Living Fund wants to work more with people who use services. They said that they have done some good work on this but we feel that a lot more needs to be done.



The meetings we had with people for this project were the first chance that most people had had to talk about the Independent Living Fund and their experiences.



The Independent Living Fund did have a user group but it does not seem to meet anymore. People said that the rules were too strict about what it could and could not do.



People also said that the group did not have many members and many people did not even know about the group.



We know that it is sometimes difficult to arrange meetings that people can get to and that are accessible but there are organisations who could help with this, like Shaping Our Lives.



The Independent Living Fund said that it could see that it had not been good enough at involving people. It said that it is going to set up groups to talk about different issues.



We think that the Independent Living Fund is not working fast enough to involve people and that it needs to work in different ways to make sure it happens. They need to get advice about how to do this.



The Disability Equality Duty means that it is now law to involve people who use services. The Independent Living Fund has written a plan about treating disabled people fairly and equally.



We think that the Independent Living Fund should ask an organisation run by people who use services to help them write a plan about involving people in lots of different ways.

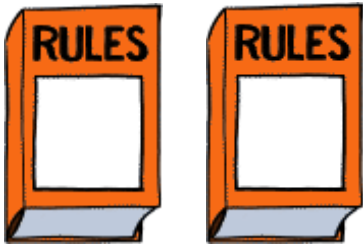


We also think that the Independent Living Fund should work with the Office for Disability Issues and Centres for Independent Living so it gets better at working with people who use services.

New rules for the Independent Living Fund: What needs to change?



The Independent Living Fund has to follow some legal rules. The rules are written down in papers called Trust Deeds.



At the moment there are 2 funds and 2 sets of rules. Some of these rules limit what the Independent Living Fund is allowed to do.



A new set of Trust Deeds for both funds started in 2006. They will give the Independent Living Fund more power to meet the needs of Independent Living Fund users and make changes when needed.

We think that there are some things that need to change:



- **We think that most people on the board of Trustees should be disabled people.**



- **We think that people should be able to spend their Independent Living Fund money on support for things they do in their spare time and for taking part in their community.**



- **We think that the Independent Living Fund should look now at how it will be able to use the new rules and powers to make its service better and more modern.**

How the Independent Living Fund is run at a national level



At the moment the Independent Living Fund reports to and is paid for by the Department for Work and Pensions.

We think that this should not change.



Government Departments need to work together on making independent living happen. The Office for Disability Issues (ODI) is an important part of trying to make this happen.



ODI is doing a review on independent living at the moment.

The information from that review and this report should be used by ODI and the Department for Work and Pensions to think about how the Independent Living Fund should be in the future.



The Independent Living Fund covers England, Scotland, Wales and Northern Ireland. At the moment it only has offices in Nottingham.



We think that the Independent Living Fund should set up offices in Scotland, Wales and Northern Ireland and in the English regions.



Some rules and laws are different in England, Scotland, Wales and Northern Ireland.



We think that the Independent Living Fund should make sure that all the information it gives out works for the country that it is used in.



At the moment Individual Budgets are only being tried out in England. People in Scotland, Wales and Northern Ireland said that they would like to try them too.



We think that Individual Budget projects should be set up in Scotland, Wales and Northern Ireland and a group made up of people from the 4 countries should work on disability and independent living issues.

The Future



We know that a lot can be done to make the Independent Living Fund and the way it is run better. We have said what we think should be done.



Many people are worried that the Independent Living Fund and other organisations do not fit together well as ways of supporting people.



They think that bigger changes may be needed so that there are simple and good ways of getting support for everyone.



The Independent Living Fund needs to be clear about what will be changed and when. It needs to keep up with changes in social care.



It is important that people who get support money at the moment do not lose out.

However the Independent Living Fund changes, it must work in ways that:



- are fair and equal



- are clear



- are accessible



- make sure people are in control



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



- make a difference to people's lives

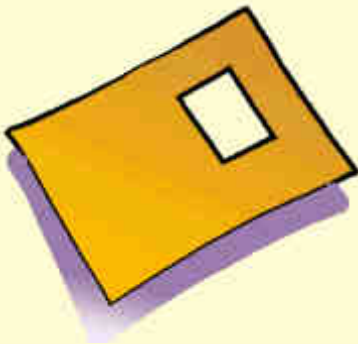
What should the Independent Living Fund be like?



We heard a lot of different views about what the Independent Living Fund should be like in the future.



Some people said that it is good to have the money handed out from a national level. Others felt that this is not a modern way of doing things and that it does not fit with putting people in control.



We think that the Independent Living Fund should make a lot of changes now. We have put these things in this report.



But we do not think that it should make big changes to the way it is set up until at least 2009 - 2010. This is because a lot of changes are happening at the moment.



It is hard to know exactly what will happen in social care, but we think that Individual Budgets will be the way forward. If the test projects go well, they will be used all over the country by 2009-2010.



In 2009 and 2010 the Independent Living Fund will be able to look at information from all the projects that have been done about independent living.



It will be clearer how it fits in with supporting people to have choice and control.



We think that the Independent Living Fund will need to become part of Individual Budgets and that it should start to think about how to do this now.



It should work with the Department for Work and Pensions and Department of Health to plan this.

Credits



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