

# Independent Living Fund Report Summary



The Independent Living Fund was shut for good on 30<sup>th</sup> June 2015. One week before this, wheelchair users tried to get into the House of Commons during the Prime Minister's Question Time. This was a last try to stop the Fund from closing.

Disabled people getting support through the Independent Living Fund know what day to day care and support look like in local authorities. This is why they were worried that closing the Fund would mean getting rid of the support that they need.



The government gave the money that they would have spent on the Independent Living Fund to local authorities. They did this from 01 July 2015 to 31 March 2016. This was to try and make sure that closing the Fund did not have such a bad impact on people.



In May 2016 the government decided that this money would be given to local authorities for another 4 years. However, this money is not protected which means that it is up to each local authority how they spend the money.



It has been important to keep a check on how the closing of the Fund has affected people. This is because nobody is sure what is going to happen in the future to the people who used to use the Fund. As well as this the experiences of people who used the Fund has shown in a clear way, how the new Care Act 2014 is being put into place.



There are very big differences in how different councils have used the Independent Living Fund money. This means that at the moment we cannot say exactly how closing the fund has affected people in general.



However, as people keep on sharing information and experiences and through **peer support** we can see that a number of things are happening.



**Peer support:** this means a way of disabled people supporting each other and sharing ideas and experiences.

As well as this we can look at different cases taken against local authorities after reassessments. We can look to see what happened in each case to see if things were done in different or the same ways.



This report was written as information about how closing the Independent Living Fund has affected people. It looks more at what has happened in London. It brings together information from all 33 London boroughs.



This information came from three places:

- **Freedom of Information Requests** sent to local authorities
- A survey sent out to London Deaf and Disabled People's Organisations
- Full case studies from people that used to use the Independent Living Fund, looking at their experiences of the move to local authority support

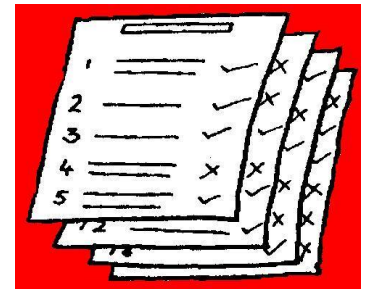


**Freedom of Information Request:** this is when a person or organisation asks for information from a public or government organisation. By law the organisation must then send you the information that you have asked for.

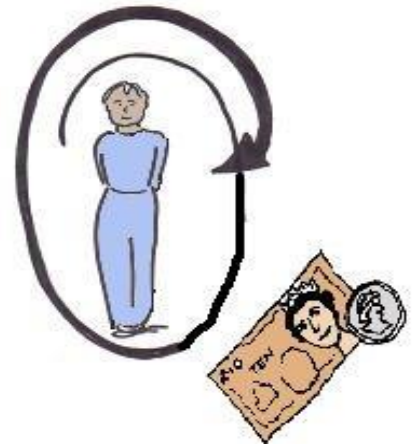
Freedom of Information requests were sent to all 33 London boroughs in June 2016. They asked for information about what has happened in the local authority after closing the Independent Living Fund.



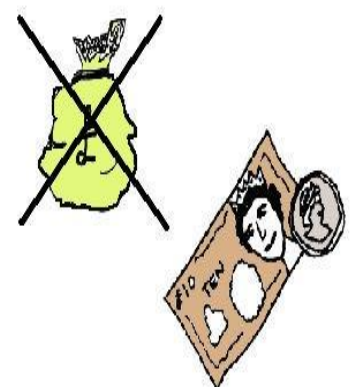
All London boroughs sent information. Enfield sent information that they had already sent to someone else after they had asked for the same sort of information.



The main point that could be made after getting back all of the Freedom of Information requests was the very big differences that there are between boroughs. A number of Councils have decided to keep the same amount of support for people as when they used the Independent Living Fund.



Other Councils have made big cuts which seem to show that they are working to bring down all support packages to a certain level. These cuts are being made even though the Government has said that they will keep paying Independent Living Fund money to local authorities for 4 more years.



Another thing that was clear from the Freedom of Information requests was that a lot of time was wasted in some boroughs. This was because they tried to get people to use the NHS Continuing Healthcare fund when they were not able to use this fund. This shows that local authorities work in different ways. Some local authorities have ways of checking if a person should be able to use a fund or service before they are then passed over.



Also the Freedom of Information requests gave very little information about people who were made to move into residential care after the Independent Living Fund closed.

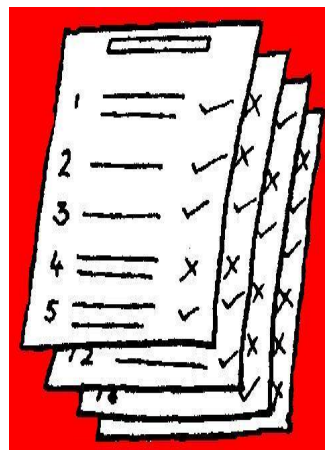


At the moment no London borough that we know about has put a limit on the amount of money that a person can get for care and support. This is happening in other parts of the country.





Surveys were sent out to London Deaf and Disabled People's Organisations that Inclusion London have the contact details of. 14 organisations filled in and sent back the surveys, 11 of these organisations worked in a borough and 3 organisations worked across London. As well as this 1 organisation sent in full information in freeform text.



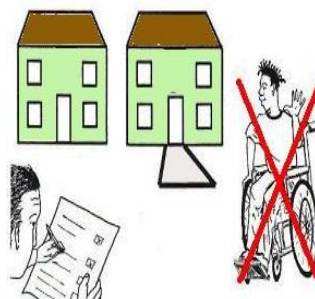
Most of the organisations (8 out of 12), did not want to give their name. This shows that they are worried about what their local council may do for speaking out about the bad things that are happening.



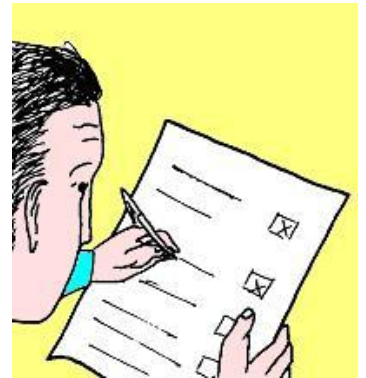
Quite a high number of Deaf and Disabled People's Organisations did not know what their council was doing about protecting the Independent Living Fund money. People do not know what is happening and are waiting for decisions about their future; this can make people very worried and upset.



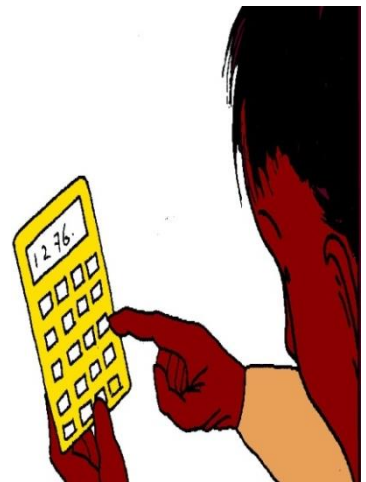
There is a postcode lottery, this means that the experience that people have is different in different areas. The postcode lottery can be seen by the big difference in people's experiences in different boroughs.



Some Disabled People's Organisations gave their local authority a good score for how they were managing the change without having a bad impact on people. Others gave their local authority bad scores, saying that there was bad management which had a bad impact on people.



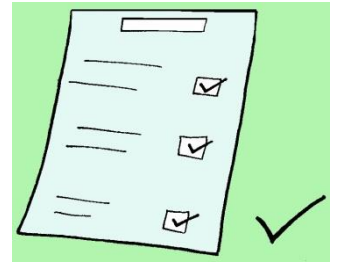
Most Deaf and Disabled People's Organisations said there has been a bad impact after the fund was closed. However, none said that there had then been a good impact on other people that use social care. This could have happened if money was being shared out between those that had support through the Fund and those that did not.



Deaf and Disabled People's Organisations have also been affected in a bad way because of the Fund being closed. This is because people that used the fund have needed more support. This has meant that more of the organisations time and money is being spent on these people at a time when organisations are already too much work and too little funding.



When looking at all of the information that was collected, there have been a number of things that have come up:



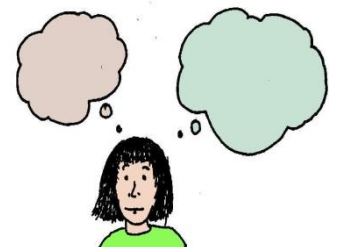
- There is a post-code lottery across Local Authorities, this means that the support or money that you get is different in different areas.



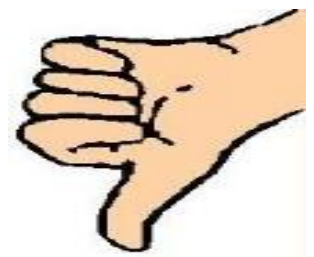
- There has been a bad impact after closing the Fund on the people that used it. This goes from people being very upset and worried, to people having the support that they need each day, taken away.



- Local Authorities are working in different ways around how they decide if a person should try to get NHS funding.



- There are problems with the way that care and support are working in local authorities and how the Care Act is being put into place.



- The support that was given through the Independent Living Fund was very good.

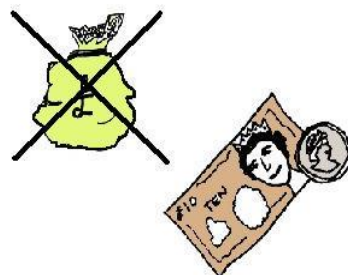




- Deaf and Disabled People's Organisations are very important for making sure Deaf and Disabled people know about and are supported to use, their rights.



Closing the Independent Living Fund has meant that support has been taken away from Disabled people with high support needs, even though it was said in June 2015 that this would not happen.



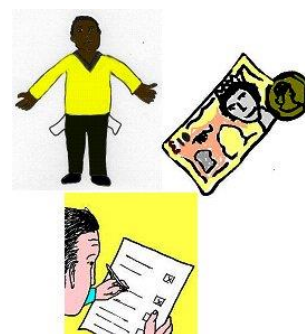
Where support has been kept the same, this is only because the Government is paying money to local authorities for people that used to use the Independent Living Fund. This money was only given to local authorities because of campaigning by Disabled people, our organisations and other supporters.



In summary, closing the Independent Living Fund is a clear step backwards in independent living support for Disabled people.



How local authorities are putting the Care Act 2014 into place needs to be looked at. People's experiences of going through a reassessment are showing big problems with the way that assessments are being done.



They do not put the Disabled person at the centre of decisions. Decisions about money for care and support are being made in a way that takes away people's choice and control and affects people's well-being. Choice, control and well-being are all part of the main duty in the Care Act.



The experiences of people that used to use the Independent Living Fund are the same as the experiences of other people that use adult social care. They are all finding it difficult and are not getting the right amount of support to access full choice, control and independence.



The Care Act 2014 says many good things. The problem is that there are not enough things in place to make sure that local authorities are not breaking the law. This means that it is up to Disabled people, who have the biggest barriers in society, to make sure that local authorities work in line with the law.



Even when a few people have the confidence to stand up to local authority decisions or take a legal case, the cuts to legal aid make this even more difficult.



There is an urgent need to think again about how Disabled people are supported to live independently. Disabled people who use independent living support must have an important role when thinking about new ideas.



There must be enough funding so that Disabled people really can be a part of these ideas and decisions.



This also needs to happen quickly. It needs to happen before people forget what good independent living support looks like and how much disabled people can give when our support needs are met.



**Recommendations: this means things that we think need to happen to make things better for Disabled people**



1. To set up a national system for giving independent living support that is not managed by local authorities. This system should be based on a person's needs; it should be free and paid for through taxes.



This system should use the learning from the Independent Living Fund. It should also be used as a way of making sure that Disabled people's rights under the UN Convention of the Rights of Persons with Disabilities are fully met across the country.

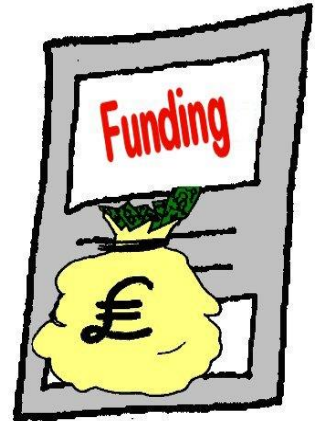


2. An independent living **task force** should be set up and led by Disabled people and social care service users. This group should be at the centre of getting together ideas for setting up a national system.



**Task force:** this is a group set up to look at an area of work, here this would be a group to look at independent living.

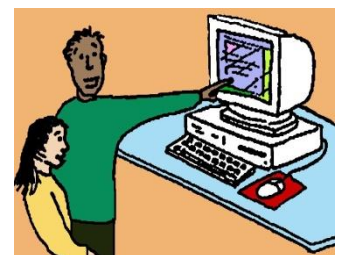
3. The right amount of money needs to be spent on independent living. This is to make sure that Disabled people have the support that we need in all areas of our lives. This should also make sure that we can get and keep the Personal Assistants that we need and that they have the right skills and experience.



4. The right amount of money should be spent so that independent living support in the community is good quality and fully accessible.



This also means services run by Deaf and Disabled People's Organisations. This should be done to make sure that Disabled people can set up, manage and keep their independent living support.



5. Research should be done to get information about why it makes good business sense to spend the right amount of money on independent living support for Disabled people.





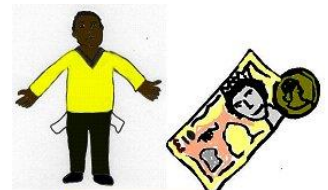
6. An evaluation needs to be done on how the changes to legal aid affect Disabled people's access to justice. As well as this, ideas for fixing these problems should be put forward to get rid of the barriers that these changes have made.



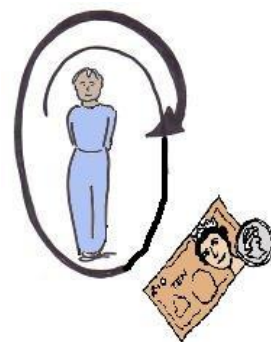
7. A national way of checking up on Local Authorities needs to be put in place. This is to check on how well they are putting the Care Act into place. There should be information about:



- The way that assessments are done
- The types of support that are paid for, for example home support, support to get out and support with personal care
- The amount that can be paid each hour that is set by local authorities
- The choices that Direct payment users have for managing their budgets
- How the council decides to spend its money and what impact this has on people
- There should be something done when local authorities break the law



8. The money given to local authorities for people that used to use the Independent Living Fund should be protected. This means that it can only be spent on the people that used to use the Fund.



9. The Independent Living Fund money paid to local authorities by the government needs to carry on until a national social care system is up and running. This money should keep on being paid by government and should not be managed by local authorities.



10. There should be better ways of sharing good practice between different local authorities and different areas of adult social services.



11. Local Authorities should make sure that staff working in adult services have good training about the Care Act 2014. They should also have good training on employment law that is used by people who employ their own staff.



12. Make sure that local authorities have the right amount of social care staff with the right experience to carry out assessments and reviews. This should make sure that Disabled people are able to take part in all decisions about their care and support.



13. Money should be spent on Deaf and Disabled People's Organisations so that they can support independent living. A new aim is needed so that there is a Deaf and Disabled People's Organisation in every Local Authority.



There needs to be enough money for this to happen. This will also make sure that there is enough funding to keep our organisations going strong.



14. Work needs to be done to try to get more people to want to work as Personal Assistants. This work should be led by Disabled people.

