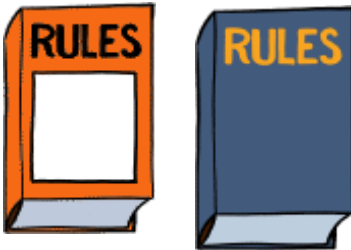


Looking at how much money a person has to pay for their care



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.

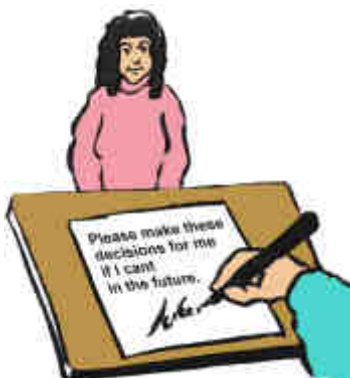


We think that the Independent Living Fund should work on a plan for helping people with life planning. They should work with local authorities and other organisations on this.

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

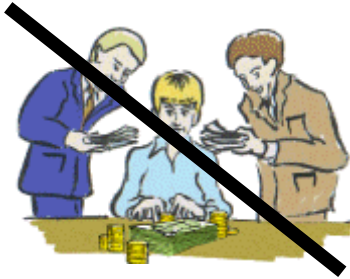
People who get support money have to show how it is spent. They may also have to do this in a different way for other money they get, for example through Individual Budgets or Direct Payments.



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.



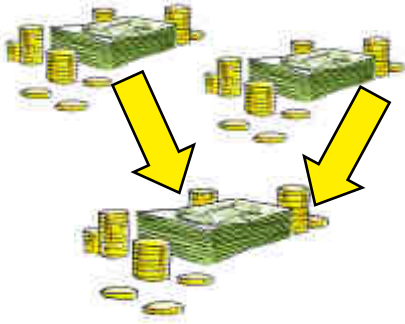
A few people said that Independent Living Fund money could be given to local authorities to give out like other money for services and support.



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.

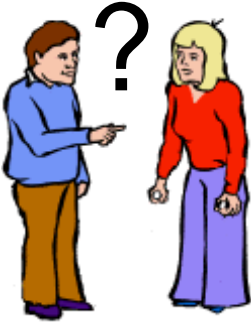


We found that the Independent Living Fund wants to get better at working with people who use services but that they still have a long way to go.

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.

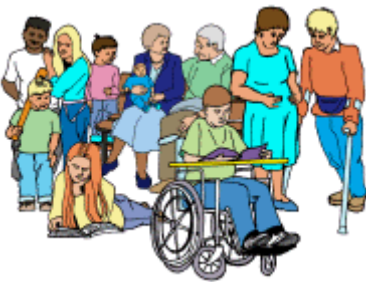


We think that the trustees should hold their meetings in public and that people should be able to see meeting notes.



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.

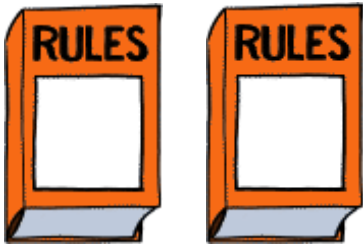


We also think that the Independent Living Fund should work with the Office for Disability Issues and Centres for Independent Living so it gets better at working with people who use services.

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

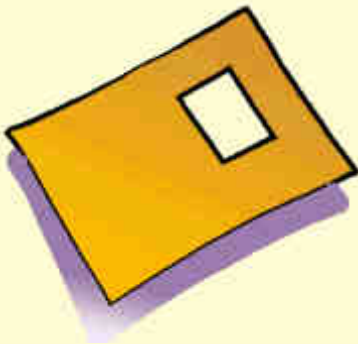
What should the Independent Living Fund be like?



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.

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