

People First

a voice for people with learning difficulties

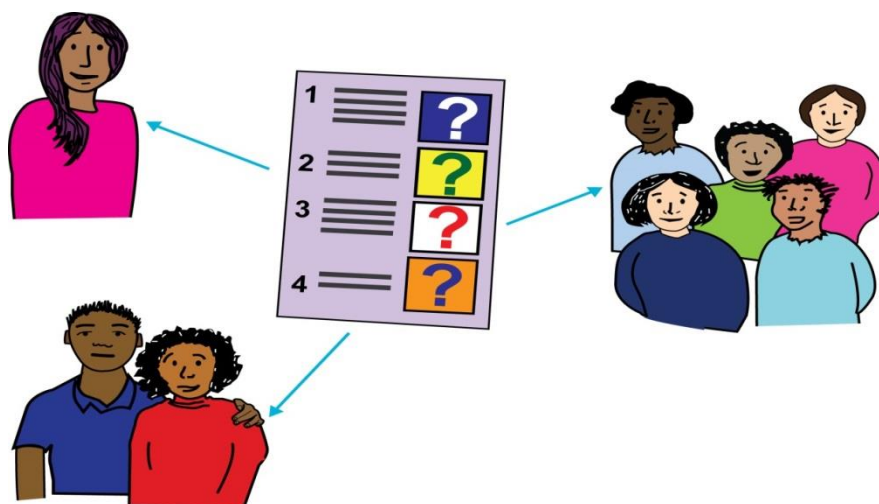


Barnet Centre for
Independent Living



PEOPLE'S CHOICE

Cuts Impact Action Now Research Report Summary



Research into the impact of cuts and changes to benefits and services on local people with learning difficulties in the London Borough of Barnet

This research was done by People First (Self Advocacy) together with People's Choice at Barnet Centre for Independent Living

A Summary of the Cuts Impact Action Now Report

1. Introduction

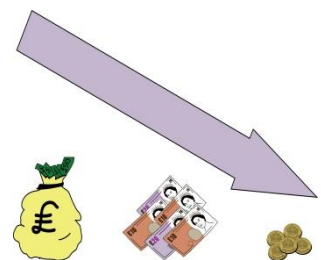
People with learning difficulties are one of the groups of people that are most left out of society. They are also one of the poorest groups of people. For people with learning difficulties, some of the main barriers to being a part of society are:

- Information not being accessible
- Not having the advocacy and support that they need
- Discrimination

These barriers mean that it is difficult for people to get their voices heard, take part in society and have control over the decisions in their lives.

This research was needed because there were so many local and national cuts and changes to benefits and services. There are facts and numbers about how the cuts and changes affect the amount of money that people have.

However, there is no research into how cuts and changes affect people's day to day lives.



By doing this research we are showing how important it is for people with learning difficulties to have their voices heard and their experiences understood.



We would like to thank Trust for London for giving us the funding to make this project happen. We would also like to thank the John Ellerman Foundation and the Persula Foundation for funding the organisation costs of People First (Self Advocacy). This meant that we could run a project of this size.



The Cuts Impact Action Now research aims to:

- Make sure that people with learning difficulties have a strong voice in policy
- Get information about the impact that cuts and changes to services and benefits have had on the lives of people with learning difficulties
- Test out a model for getting information from people with learning difficulties
- Make sure decision makers and organisations that run services know how the cuts and changes are affecting the lives of people with learning difficulties
- Make sure that cuts and changes do not affect people with learning difficulties so badly



2. Background

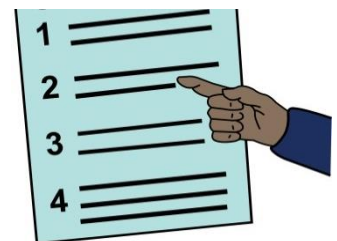
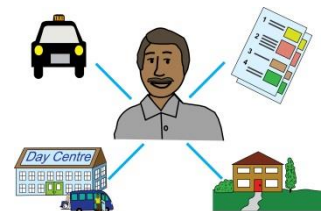
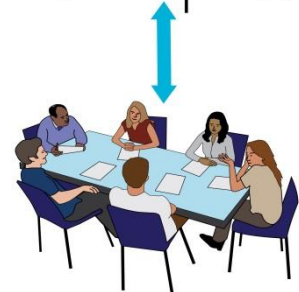
The Cuts Impact Action Now research project was done together by two organisations:

- People First (Self Advocacy), a national user-led organisation.
- People's Choice at Barnet Centre for Independent Living, a local user-led self-advocacy group which will be called Inclusion Barnet from 26th January 2016.

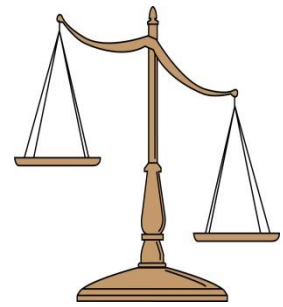
To understand what is happening in the lives of people with learning difficulties, it is important to know about the most important cuts and changes that people are going through.

Below we have written about some of the most important things that are affecting the lives of people with learning difficulties:

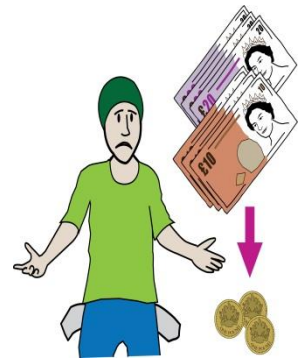
Life before the cuts and changes: even before the cuts and changes started, people with learning difficulties did not have equal access to a lot of things in life. They did not have equal access to health or education. They did not have equal opportunities in work, with less than one in ten people with learning difficulties in work.



They did not have equal access to justice: this means that when they were a victim of a crime or treated in an unfair way, they did not have a fair chance of reporting crimes, taking crimes to court or getting a result.



National changes to benefits and support: there have been big cuts and changes to benefits and support from the government, this is called Welfare Reform. This has meant that many people with learning difficulties now get less money or no money from the Government. Below are some of the changes that have happened:



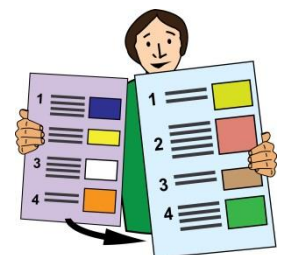
- The Independent Living Fund closing: this was money that people could use to get the care and support that they needed to live independently.



- A benefit cap: this means that the benefits that a person gets cannot go over a certain amount of money.



- Personal Independence Payment: this is now being used in the place of the Disability Living Allowance.



- Getting rid of the Spare Bedroom Subsidy, this is also known as 'The Bedroom Tax'. This means that some people will get less money in their Housing Benefits



- The new Employment and Support Allowance: this is now being used in the place of Incapacity Benefits and some other benefits.



- Universal Credit: this is a new way that the government will be paying benefits. It brings together many benefits into one payment.



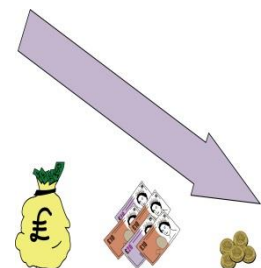
Changes to services: there have been big cuts to the money that local authorities can spend on local services and support. This has meant that people with learning difficulties now have to pay more for support and services.



There have been cuts to funding for local self-advocacy groups. There have been cuts to Legal Aid, which is the support people get to take cases to court when they feel that they have been treated in an unfair way. As well as this, the Equality and Human Rights Commission helpline for taking on cases has been closed.



Local changes in Barnet: there has been a 26% cut to the amount of money that Barnet Council has to spend on local support and services. There is no longer any funding from the Council for the Barnet Learning Disability Parliament.



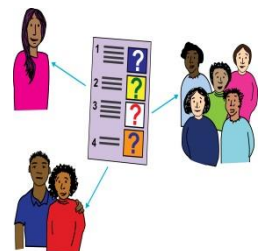
As well as this, many of the services run by Barnet Council have been passed over to a **Local Authority Trading Company** called Your Choice. There have been worries about the services run by Your Choice and about the way that Your Choice makes decisions.



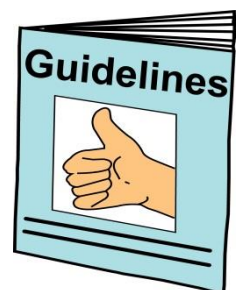
Local Authority Trading Company: this is a way of councils running their services like businesses. Working like a business means that the company can make money; however any money that the company makes must either go back into the company to make their services better or go back to the council.

3. How the research was done

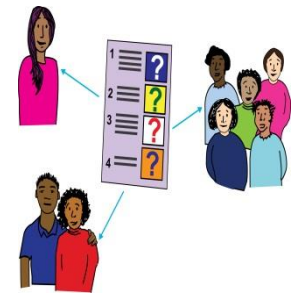
The research was done between January 2014 and September 2014. To get information from people with learning difficulties in Barnet we did 35 interviews and had 3 focus groups. We also did 3 interviews with service managers.



The interviews were done using an interview guide. The guide had information that was used by the person running the interview. This was so that they knew which areas to talk about and how to run the interview. Some of the areas that were looked at in the interview were: housing, transport, advocacy and support. Each person that we interviewed gave personal information. This was to make sure that we had people with different backgrounds taking part in this research.



When we had all of the information, we used **triangulation** to write about what had been found out. We used **quotes** from people that took part in the research.



Triangulation: this is a way of carrying out research. You use two or more ways of getting information about the same thing. By doing this it means that what you find out has more chance of being right. In this research we used interviews and focus groups; we also interviewed both people with learning difficulties and service managers.

Quotes: this is when you copy what another person has said or written. In this research we used quotes from people who took part in the interviews and focus groups.

The main areas or issues that came out of the research were then written about. This was then used to put together recommendations; these are the things that we think should be done to make the lives of people with learning difficulties better.



The recommendations were written so that Barnet Council, other local authorities, national government and health and social care organisations could use the information to make good changes for the future.



4. What we found out

Assessments and reviews seemed to be done in a way that did not really look at the needs of people with learning difficulties.



Almost everyone that was a part of the research said they thought that the main reason for going through assessments and reviews was to cut their support.



Of the people who had already had cuts in support and services, 80% felt that in reviews and assessments either:

- Important information about their needs had been left out
- Or, that they could not get their voices heard.



People felt that they were not given the chance to understand what was happening. For many people this was because they did not have accessible information or support. This meant that they could not be a part of the changes, make decisions or make sure they were listened to.



People did not understand what was happening: they were not given information about how decisions are made and therefore could not really take part in decisions about their lives.



The research showed in a clear way that people did not have enough information about the planned cuts and changes to services and benefits. They did not have information about what the cuts and changes would mean for them.



Most of the people that were interviewed did not know about the planned cuts and changes to services and benefits. People are going into national benefit and local authority assessments without good information or the support that they need to talk about their needs.

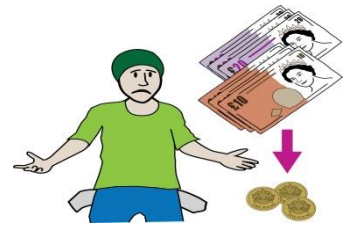


This made it clear that there is a need for accessible information and **independent support** in reviews and assessments.



Independent support: this is a person that supports someone to understand information and to make decisions. Independent means that the supporter does not have links with other organisations or people that are part of a person's care and support. This means that they work 100% for the person that they are supporting.

How people were affected by cuts to benefits, support and services and having to pay more money for care and support.



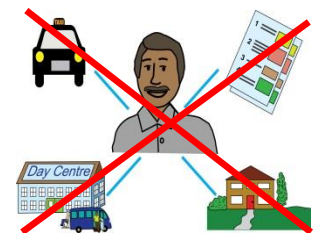
Of the people with learning difficulties interviewed who had been through a review or an assessment, everyone had gone through some kind of cut. Over half of these people had been through more than one cut or change to a service.



People with learning difficulties had no support after cuts had been made. People had to use support from people that they knew, to deal with what was happening.



It was clear that cuts and changes to services and benefits meant that people were less able to live independent lives and take up opportunities.



People had to use support from family and other people in their lives to live their day to day life, pay for things and get out and do things. For some people this felt like losing their independence.



Support was seen as very important when going through assessments and after assessments, to deal with cuts and changes. The research showed that people needed a lot of support to:



- Go through a review or assessment
- **Appeal a decision**
- Deal with cuts and changes to support and services after a decision had been made



Appeal a decision: when a person is not happy with the result of an assessment or review, a person can ask for the information to be looked at again to see if the decision can be changed.

In most cases, when a person had support in assessments and appealing a decision, they got a good result. There were many people who did not have support and therefore did not appeal a decision. Some people did not know that they could appeal a decision.



People know what independence looks like and what they need.

This research showed that people with learning difficulties have not been listened to properly. It also showed that they have not been a real part of the decisions that are being made about their lives.

However, it was clear that people with learning difficulties:

- Know what they need
- Know what independence looks like in their life
- Know what works for them in areas such as support, benefits, having the right place to live, work, volunteering and getting out and about

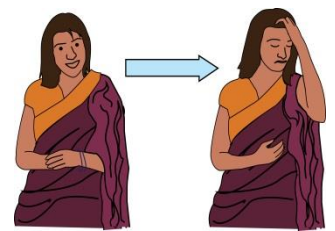


5. Conclusion

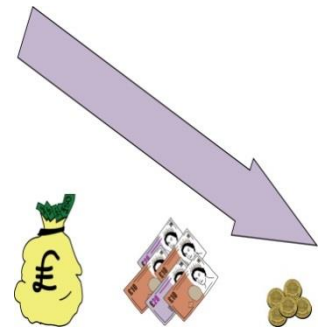
The Cuts Impact Action Now research project has shown that there are lots of barriers in the lives of people with learning difficulties. Welfare Reform and cuts to local authority money mean that there are now even more barriers.



This research found that changes to benefits, services and support did have a big impact on people's lives. This affected the lives of people with learning difficulties in a bad way. It meant that:



- People had less support and services
- Their health and mental health got worse
- People were less able to take up opportunities
- People felt less independent
- People had less money



Most people thought that the aim to spend less money was being seen as more important than people's needs. It was thought that the people making decisions and carrying out reviews and assessments did not understand all of the cuts and changes that people were going through at the same time. They did not understand how all of these cuts and changes together were affecting people's lives.



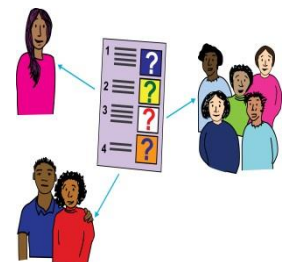
People could not really take part in reviews and assessments because they did not have accessible information or independent support. This meant that people could not be a part of decisions about their own care and support. This was also a problem when people were appealing review and assessment decisions.



After a decision had been made, there was nothing in place to make sure that people could deal with cuts and changes. Overall, reviews and assessments were felt to be a very bad experience.



This research project has set up a **model** for collecting evidence from people with learning difficulties at a local level. This model will be used in other local areas to make sure that people with learning difficulties can do their own research and use this to campaign.



Model: this is a way of doing something that has usually been tried and tested.

The model will also support local people with learning difficulties to be part of a national voice to make change happen at a national level. This will be done through working with People First (Self Advocacy).



6.Recommendations

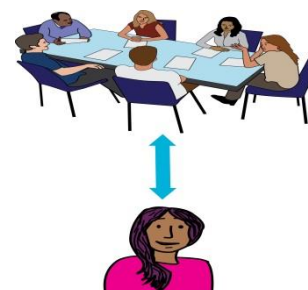
Using the information that we found out in this research, these are the things that we think should be done to make the lives of people with learning difficulties better.



The recommendations below are aimed at Barnet Council and national government departments. However, many of the recommendations that talk about Barnet Council should also be used by other councils.



The recommendations in this report were made so that organisations and decision makers can work with people with learning difficulties in a better way.



The recommendations aim to make reviews and assessments work better for people with learning difficulties. They also try to make sure that the cuts and changes to benefits, support and services do not affect people with learning difficulties so badly.



Recommendation 1: Being a part of assessments and reviews

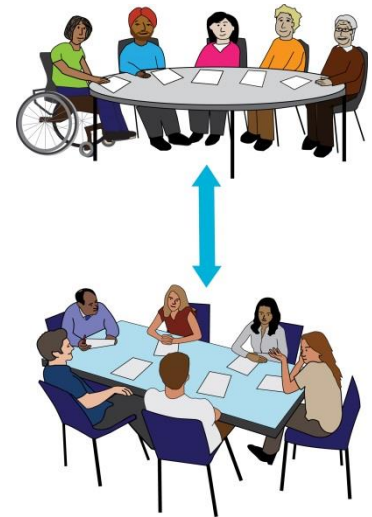
Barnet Council needs to look at the way that they do assessments and reviews. The Council needs to make sure that there is accessible information about:

- When assessments and reviews will happen
- What each part of the assessment or review is about
- How much the local authority is looking to cut from each person's support
- Why cuts are needed
- When cuts or changes will happen
- What choices each person has

This will mean that people with learning difficulties can take part in the decisions about their care and support. This should start by April 2016 and be finished by March 2017.



How will we know it has been done? We will work with Barnet Council to put together guidelines and training about how assessments and reviews should be done. We will also tell Barnet Council what information is needed to make assessments and reviews accessible for people with learning difficulties.



Recommendation 2: Getting my voice heard

Barnet Council should carry out an assessment to decide whether there should be an independent support service for people with learning difficulties. It would be a service that all people with learning difficulties could use when going through assessments and reviews. This service should make sure that people can:



- Get ready for assessments
- Show their needs in an assessment
- Think through the choices that they have
- Talk about their needs and make sure that they have been understood
- Get support after a decision has been made so that they can deal with any cuts or changes to support, services or benefits.



This will make sure that people have choice, control and an equal voice in the decisions being made about their lives. Barnet Council should do the assessment and decide whether this type of service is needed by 30th June 2016. The service should be in place by April 2017.

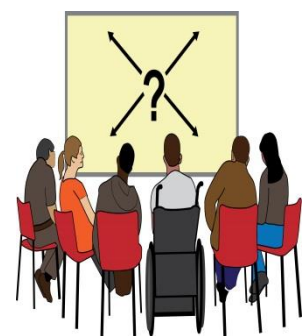


How will we know it has been done? We will work with Barnet Council and the **Commissioning Team** to make sure that if needed, this service is set up for people with learning difficulties.

Commissioning Team: this is the team of people that work for the Council in a local area to decide what services are needed and which is the best organisation to run the service.

Recommendation 3: Understanding the needs of people with learning difficulties and the barriers that they face

Social workers and other professionals in Barnet that are part of assessments and reviews should have user-led learning difficulty training. This will make sure that professionals understand the needs and life experiences of people with learning difficulties.



This training will also have information about how to tell people with learning difficulties about the decisions made after assessments and reviews.



It will look at how to tell people about bad news, such as cuts in support. There should be training for staff who are already part of assessments and reviews. Training should also be a part of **inductions** for new staff. This should start in April 2016.



Induction: this is done when a person starts a new job. It is made up of training and information about their new job and the organisation.

How will we know it has been done? This will be talked about with Barnet Council. The training will be put together with a number of people and organisations that have skills and experience of assessments and reviews.



Recommendation 4: What happens after an assessment or review decision has been made

Cuts to the money that local authorities have to spend mean that less and less people are able to get local authority support. However, this does not always mean that a person does not need support; it can also mean that the local authority does not have the money to pay for this support.



The local authority still has a **duty** to make sure that people with learning difficulties can get other support, even if it is not paid for by the local authority. Therefore, this recommendation is about what happens after a person gets a cut in their support or loses all of their support.



Duty: this is something that the government, local authorities or organisations paid for using government money, must do by law.

For people with learning difficulties who have had a cut or have had all of their support taken away, Barnet Council should make sure that a plan is a part of the assessment. This plan should have information about where a person can go to get extra support.



There should be information about organisations that give support in different areas of a person's life. There should also be information about activities in Barnet.



They should make sure that each person has the support that they need to make contact with these organisations. This support could come from a family member, a carer or an independent supporter from a local organisation.



There should also be an impact meeting after cuts or changes to support have been made. This meeting is to find out about how the cuts or changes have affected the life of the person with learning difficulties.

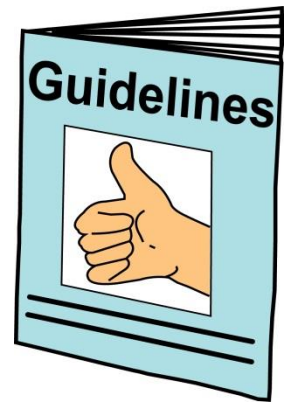


The meeting should look at:

- National benefit changes
- Local authority support changes
- Changes to local services
- Changes to service charges



How will we know it has been done? This will be part of the guidelines that we will write with Barnet Council around making assessments and reviews accessible. An impact report should be written by Barnet Council at the end of each year.

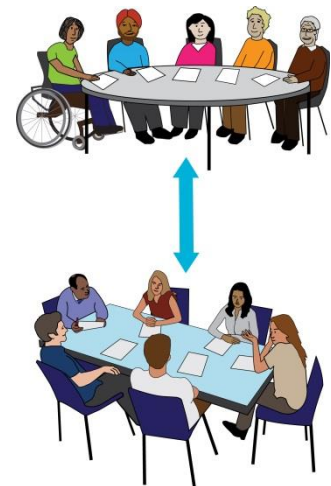


Recommendation 5: Accessible written information

All written information and communication from national government departments and Barnet Council should be accessible to the person using it. A People First (Self Advocacy) campaign to make sure that this happens will start in January 2016.



How will we know it has been done? This will be a part of the assessment guidelines and learning difficulty training that we will put together with Barnet Council. People First (Self Advocacy) will make sure that this is done by national government departments through national campaigning work.



Recommendation 6: Cumulative Impact Assessment

Cumulative Impact Assessment: this assessment is a way of looking at all of the cuts and changes that are happening to different groups of people. It is there to make sure that any cuts or changes to services or benefits that the government or local authorities make, do not affect anyone in an unfair way.

There needs to be a Cumulative Impact Assessment done for disabled people. The assessment also needs to give information about people with different impairments; one of these groups is people with learning difficulties.



The assessment needs to look at national welfare reform. It also needs to look at cuts to the amount of money that local authorities have and how this affects local services and activities, service charges, as well as local authority support.



This needs to be in place to make sure that disabled people and people with learning difficulties are not being affected by changes in an unfair way, which this report shows is happening.



This will make sure that all local authority and national government decisions are made in a better and more equal way. This will start once the second part of the Cuts Impact Action Now project has been done. This is where the project will support other user-led self-advocacy groups to do their own research in their own local authorities around the UK. Once we have worked with other local groups, there will be more information about the impact of cuts and changes on people with learning difficulties.



How will we know it has been done?

People First (Self Advocacy) will work together with national organisations to campaign for a Cumulative Impact Assessment.

Recommendation 7: Taking part, having choice, control and a voice

It should not be thought that people with learning difficulties do not have views and cannot make decisions. Every chance should be taken to make sure that each person can take part as much as possible in decisions about their support.



People should get the information and the support that they need to be able to do this. This should be done in line with the **wellbeing principle** of the Care Act 2014. Barnet Council should show how they are meeting this duty. Barnet Council will be asked for information about how they are doing this at the end of each year.



The wellbeing principle in the Care Act means making sure that people:

- Feel valued and respected
- Feel happy and healthy
- Are safe from abuse
- Have control over their day to day life
- Can take part in work, education, training or other activities
- Have a life and enough money
- Have a family and personal life
- Have the right place to live
- Can be a part of society

How will we know it has been done? From the information in this report, it is clear that this is not happening. Therefore, information will be asked for from the Council about how they are meeting the wellbeing principle under the Care Act 2014 for people with learning difficulties.



January 2016



Trust for London
Tackling poverty and inequality



For information about this report please email People First (Self Advocacy) at:

peoplefirstltd@gmail.com