

People First

a voice for people with learning difficulties

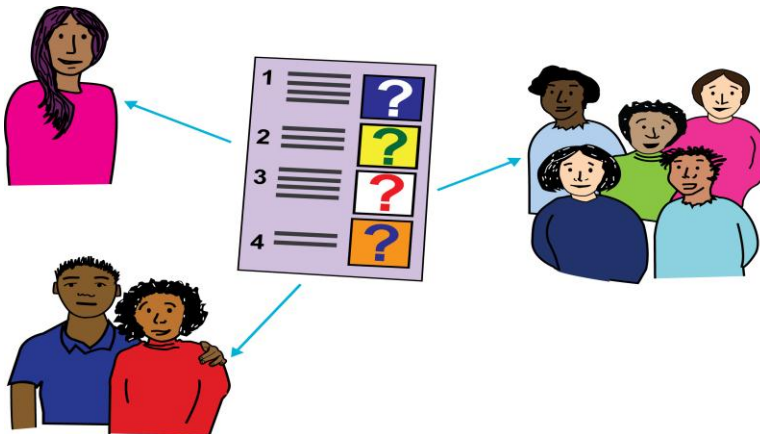


Barnet Centre for
Independent Living



PEOPLE'S CHOICE

Cuts Impact Action Now Research Report



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

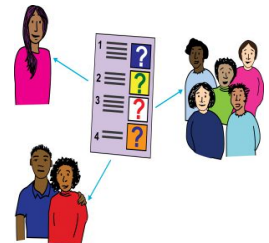
September 2015

Important words in this report

Impact: in this report this means how the cuts and changes affect people's lives.



Research: in this report this means when a person or group of people look at what is happening in the lives of people with learning difficulties. There are different types of research.



For example, research can be done by sending out questionnaires, speaking to people face to face in interviews or looking at documents and reports that other people have written.



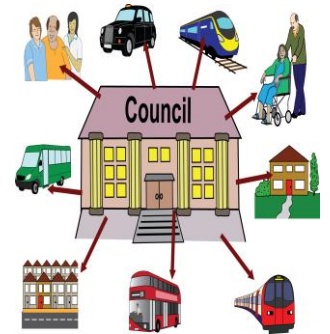
Evidence: this is when you get facts or information to show what is happening.



Policy: this is a set of ideas or plans about what should be done by an organisation. In this document we talk about government and local authority policy, which means what they plan to do in different areas such as disability, health, education and work.



Local authority: this is the local government organisation that is responsible for the services in a local area such as transport, social care and health services. In this document we talk about local authorities in general and Barnet Council which is the local authority organisation in Barnet.

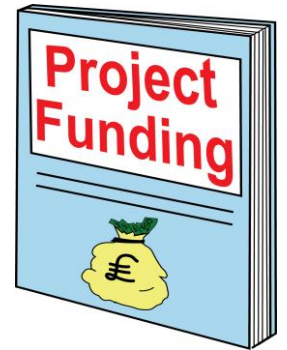


Model: This is a way of doing something that can usually be used by other people or organisations. In this document the model is a way of carrying out research with people with learning difficulties that other self-advocacy organisations can use in the future.



The people and organisations that we would like to thank

The Cuts Impact Action Now research project was paid for by Trust for London. People First (Self Advocacy) and People's Choice at Barnet Centre for Independent Living would like to thank the Trust for their support in making this research possible.

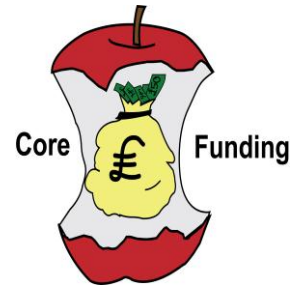


Both organisations would also like to thank the Trust for their important work in supporting projects that push for social change to support groups of people that are left out of society. This type of work is difficult to get funding for and the Trust's support is what made the Cuts Impact Action Now research project possible.



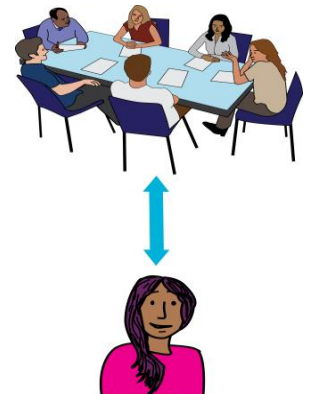
We would also like to thank a number of people and organisations for their support in this research project:

- The John Ellerman Foundation and the Persula Foundation for funding People First's **core work**. This made sure that the organisation had the money to carry out a project this big.

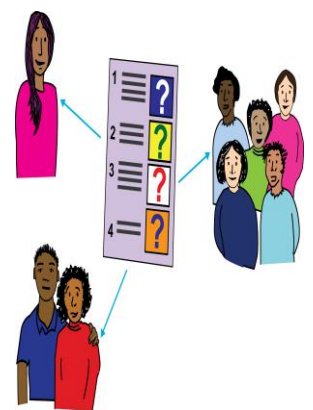


Core work: this is the main work of the organisation that is not project work.

- The local organisations that helped us to get in touch with people with learning difficulties in Barnet.
- The national organisations that shared the information needed for this research.

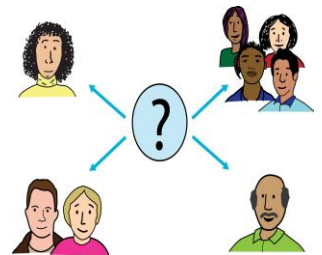


Most of all we would like to thank the people with learning difficulties, supporters and service managers in Barnet, who took part in this research. We would like to thank them for being a part of the interviews, focus groups and for sharing their views and experiences. We would also like to thank them for trusting both organisations with the information that they gave and for being so open with us about their experiences.



About the information in this report

This report was written using the evidence collected by the People First (Self Advocacy) Research Team. People's Choice at Barnet Centre for Independent Living supported this research and made it possible. The information in this report comes from the views and opinions of the people that took part in the research and not from the organisations that have carried out and supported this research.



The Research Team

The research was carried out and the report was written by:

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A short message from the Director of Policy and Campaigns, People First (Self Advocacy)

When the Government started making cuts to benefits and services, People First wanted to find out how the cuts were affecting people with learning difficulties. We also wanted to find out what people knew about the cuts and changes that were happening.



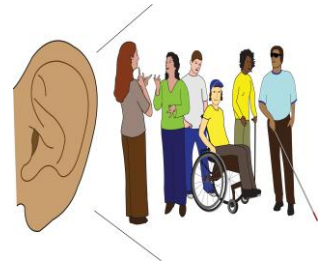
We wanted to make sure that there was a way for people with learning difficulties to get their voices heard by decision makers.



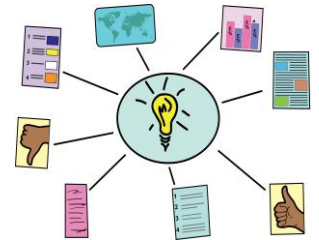
From experience we know that sometimes the Government, local authorities and services do not give people with learning difficulties information that is accessible to them. A lot of the time, decisions are made and people with learning difficulties are the last to know about them.



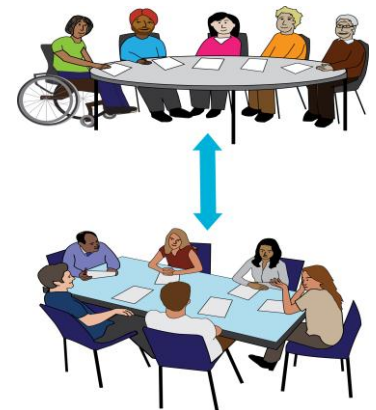
This is why the Cuts Impact Action Now project is so important. It will make sure that decision makers and professionals know what is happening at a local level and that people with learning difficulties have a voice.



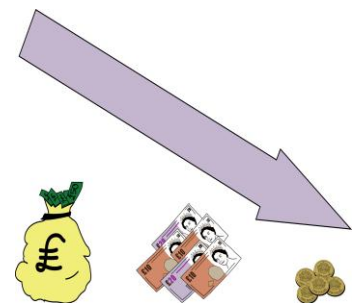
We decided to work with People's Choice at Barnet Centre for Independent Living to test run this way of getting information from people with learning difficulties.



People's Choice has a history of campaigning and runs the local Learning Disability Parliament. The Parliament has been a very useful way of getting in touch with people with learning difficulties, organisations that run services, other organisations and Barnet Council.



This research project has shown that decisions about people's care and support are being made based on the cost, instead of people's needs. There is a gap between the support that people need and the support that they are getting.



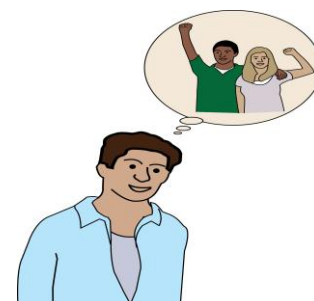
It has also shown that there is a problem with the way that cuts and changes are being put into place. It has shown how important support is for people with learning difficulties. Support in assessments, reviews and day to day life was very important in making sure people's views were listened to.



As a person with learning difficulties, I know the barriers that people have to face. I hope that this research project can be the start of more local groups using this model. I also hope that decision makers use the findings from this research and put into place the recommendations that have been made.



I hope that together we can start to make independence, choice and control a real life experience for people with learning difficulties.



Andrew Lee

Director of Policy and Campaigning
People First (Self Advocacy)

1. Summary of the Report

1.1. 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
- 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 national cuts and changes affect people's day to day lives.

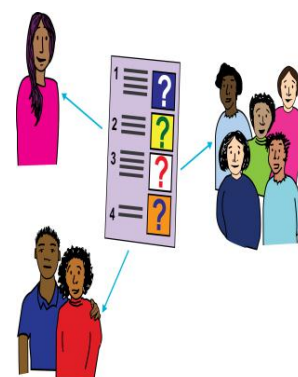


By doing this research we are showing how important it is for people with learning difficulties to have their voices heard and their experiences understood.



The Cuts Impact Action Now research aims to:

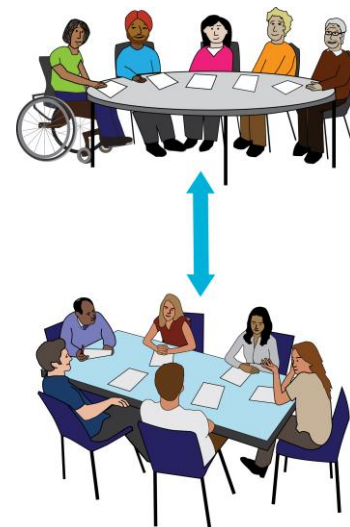
- Make sure people with learning difficulties have a strong voice in policy
- Get information about the impact that cuts and changes to services and benefits have had on the lives of people with learning difficulties
- Test run a model for getting information from people with learning difficulties
-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



1.2. Background

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

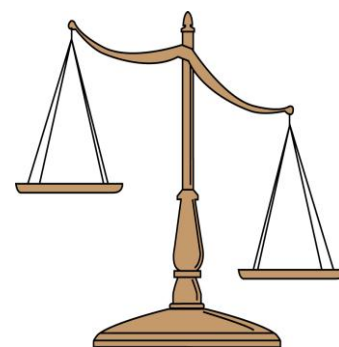
- People First (Self Advocacy), a national user-led organisation
- People's Choice at Barnet Centre for Independent Living, a local user-led self-advocacy group which will be called Inclusion Barnet from 26th January 2016.



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



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.



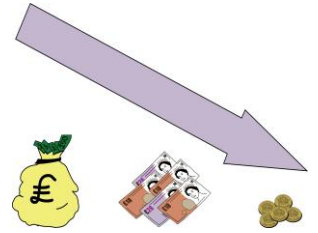
National changes to benefits and support: there have been big cuts and changes to benefits and support from the Government, this is called Welfare Reform. This has meant that many people with learning difficulties now get less money or no money from the Government. Below are some of the changes that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



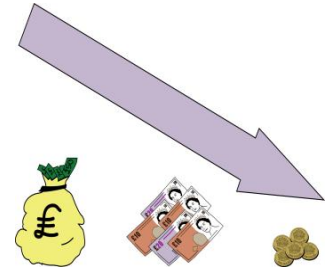
- The New Employment and Support Allowance: this is now being used in the place of Incapacity Benefits and some other benefits.



- 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.

1.3. 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 had 3 interviews with service managers.



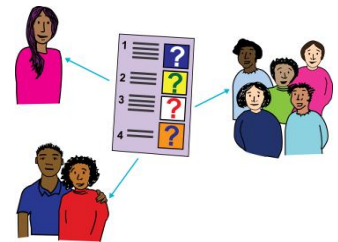
The interviews were done using an interview guide. The guide had information that was used by the person running the interview so that they knew which areas to talk about and how to run the interview.



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 this research report 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 there is more chance of what you find out being right.

Quotes: this is when you copy exactly what has been said or written by another person. Here we used quotes from people who took part in interviews.

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.



1.4 Findings: 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 person that a person with learning difficulties can use to make decisions and go through assessments and reviews. 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.

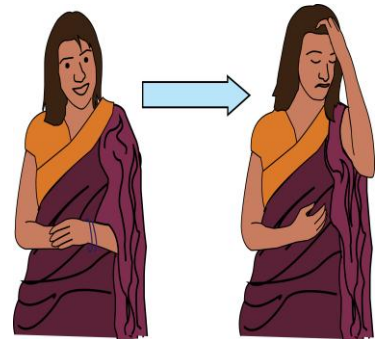
Of the people with learning difficulties interviewed who had been through a review or an assessment, everyone had gone through some kind of cut. Over half of these people had been through more than one cut or change to a service.



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 cope 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



1.5 Conclusion

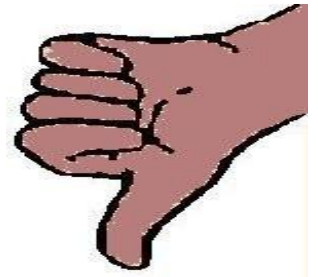
The Cuts Impact Action Now research project has shown that there are lots of barriers in the lives of people with learning difficulties. Welfare Reform and cuts to local authority funding mean that there are now even more barriers.



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.



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).



1.6 Recommendations: using the information that we found out in this research, these are the things that we think should happen 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.

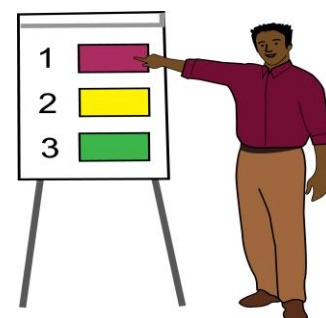


The recommendations in this report were made so that organisations and decision makers can work with people with learning difficulties in a better way. The recommendations are aimed at a number of people such as **policy makers**, decisions makers and health and social care professionals.



Policy maker: this is a person that usually works for the Government and helps to make new laws and rules.

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.



Below is a summary of the seven recommendations that we have made:

- Barnet Council should make sure that accessible information is given to people with learning difficulties so that they can really take part in reviews and assessments.



- Barnet Council should pay for an independent support service that can be used by people with learning difficulties. This is to make sure that the voice of people with learning difficulties can be heard in reviews and assessments.



- Barnet Council should train health and social care professionals so that they better understand the needs of people with learning difficulties and the barriers that they face.



- After an assessment or review when a decision has been made to cut a person's support, Barnet Council should make sure there is a plan in place. This plan should be about where a person can get the extra support that they need and it should have information about organisations that give support in Barnet.



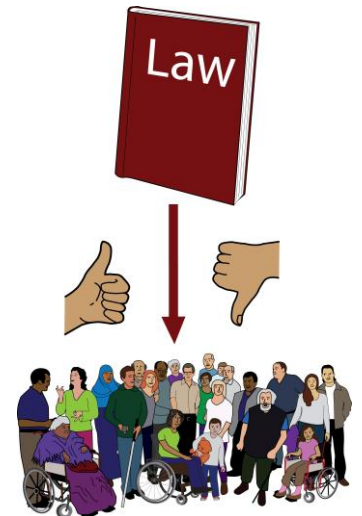
- All written information and communication from the Government and Barnet Council should be accessible to people with learning difficulties.



- A cumulative impact assessment should be done to look at how cuts and changes have affected disabled people. This should look at all of the local and national cuts and changes that have happened. This assessment should look at how cuts to local authorities' money have affected local services and activities, service charges and local authority support.



- Local authorities should take every chance to make sure that people with learning difficulties can fully take part in decisions about their support. This is an important part of the Care Act 2014. Every year Barnet Council should show people with learning difficulties how they are doing this and meeting their duties under the Care Act 2014.



2. Introduction

This section has information about why we decided to carry out the research, how important it is that national and local organisations work together and the aims of the research.

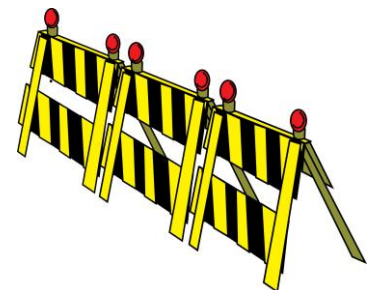


2.1 Why we decided to carry out this research project

2.1.1 Barriers: It is well known that it can be very difficult for people with learning difficulties to get their voices heard. People with learning difficulties are one of the poorest groups of people. They are also one of the groups that are most left out of society.



There are a number of barriers that stop people with learning difficulties from being a full part of society. These barriers also stop people being a part of the decisions that affect their lives.



Some of the barriers are:

- Not having accessible information
- Not having enough support or advocacy
- Being discriminated against

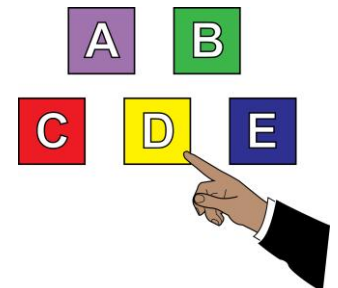


These barriers can mean that people with learning difficulties feel that they do not have power or control. This can then mean that people are not able to speak up and get their voices heard.



2.1.2 Cuts and changes to services and

benefits: There have been a lot of local and national cuts and changes happening at the same time.



Through People First's work and links with other disabled people's organisations we have information about how the cuts affect the amount of money that people have.



However, there is not much information about how these cuts are affecting the day to day lives of people with learning difficulties.



Local authorities no longer have as much money to spend in their local areas. Through People First's work with People's Choice and other local self-advocacy groups we have been told about cuts and changes to local services and support.



The problem is that at no point have national and local cuts and changes been looked at together. This needs to be looked at to see the full effect that this is having on the lives of people with learning difficulties.

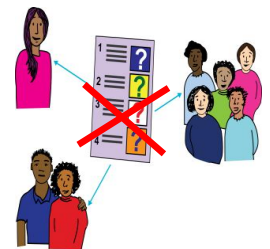


2.1.3 What is happening locally: Different cuts and changes are happening in different local areas. To understand the impact of cuts and changes, it is important to do research at a local level. Only then can we understand the full impact of cuts and changes to benefits and services on people with learning difficulties.



2.1.4 Being consulted and listened to:

Using information from almost 30 years of policy work, People First can say that a lot of the time people with learning difficulties are not **consulted** in an accessible way.



Being consulted/to consult: this is when an organisation person or a government organisation ask people what they think about plans, a document, a new law or a change in the way that something will work.

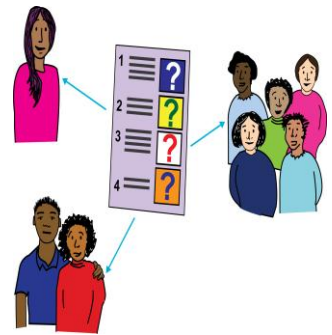
They are not listened to or given the chance to have a strong voice. We have been getting more and more worried about the real life impact of cuts and changes on the lives of people with learning difficulties.



In doing this research, People First is making it clear that people with learning difficulties need to have a chance to have their voices heard and their experiences understood.



We are using this **pilot** research project to test run a way of making sure that the voice of people with learning difficulties is heard in local areas. This model that has been tested in Barnet can then be used in other local areas.



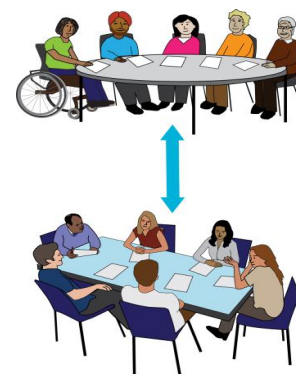
Pilot: this means a test run of something. In this document we are test running a way of doing research and using this to make change happen.

When research has been done in different local areas this will be joined together to make sure that the national voice of people with learning difficulties is heard and that action is taken.



2.2 Why it is important that a national and a local organisation work together

A national and local organisation working together is a good way of collecting evidence. This is because it uses the skills, links and experience of both organisations. Both organisations bring different things to the research.



What People First (Self Advocacy) brings to the research:

- Strong links with other national organisations
- Links with national Government and ministers
- Links with other public organisations such as the Equality and Human Rights Commission
- Expert information about national policy
- An understanding of local policy changes that are happening



- An understanding of the barriers and issues that people with learning difficulties have all over the country



What People's Choice at Barnet Centre for Independent Living brings to the research:

- Links with local people with learning difficulties
- Links with Barnet Council, local service providers and other organisations that work with disabled people in Barnet
- They run the Barnet Learning Disability Parliament and have strong links with the organisations that are part of this
- The Team Leader at People's Choice Co-Chairs the Learning Disability Partnership Board and a member of staff chairs the Speaking Up sub-group



2.3 Aims and Objectives of the Cuts Impact Action Now Pilot Research Project

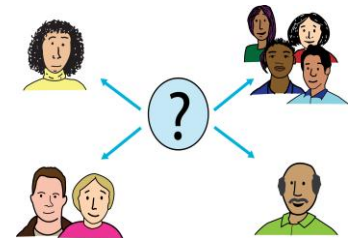


The aims of this pilot research project are:

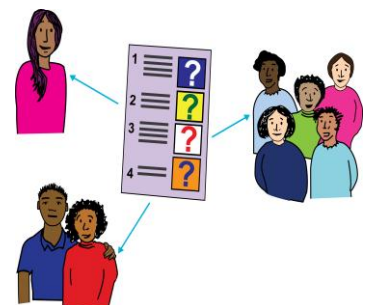
1. To make sure people with learning difficulties have an important voice in local and national policy. It is important that they can speak up about how benefit and service cuts and changes are affecting them.



2. To collect evidence about the impact of both local and national cuts and changes to services and benefits on people with learning difficulties.



3. To make a model for collecting evidence, which other local self-advocacy groups can use to do research. This is so that groups can support people with learning difficulties to have a local and national voice.



4. Make change happen by telling policy makers and service providers about the impact that cuts and changes are having on people with learning difficulties.



5. To make sure that the cuts and changes do not have such a bad impact on people with learning difficulties.

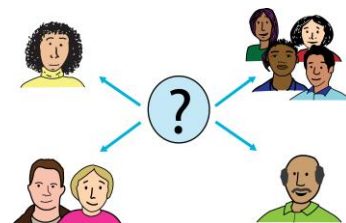


Objectives: How we plan to meet the aims of the project

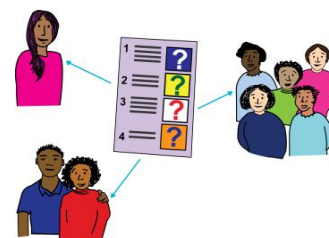
1. Set up an accessible way of collecting evidence about the impact of cuts and changes that includes all people with learning difficulties.



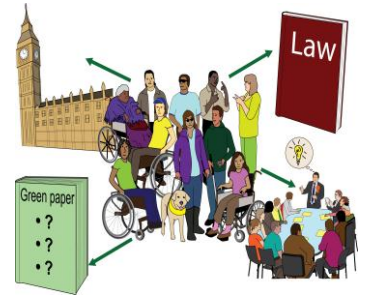
2. Get information about how the cuts and changes in a local area are affecting the lives of people with learning difficulties and their families/carers.



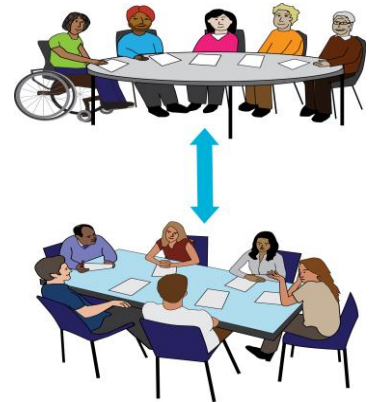
3. Give evidence of the impact that cuts and changes are having on people with learning difficulties.



4. Work with local and national policy makers and service providers to make change happen. This is to make sure that cuts and changes do not affect people with learning difficulties in such a bad way.



5. Set up a model for collecting evidence which can be used in other local areas. This will be used to get a national picture of what is happening and to give a national voice to people with learning difficulties.



6. Set up links and networks for giving evidence to policy makers and service providers at a local, regional and national level.



3. Background

This section has information about the organisations working on the Cuts Impact Action Now Project. There is information about the local and national cuts and changes that may affect people with learning difficulties.



There is general information about people with learning difficulties and information about those that live in Barnet. As well as this there is information about the services in Barnet for people with learning difficulties.



3.1 About the organisations working on this research

People First (Self Advocacy) is a national organisation run and led by people with learning difficulties. The Management Committee members are people with learning difficulties from different parts of the country.



The organisation aims to **raise awareness** of the rights of people with learning difficulties. It supports self-advocacy groups and people with learning difficulties by giving support, information, training and advice. The organisation works to make sure that their voices are heard by the Government.



Raise awareness: this means giving people, organisations or the government information about something that means that they then know more about an area.

People's Choice at Barnet Centre for Independent Living is a local self-advocacy group in Barnet run and led by people with learning difficulties. They aim to raise awareness of the rights of people with learning difficulties in Barnet, making sure that their voices are heard.



The organisation runs 6 self-advocacy groups: The Learning Disability Parliament, Speaking Up, Advocacy and 3 drop-in groups in Barnet. In these groups people talk about issues that Barnet Council and the NHS have asked them to look at as well as about issues that they have with organisations.



They also talk about things that they are worried about or things that are important to them. Some of the issues that have been talked about are: Bedroom Tax, benefits, transport issues, good and bad support and support for carers.

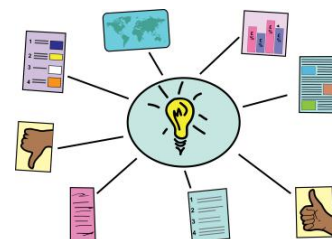


3.2 What the big picture looks like for people with learning difficulties

This section aims to give a picture of what life looks like for people with learning difficulties at the moment. It looks at barriers that people face and the changes and cuts to benefits and services that people are going through.



A lot of the information about cuts and changes to benefits is about disabled people in general. Where possible there is information about people with learning difficulties.



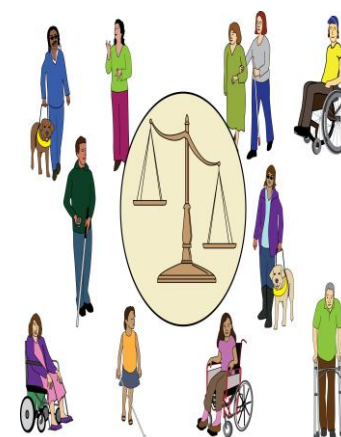
With benefit changes such as Universal Credit, the numbers given may cross over with the numbers given for other benefit changes.



3.2.1 What the big picture looked like before cuts and changes to benefits and services: did people have equal access?



Before the cuts and changes to benefits and services started, there were areas in the lives of people with learning difficulties where they did not have equal access. This section looks at those areas and it is likely that these things will get worse because of cuts and changes that have happened and are now happening.



Equal access to health is a right that people with learning difficulties still do not have. The NHS has been talked about as being ‘unsafe’ for people with learning difficulties.¹ Research into this has shown that the main reasons that people with learning difficulties do not have equal access to health care are:



¹ <https://www.mencap.org.uk/sites/default/files/documents/Death%20by%20Indifference%20-%2074%20Deaths%20and%20counting.pdf>

- Bad communication
- Staff taking too long to find out why a person is not well
- Staff not always being able to tell when a person is in pain²



There are also other things that mean that people with learning difficulties are not as healthy as other people, such as:

- Not having the right housing³
- Not having a job
- Living in poverty: this means not having enough money to live on
- Being discriminated against and left out of society⁴



All of these things together mean that a person is more likely to need to use the NHS. However, when they use the NHS they get a worse service than people without learning difficulties.

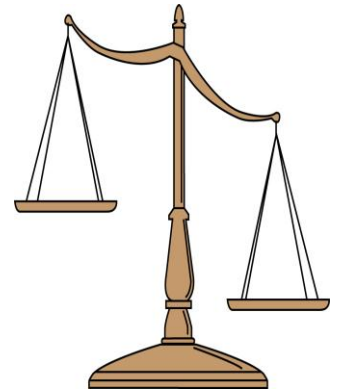


² <https://www.mencap.org.uk/sites/default/files/documents/Death%20by%20Indifference%20-%2074%20Deaths%20and%20counting.pdf>

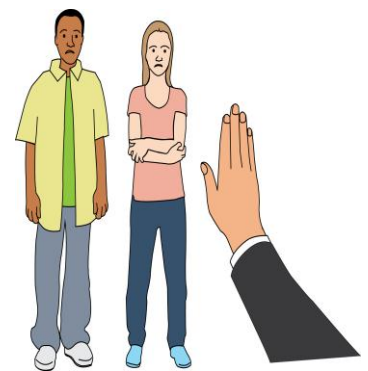
³ The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study, by Dr Pauline Heslop, Ph, Peter S Blair, PhD, Prof Peter Fleming, FRCP, Matthew Hoghton, MRCP, Anna Marriott, MSc, Lesley Russ, RNMH, The Lancet 2014.

⁴ Health Inequalities and people with learning disabilities in the UK, Improving Health and Lives, the Learning Disabilities Observatory, Eric Emerson and Susannah Baines, 2010.

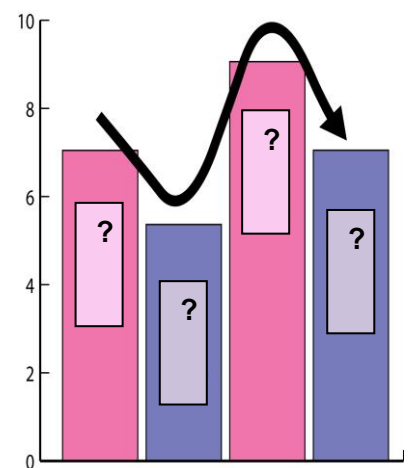
Equal access to education is not possible for most people with learning difficulties. Mainstream education is not an option for many children: this means going to school with other non-disabled children. The latest numbers from 2011/12 show that this is the case for:



- 12% of children with moderate learning difficulties
- 77% of children with severe learning difficulties
- 82% of children with profound and multiple learning difficulties⁵



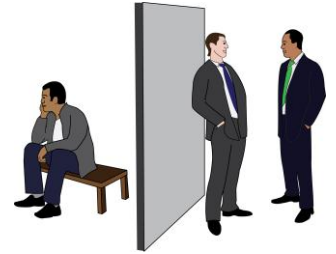
As well as this, accessing education depends on where a child lives. In some local authorities only 1% of children with a moderate learning difficulty are left out of mainstream education. In other local authorities over 25% of children with moderate learning difficulties are left out of mainstream education.⁶



⁵https://www.improvinghealthandlives.org.uk/publications/1241/People_with_Learning_Disabilities_in_England_2013

⁶https://www.improvinghealthandlives.org.uk/publications/1241/People_with_Learning_Disabilities_in_England_2013

Children with learning difficulties do not get as good results as children without learning difficulties. As well as this, they are more likely **to be excluded from school**.



To be excluded from school: this is when a school decides that a child is not allowed to go to school for a number of days. A school can also decide not to let the child go back to a school ever.

At the age of 18, it was found that disabled young people were twice as likely not to be in employment, education or training as non-disabled young people.



As well as this it was found that students with learning difficulties were four times more likely to be on independent living courses or employment courses than studying courses and qualifications like other non-disabled young people.



Changes to the way that **apprenticeships** work mean that people need certain GCSEs in writing and maths to do an **apprenticeship**. This has meant that the number of people with learning difficulties doing **apprenticeships** has gone down.⁷



Apprenticeships: this is where a person learns how to do a job, on the job. They usually have a set number of hours to work and are quite low paid.

Equal opportunities in work are still out of reach. Only 6.6% of people with learning difficulties are in some kind of paid work. Most of the people that are in work, work part time. This is much lower than the 46.3% of disabled people in general and the 76.4% of non-disabled people in paid work.⁸



⁷ ALLFIE - Children and Families Bill's Proposed Amendments for consideration at Committee stage (March-April 2013)

⁸ <http://www.learningdisabilities.org.uk/help-information/Learning-Disability-Statistics-/187693/>

Getting a job is difficult and there are many barriers. The biggest barrier is people thinking that people with learning difficulties cannot work.⁹ This is worrying when actually 65% of people with learning difficulties would like a paid job.¹⁰



The services that support people with learning difficulties to find a job are not as good as they could be. This is because services need to work better to change the way that employers see people with learning difficulties and tell them about the support on offer for disabled people.



They also need to work to make sure there are more opportunities for people with learning difficulties to work.¹¹



⁹http://www.ndti.org.uk/uploads/files/3.The_cost_effectiveness_of_Employment_Support_for_People_with_Disabilities,_NDTi,_March_2014_final.pdf

¹⁰ Valuing Employment Now, HM Government, 2009

¹¹http://www.ndti.org.uk/uploads/files/3.The_cost_effectiveness_of_Employment_Support_for_People_with_Disabilities,_NDTi,_March_2014_final.pdf

There has been research into the experience of disabled people in the work place. It found that people with learning difficulties and mental health issues are more likely to be treated unfairly and face bigger barriers in the work place.¹²



As there are so few people with learning difficulties in work, it means that 93.4% of people with learning difficulties will probably use some sort of support from the Government or their local authority.



This means that they are one of the groups most affected by cuts and changes to benefits and services. They are also one of the groups most affected by changes to local authority assessment rules.



¹² Barriers to employment and unfair treatment at work: a quantitative analysis of disabled people's experiences, Nick Coleman, Wendy Sykes, and Carola Groom. Equality and Human Rights Commission, Research report 88, Independent Social Research (2013).

Disability Hate Crime has been a problem for disabled people for a long time. It only became part of the law in 2003, as part of the Criminal Justice Act.¹³ Research done by Mencap found that 88% of people with learning difficulties had been victims of hate crime in the last 12 months.¹⁴



Even though the level of hate crime is high, only 3% of these crimes are known about by the police as hate crimes. Not many people with learning difficulties report hate crimes. This is usually because of a bad experience of reporting in the past.



Even when crimes are seen as hate crimes, many do not make it to court. In many cases this is because there is a question of whether people with learning difficulties can be believed.



¹³ <https://www.mencap.org.uk/blog/four-things-you-probably-didnt-know-about-disability-hate-crime>

¹⁴ <https://www.mencap.org.uk/blog/four-things-you-probably-didnt-know-about-disability-hate-crime>

These barriers mean that people with learning difficulties do not have equal access to the police and cannot get a fair result using the courts.



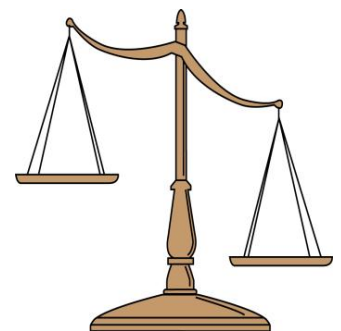
3.2.2 Financial changes: these are national changes to how much money and support a person gets towards the extra costs of being a disabled person



One of the big issues for people with learning difficulties is poverty: this means not having enough money to live on. When a disabled person is part of a family, the family is more likely to live in poverty. This could be as high as one out of three disabled people living in poverty.¹⁵



With only 6.6% of people with learning difficulties in paid work,¹⁶ changes to how the Government and local authorities spend their money affects people with learning difficulties more than most other groups of people.



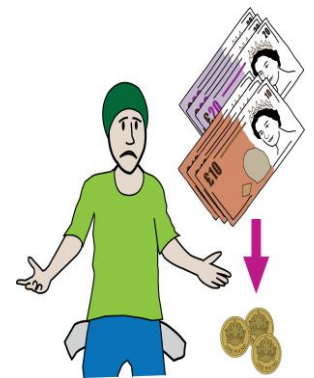
¹⁵ <http://www.disabilitynewsservice.com/report-finds-nearly-a-third-of-disabled-people-in-poverty/>

¹⁶ <http://www.learningdisabilities.org.uk/help-information/Learning-Disability-Statistics-/187693/>

In 2013 the Centre for Welfare Reform did some research that showed that disabled people, who make up 8% of everyone in the country, will be hit by 29% of the cuts. On average, each disabled person will lose around £4,410 each year.



They will lose 9 times more than most other people in the country. This is even worse for disabled people with higher support needs, who will lose 19 times more than most other people in the country. Each person will lose around £8,832 each year.¹⁷



There have been big changes to benefits, support and services, with some people having 6 cuts and changes at the same time.¹⁸ Below is some information about the most important changes that will affect people with learning difficulties:



¹⁷ <http://www.centreforwelfarereform.org/uploads/attachment/354/a-fair-society.pdf>

¹⁸ http://www.demos.co.uk/files/Destination_Unknown_Summer_2012_-_web.pdf?1340294386

The change from the Disability Living Allowance to the new Personal Independence Payments:

This change will lead to 28% fewer disabled people getting this benefit.



This is around 607,000 disabled people.¹⁹ The rules for assessment have been changed which mean that a lot of disabled people who used to get the Disability Living Allowance will no longer be able to get Personal Independence Payments.



As well as this 428,000 people who used to get the **Enhanced Mobility Component** will no longer get this payment and will therefore get less money.²⁰



Enhanced Mobility Component: this is part of the benefit that you get if you find it difficult to get around or get out and about.

¹⁹ (Personal Independence Payment) Regulations 2013 - Parliament
<http://www.legislation.gov.uk/ukdsi/2013/9780111532072/contents>

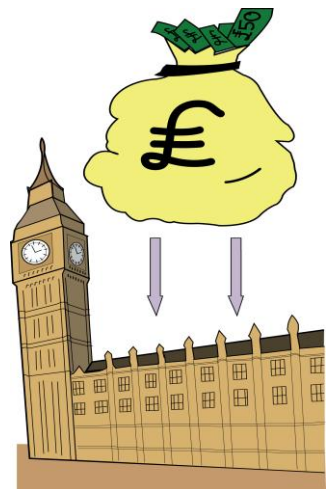
²⁰ (Personal Independence Payment) Regulations 2013 - Parliament
<http://www.legislation.gov.uk/ukdsi/2013/9780111532072/contents>

The Independent Living Fund

Closing: The decision to close this fund was made in March 2014 after two court cases were taken by disabled people using the fund. One out of three people using this fund were people with severe learning difficulties.



It was decided that in June 2015 that this fund would be closed to the 21,000 disabled people using it.²¹ This money will be given to local authorities. The problem is that this money is not protected which means that the local authorities do not have to spend this money on disabled people.



For most people, losing this fund means that they will have to leave their homes and move into residential homes, as local authorities will not have the money to pay for the support needed for people to stay in their homes.²²



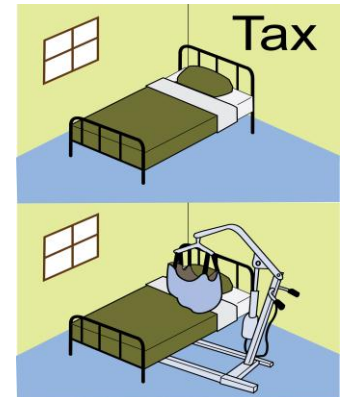
²¹ <http://www.dwp.gov.uk/ilf/news/>

²² <http://www.theguardian.com/commentisfree/2014/mar/31/independent-living-fund-disabled>

A Benefit Cap: this means that the total of the benefits that you get cannot go over a certain amount of money. The Benefit Cap will mean that 142,500 disabled people will lose around £2 billion by 2018.²³



The Spare Room Subsidy being taken away: This is sometimes called the Bedroom Tax. People with one 'extra' bedroom will now have 14% less money in their housing benefit. People with two or more 'extra' rooms will have 25% less money in their housing benefits.



72% of the houses affected by this change have a disabled person or a person with a health issue living there.²⁴



This change is having an unfair effect on disabled people mainly because it is very difficult for disabled people to find a new smaller house that meets their access needs. Many disabled people have spent time and money making their house more accessible.



²³ <http://www.demos.co.uk/files/Table1-headline.pdf>

²⁴ <http://inactualfact.org.uk/fact/72-of-households/http://www.affinitysutton.com/media/808765/housing-futures-report-final.pdf>

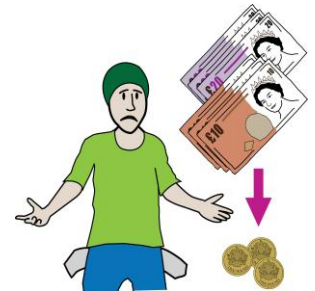
It is also unfair because many disabled people need an 'extra' room for access equipment or for a carer to sleep in.



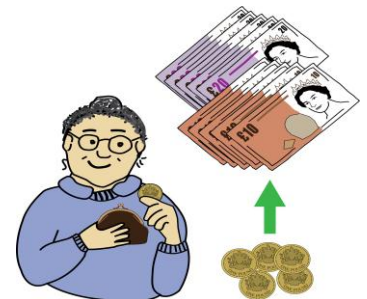
People with learning difficulties need support to find a new place to live, support to actually move and to make links in their new area. As well as this they may not get the same level of support in a new local authority.



All of these barriers to moving house mean that many disabled people just have to pay more money to stay where they are. This means that people are left with less money to live on.



Discretionary Housing Payments: these are payments that can be made by local authorities to give people extra housing money. People can use this to pay the extra costs of their house whilst they try to find a new smaller house to live in.



41% of the disabled people that have been affected by the Benefit Cap as well as the Bedroom Tax have not been given this extra money by their local authority. Some disabled people have not been given this money even when they cannot find housing that meet their access needs.²⁵

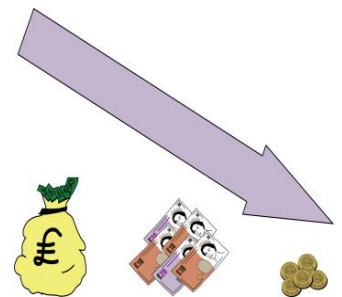


To pay for these extra costs:

- 9 out of 10 disabled people are cutting back on food and bills
- 4 out of 10 disabled people are cutting back on getting out and transport
- More than 1 out of 4 disabled people are spending less on medication and other therapies that they need²⁶



Changes to how much money people get to pay for housing will mean that 827,000 disabled people will lose £2.43 billion by 2018.²⁷



²⁵

<http://www.papworthtrust.org.uk/sites/default/files/Making%20Discretionary%20Housing%20Payments%20work%20for%20disabled%20people.pdf>

²⁶ <http://www.papworthtrust.org.uk/news/disabled-people-cutting-back-on-food-or-bills-to-pay-bedroom-tax>

²⁷ <http://www.demos.co.uk/files/Table1-headline.pdf>

The Employment and Support

Allowance: this benefit is being used instead of the Incapacity Benefit and some Income Support benefits. It is for people who are not able to work because of a disability or illness. The Work Capability Assessment is being used to find out if a person can get the Employment and Support Allowance.



The Work Capability Assessments have been found to be unfair, stressful and do not get the right results. The British Medical Association asked for the assessments to be stopped because there were so many problems with it.²⁸



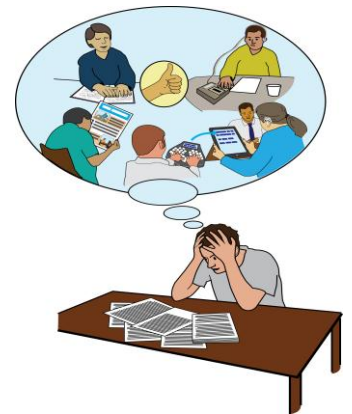
²⁸ <http://bma.org.uk/news-views-analysis/news/2012/june/scrap-work-capability-assessment-doctors-demand>

When people feel that their assessment did not get the right result they **make an appeal**. Nearly 51% of these appeals are won.²⁹ This means that more than half of the people, who **make an appeal**, win and get extra support when their application is looked at again.



Make an appeal: 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.

It has also been found that when making an appeal, people with learning difficulties, mental health issues and autism face more barriers. They are not as likely to win appeal. This is because they find it difficult to get together the information needed to make an appeal.³⁰



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https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/411937/esa_wca_summary_Mar15_final.pdf

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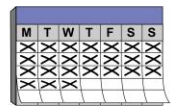
https://www.learningdisabilitytoday.co.uk/government_loses_appeal_against_esa_benefit_ruling_25769804847.aspx

People who get the Employment and Support Allowance are put into one of two groups:

- A Work Related Activity Group: this is where a person has meetings and interviews with their advisor. This support lasts one year.
- A support group: there is no time limit and a person does not have meetings or interviews.



The one year time limit of Work Related Activity Groups will affect 700,000 disabled people and will cost disabled people around £4.4 billion.³¹



People who do not stick to the Employment and Support Allowance rules can be left without money for a long time. However, when people are making appeals, the Department for Work and Pensions do not have a time limit to carry out another assessment or make a decision.



³¹ <http://www.demos.co.uk/files/Table1-headline.pdf>

Whilst people are waiting for this to happen they can choose to either go without money whilst they wait, or apply for Job Seekers Allowance. The problem is that if they apply for Job Seekers Allowance it gives the idea that the person is fit for work.



This means that making an appeal can be very long and stressful. Over 3 out of 4 disabled people said that their health got worse because of their assessment for the Employment and Support Allowance.³²



Universal Credit: this will bring together 6 different benefits and it will be paid as one benefit. The benefits that will come under Universal Credit are:



- Job Seekers Allowance
- Employment and Support Allowance
- Income Support
- Working Tax Credit
- Child Tax Credit
- Housing Benefits



³² <https://www.mencap.org.uk/news/article/disabled-people-reach-tipping-point>

In total disabled people will lose £2.2 billion by 2018 because of Universal Credit³³:

- Up to 116,000 disabled working adults will lose up to £40 each week
- 230,000 severely disabled people who live alone or have a young carer will lose between £28 and £58 each week³⁴.



This benefit can only be applied for online. For many disabled people and especially people with learning difficulties, this is not accessible. As well as this, the benefit will be paid each month, instead of each week.



People will need support with this change so that they can budget for this longer amount of time. From what we have seen of local authority cuts to support, the support needed for this change may not be there.



³³ <http://www.demos.co.uk/files/Table1-headline.pdf>

³⁴ http://www.citizensadvice.org.uk/holes_safety_net.htm

Access to Work: this supports many disabled people in work. For people with learning difficulties it is getting harder to get this support.



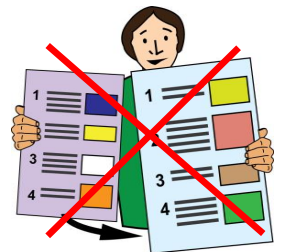
The Department for Work and Pensions has said that they are trying to support more disabled people, but they are not spending more money on Access to Work.



As many people with learning difficulties need more expensive support packages, in many cases they are not getting the support that they need to access work.



The Department for Work and Pensions has not said that there has been any change in how they deal with support for people with learning difficulties in work.



However, through experience of People First staff and staff in other local self-advocacy groups, we know that this is happening, with a number of people having their support reduced to 20% of what they were getting last year, even though their impairment has not changed.



It shows that Access to Work do not understand the access needs of people with learning difficulties in work, who are a group that already face many barriers in employment.



3.2.3 Service Changes

Funding for adult social care has had big cuts: this has happened in local authorities all over the UK. Between April 2011 and March 2013, there were cuts of £1.89 billion.³⁵ This is happening at a time when the number of disabled and older people is going up by 3% each year. These numbers are going up the most for older people and people with learning difficulties.³⁶



³⁵ <http://www.adass.org.uk/A-new-system-for-care-funding/>

³⁶ ADASS Budget Survey (April/May 2012)

As well as this, it was said in June 2013 that local authority funding would be cut by another 10%.³⁷ This has meant that 100,000 disabled people are at risk of not getting the support that they need.³⁸ So far 69,000 disabled people have been pushed out of social care.³⁹



Research done by the charity Leonard Cheshire shows that more 15 minute visits are being used by councils in their community services that support people in their homes. Some councils give more than 3 out of 4 of their care visits in 15 minutes.⁴⁰ As well as this, 83% of councils only support people with high support needs.⁴¹



³⁷ <http://www.theguardian.com/politics/2013/jun/26/spending-review-2013-the-key-points>

³⁸ <http://www.scope.org.uk/campaigns/other-care-crisis>

³⁹ <http://www.scope.org.uk/news/other-care-crisis>

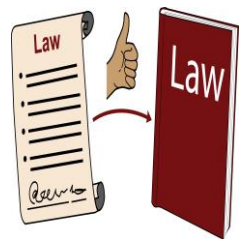
⁴⁰ <http://www.leonardcheshire.org/sites/default/files/15%20min%20care%20report%20final.pdf>

⁴¹ <http://dpac.uk.net/2012/07/ilf-consultation-how-are-local-authorities-doing-providing-care-and-support-funding-badly-of-course/>

This is making it difficult for the NHS and mental health services in the community. When people do not have the right care and support at home, they are going to hospitals to get support. Many people who had been in hospital, had to stay longer because they did not have social care support at home.⁴²



The Care Act 2014: this is a law that was put in place to bring together all of the laws around adult social care and local authority responsibilities. This law brought in a new rule that means that if you move from one local authority to another, you do not have to go through another local authority assessment. This is a good thing, however, you may not get the same level of care and support in the new local authority.



The Care Act also gives people the right to advocacy in assessments and care plans. This is a good step towards meeting access needs. However, it is not easy to get and if there is a family member or a friend that can do this then a person does not get this advocacy support.



⁴² <http://www.theguardian.com/healthcare-network/2015/jun/02/nhs-no-more-cuts-to-social-care>

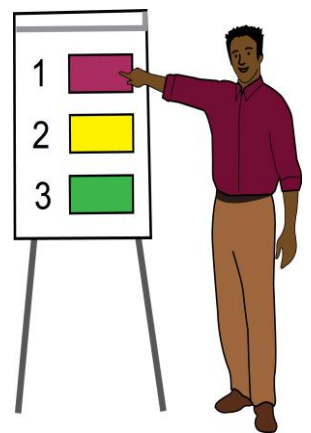
The problem with this is that, when going through assessments and care planning, most family and friends do not have the skills to make sure that they get the best result for the person that they are supporting.



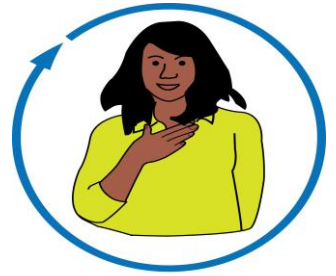
As well as this, many people with learning difficulties would need support to access advocacy support in the first place and therefore it is not accessible to many people.



The Care Act brought in a rule that even with cuts to local authority money, people with high support needs will still be able to keep the same level of local authority support. Campaigners tried to get this rule to cover people with moderate support needs as well, but they did not manage to do this.



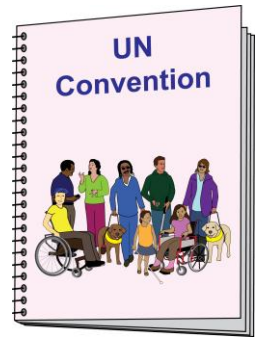
The Care Act brought in the **well-being principle**.



Well-being principle: in the Care Act this means:

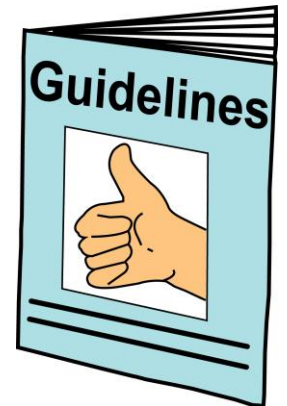
- Feeling valued and respected
- Feeling happy and healthy
- Being safe from abuse
- A person having control over their day to day life
- Taking part in work, education, training or other activities
- Having a life and enough money
- Having a family and personal life
- Having the right place to live

However, some campaigners think that this does not go as far as the Right to Independent Living which is part of **the United Nations Convention on the Rights of Persons with Disabilities**.



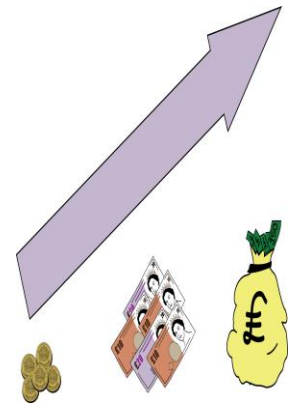
The United Nations Convention on the Rights of Persons with Disabilities: this is a human rights agreement; this can also be called a treaty. It makes sure that disabled people have their rights met.

Campaigners did manage to get the Right to Independent Living in the **Statutory Guidance** of the Care Act. This means that this right can be used as the reason for going to court if a person feels that their right to independent living has not been met.



Statutory Guidance: this is a document that has rules about the Care Act that must be followed by local authorities.

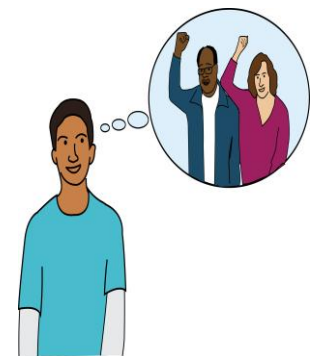
Cuts to organisations supporting people with learning difficulties and service charges going up: In the UK, in total, disabled people have been affected by charges for services going up by £77 million.⁴³ Meals on wheels charges have gone up by 20%⁴⁴ and transport costs have gone up by almost 100%⁴⁵.



Nearly three out of four organisations giving support to people with learning difficulties have had their support cut or their charges for services have gone up.⁴⁶



Cuts to self-advocacy groups: these groups give support to people with learning difficulties so that they can speak up and deal with things that are going on in their lives. They are a big part of a person's support network and are important in making sure that people can access their rights.



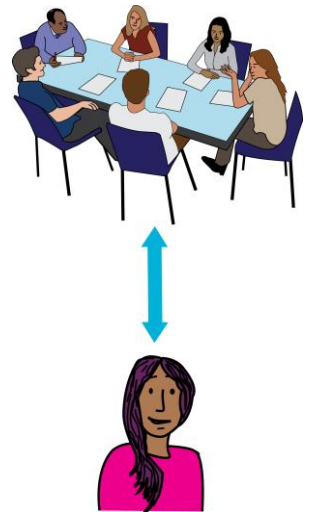
⁴³ ADASS budget survey (April/May 2012).

⁴⁴ <http://press.labour.org.uk/post/70178119271/care-charges-soar-by-740-a-year-since-election>

⁴⁵ <http://press.labour.org.uk/post/70178119271/care-charges-soar-by-740-a-year-since-election>

⁴⁶ Social Care in Crisis: the need for reform, Learning Disability Coalition, 2012

In the past people might have looked for support and advice from their local self-advocacy groups. However, People First know from their work with local groups that many groups have had cuts in local authority funding and in some cases groups have had to close down because of this.



People First is doing research into this to see what is happening for local self-advocacy groups.



Getting rid of free legal Aid for benefit and welfare cases: this is support given by law experts to take cases to court. This cut is being made at a time when the country is going through the biggest welfare changes in 60 years.⁴⁷



58% of the people that use legal aid, use it for benefit and welfare cases, this is more than 78,000 cases each year.⁴⁸



⁴⁷ <https://www.gov.uk/government/news/iain-duncan-smith-welfare-reforms-realised>

⁴⁸ <http://www.theguardian.com/society/joepublic/2011/dec/22/legal-aid-cuts>

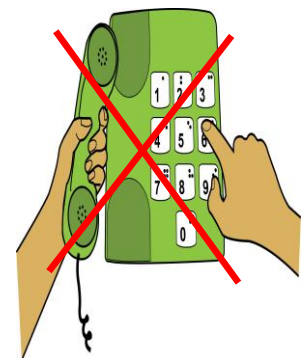
From the information above it is clear that the Government is getting things wrong. Without Legal Aid, most disabled people will not have the time or money to be able to use the law when they have been treated in an unfair way.



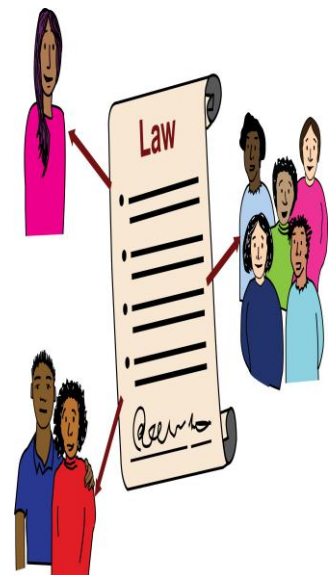
The Equality and Human Rights

Commission Helpline has closed: Big cuts have been made to the money that the Commission gets to do its work.

Between 2007 and 2015, this money was cut by nearly 40%.⁴⁹ This cut meant that the helpline that they had for advice about the law had to be cut.



Many of the cases that came through the helpline were then used as test cases to set examples in equality law. There is now an information and advice helpline in its place, but this is not the same as getting support to take a case and use equality law. With cuts to the Commission's money and to Legal Aid, what chance do disabled people have of fighting inequality?



⁴⁹ <http://www.theguardian.com/society/2012/oct/26/budget-cuts-rights-watchdog-un-status>

3.2.4 Local changes in Barnet

Barnet Council have had cuts to funding in all services of 26%, this is a cut of £72.5 million. There have been cuts to adult social care of £23.16 million. There are also plans to make cuts of £12.6 million by 2019.⁵⁰



Changes to services in Barnet: In April 2012, Barnet Centre for Independent Living started its Information, Advice and Advocacy Service.⁵¹ However, they lost this contract and as of June 2015, this service is being run by Barnet Citizens Advice Bureau.⁵²



People's Choice, the partner organisation in this research project, comes under Barnet Centre for Independent Living and they will therefore need to find other funding.



⁵⁰ <http://www.yourchoicebarnet.org/news/2014/09/your-choice-barnet-facts-file-on-the-pay-cut-dispute/>

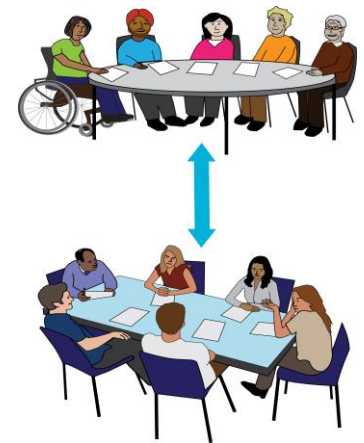
⁵¹ <http://www.barnetmencap.org.uk/files/Newsletter%202012%20Spring.pdf>

⁵² <https://www.barnet.gov.uk/citizen-home/news/Barnet-CAB-awarded-new-information--advice-and-advocacy-contract-.html>

As well as this the Learning Disability Parliament run by People's Choice will need to find other funding. The Parliament was seen as a very good way of making sure that the voices of people with learning difficulties are heard and that they reach decision makers.



Your Choice in Barnet: Another big change is that the services run by the London Borough of Barnet were passed over to Your Choice in 2012. This is a **Local Authority Trading Company** owned by the London Borough of Barnet.⁵³



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.

⁵³ <http://www.barnetmencap.org.uk/files/Newsletter%202012%20Spring.pdf>

This change has been talked about a lot and a lot of people were angry with this decision. There were **petitions** and even **strikes** because of this decision.



Petition: when a person or organisation does not agree with something or wants to change something, they write down what they want to happen and ask people to sign it. This is then sent to the organisation or Government department that has the power to make a change. It is used as a way of trying to make change happen.

Strike: this is when workers stop working as a way of showing the organisation that they work for that they are not happy about something.

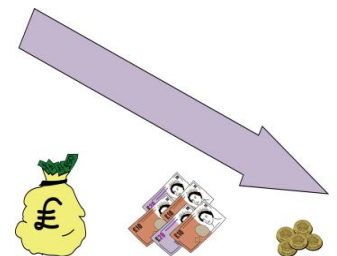
Barnet Unison wrote a report about this. It found that the decision was made without good information, and that Your Choice was run in a way that meant that if something goes wrong, no one in charge would take any blame and there was no way for people to feed into decisions.



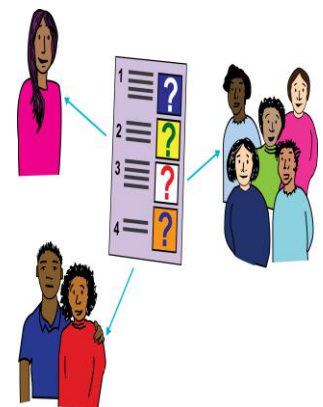
It also found that the plans would have a big impact on staff and service users.⁵⁴ By 2013, Your Choice was having big money problems.⁵⁵ 170 members of staff were asked about redundancy: this is when a person loses their job because the organisation no longer needs them or they do not have the money to pay them.



As well as this, staff in Your Choice's supported living services had their jobs moved down to assistant support workers. Staff numbers, staff pay and weekend pay all went down.



In May 2013, the Board of Directors of Your Choice did not listen to the worries of families about the planned cuts to staff and services. After one carer John Sullivan said he would take a legal case, the Board decided that it did need to consult with service users and carers before it made any changes.⁵⁶



⁵⁴ <http://www.european-services-strategy.org.uk/news/2012/local-authority-trading-company-latc-for-adult/latc-analysis-2012.pdf>

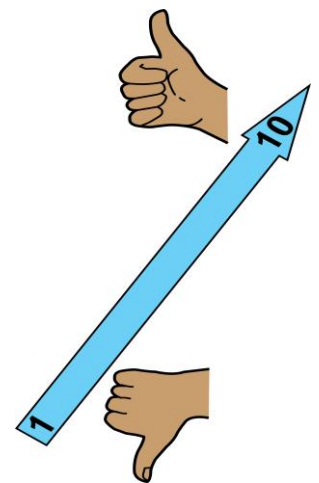
⁵⁵ <https://you.38degrees.org.uk/petitions/stop-the-ongoing-destruction-of-services-for-adults-with-disabilities-in-barnet>

⁵⁶ <http://www.newstatesman.com/politics/2013/05/secret-cuts-part-one-social-care>

A Task and Finish Group was set up to look at the money and staffing issues at Your Choice. Service users and carers then went to a meeting to talk about the report that had been written by the Task and Finish Group. The report did not cover enough areas; the Task and Finish Group did not speak with services users or carers and did not take on the help offered by Barnet Unison.



This meant that the Report written by the Task and Finish Group did not come up with any good ideas for dealing with the problems with Your Choice.⁵⁷ In March 2015, the Care Quality Commission gave the Supported Living Service run by Your Choice its lowest score of ‘inadequate’: this means not good enough.⁵⁸



In 2013 there was a 30% cut in the number of staff. In May 2015, staff at Your Choice had a 3 day strike after being told their wages would be cut by 9.5%.



⁵⁷ <http://www.brokenbarnet.blogspot.co.uk/2013/11/i-dont-have-problem-with-making-profit.html>

⁵⁸ http://www.cqc.org.uk/sites/default/files/posters/20160102_1-112848964_summary_ratings_poster_A4.pdf

All of these changes led to many staff leaving the organisation. It meant that Your Choice had to use more agency staff. This was one of the reasons why the Care Quality Commission gave Your Choice such a bad score.⁵⁹



3.3 Local and national demographics of people with learning difficulties

This means information about people with learning difficulties in the country and in the local area of Barnet.



3.3.1 National demographics

A report called People with Learning Disabilities in England 2012 says that there are around 1.14 million people with learning difficulties in England. This is around two out of every 100 people.



⁵⁹<http://socialistworker.co.uk/art/40228/Barnet+care+workers+strike+back+against+Tory+service+cuts>

There are:

- 236,000 children
- 908,000 adults over the age of 18 years old⁶⁰



Of these people, 22% are known to GPs as people with learning difficulties and 44% were getting the Disability Living Allowance when this report was written. More than half of people with learning difficulties are not known to any services.⁶¹



3.3.2 Barnet Demographics

In a report written by Barnet Council in 2012, it was thought there would be 5,874 people with learning difficulties in Barnet by 2015. Of this number, it was thought that there would be 1,326 people with severe or moderate learning difficulties who would probably be getting local authority support.



⁶⁰ https://www.improvinghealthandlives.org.uk/securefiles/150618_1719//IHAL2013-10%20People%20with%20Learning%20Disabilities%20in%20England%202012v3.pdf

⁶¹ https://www.improvinghealthandlives.org.uk/publications/1241/People_with_Learning_Disabilities_in_England_2013

By 2016, it was thought that 35% of the people living in Barnet will be from Black Minority Ethnic groups.⁶²



People with learning difficulties in Barnet are much more likely than other people to have big health problems. They are also more likely to live in poverty with bad housing, not have a job, be left out of society and be discriminated against. It was also said that for a number of reasons, the number of people with learning difficulties with support needs will grow in Barnet.⁶³



3.4 Different services available in Barnet for people with learning difficulties

The London Borough of Barnet works with Central London Community Healthcare NHS Trust. They have a number of services for people with learning difficulties that are given after an assessment by a healthcare professional and a social worker.

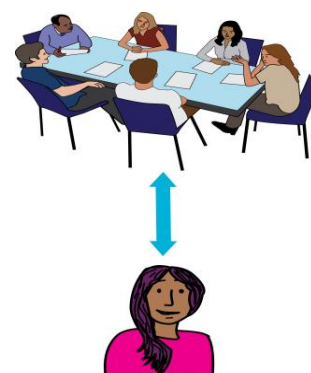


⁶² Barnet's Market Position Statement; Adults and Communities, Barnet Council, 2013

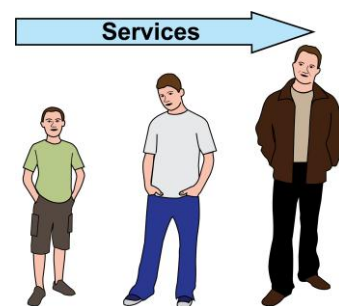
⁶³ http://www.barnetccg.nhs.uk/Downloads/Document%20Library/JSNA_2011_-_Release_version.pdf

Some of these services are below:

- Support to live independently
- Communication support
- Mental health support
- Changes to a person's house to make it more accessible
- Respite care: this is a place where someone can go so that their carer can take some time out
- Putting people in touch with other local organisations that run supported housing, social clubs and give benefits advice.⁶⁴



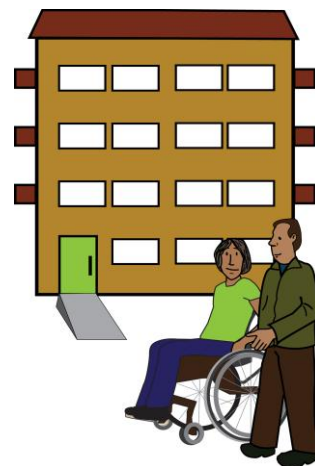
Many of the London Borough of Barnet's services for people with learning difficulties are run by Your Choice. Your Choice is 100% owned by the London Borough of Barnet.⁶⁵



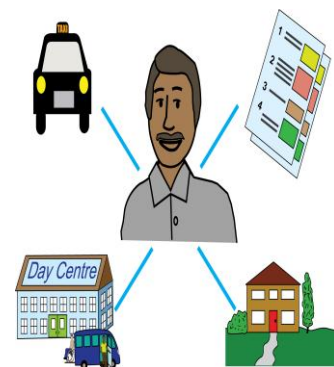
⁶⁴ <http://www.cqc.org.uk/location/1-112848946>

⁶⁵ <http://www.barnethomes.org/about-us/our-board/>

There are a number of care homes for people with learning difficulties in Barnet. They are run by a mix of voluntary and private organisations. There are also care homes for different groups of people such as older people, Asian women and Jewish people.⁶⁶



The main voluntary organisation that has services for people with learning difficulties is Barnet Mencap. The organisation runs three supported housing projects, support for people in their homes, advice sessions, short breaks, holidays, support for carers, and sport and learning activities.⁶⁷



The learning disability team called People's Choice at Barnet Centre for Independent Living run self-advocacy groups for people with learning difficulties.⁶⁸ At the time of this research Barnet Centre for Independent Living also ran a support planning service for people using direct payments.⁶⁹



⁶⁶ <http://www.autismdailynewscast.com/origin-housings-speedwell-court-for-autistic-adults-opens-in-barnet-north-finchley-uk/5565/snapshot/>

⁶⁷ http://www.barnetmencap.org.uk/About_us.htm

⁶⁸ <http://www.barnetcil.org.uk/index.php?id=4>

⁶⁹ <http://www.barnetcil.org.uk/index.php?id=4&cat=2>

As well as this there is also a support service run by Dimensions. This service is for people who live in their own homes. It supports people to get the skills and links that they need.

There is also Home Farm Trust, a national charity that supports people to get where they want to be, and Norwood, a Jewish organisation that runs services for people with learning difficulties.



4. How the research was done

The Cuts Impact Action Now project is a user-led project, to test run this way of collecting evidence. It was run and controlled by two user-led organisations, People First (Self Advocacy) and People's Choice at Barnet Centre for Independent Living.



4.1 Good ways of working that we used in the research:

- We made sure that the people who took part in the research had good, accessible information about the project before we started talking to them;
- We told people that their names would not be used in any information about the research;
- We told people that if they gave us information which showed they were at risk, then we would have to report it;



- We recorded the information to make sure we got all of the information that was given to us;



- We made sure that people felt happy talking about the issues and said that they did not have to talk about anything they did not want to;



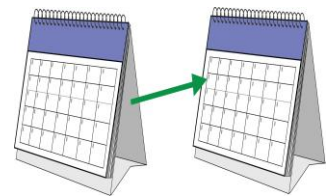
- We made sure that our interview guides talked about the cuts in a way that would not make people scared or worried;



- We worked to the People First Lone Working Policy: this is a policy used to make sure staff are safe when they are working on their own.

4.2 When the information was collected

Interviews and focus groups were carried out between January 2014 and September 2014.



4.3 How we told people about the project and got people to take part in the interviews and focus groups

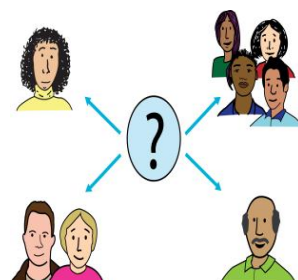
- We spoke to the main learning difficulty organisations in Barnet about the project and gave them information flyers to send out to their members. Some of these organisations were:



- The Partnership Board (Barnet Council)
- The organisations that take part in the Barnet Learning Disability Parliament (Dimensions, Rosa Morrison, Flower Lane, The Community Space, Barnet Mencap, Harold Court, Norwood, and Self Unlimited)

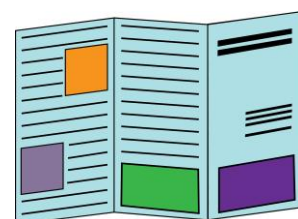


- By getting in touch with residential homes and supported living organisations



- By getting touch with the members of People's Choice

- We made flyers which told people what the project is about and how to be a part of the research



- In many cases we needed to speak to the person with their supporter, to be able to set up an interview



4.4 Some of the problems that we had

- In many cases we could not get in touch with the person with learning difficulties and we had to go through another person to speak to them. We have called these other people ‘gate keepers’;



- In this research people put themselves forward if they wanted to take part in the research. This brings up the problem of whether people came forward just because they had gone through a bad experience;



- Getting interviews was very difficult, this was actually because of people’s impairments around memory, as it was a one-off meeting. There were many times where people did not turn up to interview meetings because they had forgotten.



This happened even when they had been reminded a number of times before the meeting. In some cases we had to arrange the meeting 2 to 3 times before we were able to meet a person.



4.5 How we got the information

- One to one interviews were done with 35 people with learning difficulties. We told people that they could bring a supporter with them. An interview guide was written for the person doing the interview which looked at the following areas:



- Independence and personalisation
- Housing
- Employment and education
- Health and social care
- Transport
- Advocacy and support
- Hate crime
- Day opportunities and things to do



- When doing the interviews we worked in the following way:



- We told people about each area. We talked around each area to see if there was anything that the person wanted to talk about

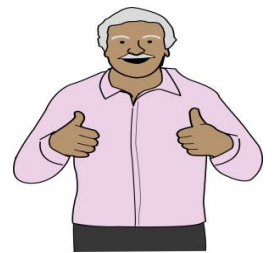
- We did not ask question in a way that made people give us a good or a bad answer



- We asked talked about any changes instead of asking about cuts as we did not want the interview to feel scary



- We made sure people could take their time to give answers. We helped people to say what they wanted to if they were finding it difficult to say what they wanted to



- Focus Groups: Three focus groups were done, and 19 people took part in total. The same interview guide was used as in the one to one interviews.



We used pictures to communicate with people with higher support needs. We made sure that everyone could say what they wanted to, even people who did not feel confident to speak up.



- Service Managers: We did interviews with three service managers. This was done to understand their point of view about what was happening. We also used these interviews to understand the experience of carers.

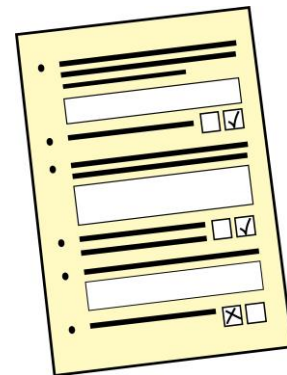


Before the interview we sent information to each service manager about the project. We told service managers that the aim of the interview was to find out if they had seen any changes happening due to cuts in local authority money.



4.6 About the people with learning difficulties who gave information

All the people who took part in the one to one interviews and in the focus groups were asked to fill in a short questionnaire to give information about themselves. This was to make sure that we had a good mix of people. We made sure that we had a mix of people under the following areas:



- Sex: 43% women, 57% men
- Age: the majority of people were aged between 30 and 59 years, however, younger and older people did take part.
- Ethnic background: 24% of people taking part were from BME communities
- LGBT communities: this information was not given by many people
- Complex needs: there was a big mix of different needs. There were people with mild, moderate and high support needs



- Where a person lives: There was a good mix of different types of housing the people lived in. There were: people who lived independently with support, without support, people who lived with their family, people who lived in residential homes and people who lived in supported living.



- Type of support used: people used different types of support. There was a mix of types of support from full time support to people who used 2 hours per week for admin.

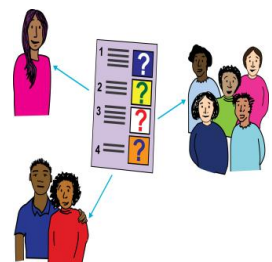


- The main benefits that people were getting: Disability Living Allowance, Employment and Support Allowance, Housing Benefits, Job Seekers Allowance, and Council Tax Benefits.



4.7 Once we had all of the information, how did we study it?

We typed out all the information from the recordings. We looked for areas that had come up a number of times for a number of different people in the interviews, focus groups and with service managers.



The areas were pulled out and we then used quotes to support these points from people who had taken part in either the interviews, focus groups or from the service managers.

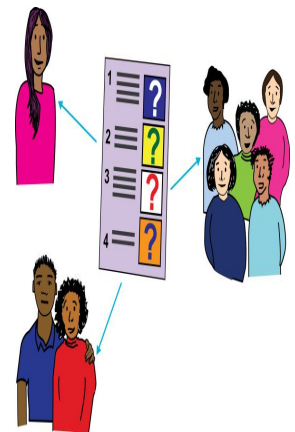


We used example quotes to show what we had found out and talked about some of the points that had come up. We used this to put together recommendations to be looked at by Barnet Council, other local authorities, national Government and health and social care organisations.



4.8 How sure are we that what we found out is right?

We used **triangulation** in this research to make sure that we had the best chance of getting it right. We had one to one interviews, focus groups as well as interviews with service managers. The idea is that you can be surer that your results are right if you use different ways of getting the information and they all point to the same results.



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 there is more chance of what you find out being right.

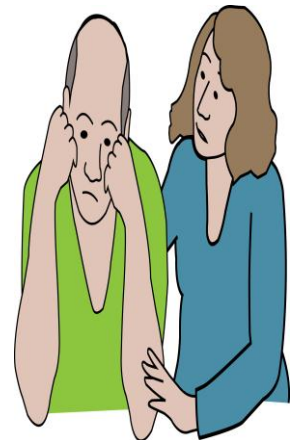
5. Findings: what we found out

Cuts and changes to services and benefits are happening, but what has this meant for people with learning difficulties in Barnet?



5.1 Introduction

When we were planning to do this research we thought that most people would tell us about the impact that cuts and changes had been having on their lives. We were then very surprised to find out that the main issue was actually how the cuts and changes had been carried out. The way that cuts and changes had been made had a very strong impact on the lives of people with learning difficulties.



Service managers and people with learning difficulties told us that the need to save money was being seen as more important than people's needs. As well as this, people with learning difficulties felt that they were not being listened to and that important information was being missed in assessments.



As well as this, there was not enough information about the cuts and changes that were being made and what they would mean for people. People did not understand what was happening and this meant that they could not really take part in the changes or have any control.



It was seen that national Government and local authorities did not understand that many people were going through a number of cuts at the same time. The impact that this is having on people is not being checked at either a local or national level.



As well as this, cuts to services and charges going up were affecting whether people could take up opportunities. This meant that people were losing independence.



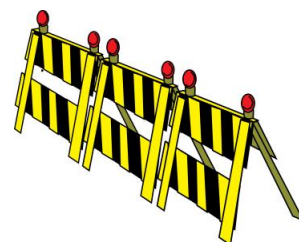
Another important issue was around support. It was clear that a lot of support was needed to go through an assessment or appeal a decision. Support was also needed to cope with the cuts and changes being made. Decision makers did not understand the level of support needed.



People were finding support where they could so that they could deal with cuts and changes. There were people who did not have any support.



Finally, the research showed that people with learning difficulties do not have equal access to assessments and reviews. This is because of support and information barriers.



However it was very clear that people know what is important to them and what support they need to be independent. The biggest problem is that because of barriers, people with learning difficulties cannot fully be a part of the decisions being made about their lives.



In each section of the findings below, there are a number of quotes from people who took part in the research. The quotes are used to show the key issues found in this research.



5.2 Assessments and reviews are not looking at the needs of people with learning difficulties

More than 60% of people interviewed had been through a local authority assessment; some of these people had also been through a benefits review.



As well as this some people in the focus groups gave information about their experience of local authority reviews and assessments.



In this research most people with learning difficulties and all service managers agreed on one thing; cuts to funding and cuts to people's support now seemed to be an important reason for carrying out assessments and reviews. The research shows the bad effect of both the cuts and people's experience of going through assessments and reviews.



30% of people who had not yet been through an assessment or review were worried about it or thought that their support would be cut at their next review or assessment.



a. It's all about the money

Of the people who had been through local reviews, most could not understand why their support or services had been cut or why their charges for services had gone up. Most felt that it was about saving money.



All service managers and most people with learning difficulties agreed on one thing. They agreed that the need for the local authority to cut money from the budget seemed to be the most important thing. It seemed to be more important than making sure that the right support and services were in place for people with learning difficulties.



From service managers:

“They are trying to cut people’s access to the service (...) it is not about peoples’ needs, it is about how they can reduce support. When people go into their review social workers are looking for a reduction in services.”

“Social services try to cut services, tweak, cut, and reduce.”



“It is all about money, it is done in such a way that people don’t even know what is happening.”



Supported by what people with learning difficulties had to say:

“My support got reduced; I get a bit emotional because I can’t get out on my own. Before it was wonderful, I got to go out more. It got cut down because of the money situation”



“At the moment I get 10 hours support a week to live independently which is just right, but that is because I haven’t been reassessed yet, I know when they get their act together they’re going to cut it down.”



“I feel like there isn’t enough money to give people the help they need.”



“I do not feel like I am getting the amount of support that I need.”

“People are still waiting for social services to do reviews. They’re digging their claws in. I haven’t had my review yet.”

“Support is getting cut. It’s a money situation”.

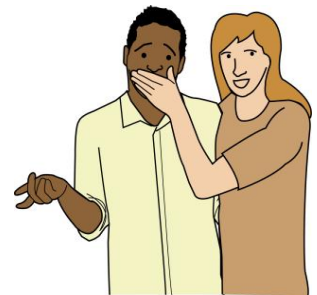


b. Are you listening to me?

Cutting costs was seen as very important. It seemed that, from what service managers and people with learning difficulties said, decisions about cuts to services and support had already been made before assessments and reviews had happened.



80% of the people interviewed who had gone through cuts in support and services; felt that either important information had been missed, or that they could not get their voices heard.



In reviews and assessments, people did not seem to be given a chance to understand what was happening. There was not enough good information and independent support for people to say what they thought, take part in decisions or make sure that they were listened to.



People with learning difficulties are going into assessments and reviews without good information and support. Without this, how can professionals then understand the views and needs of people with learning difficulties and use this information to make decisions?



From service managers:

“Social work colleagues aren’t always as responsive as they were, they have an allocated amount and that is what they have to work with (...) it is more difficult, every annual review is about cutting funds, a social worker with scissors. My staff and I are very aware of the fight to keep support and services in place.”



“It is more of a fight to get the right level of support (...) Parents and carers need to be creative to maintain the level of support, it is difficult getting the parents to understand this.”



“Parents and carers (...), those who shout the loudest, don’t get the cuts.”



Supported by what people with learning difficulties had to say:

“I had an assessment and they said I wasn’t entitled to the Employment and Support Allowance. They overlooked medical needs and it was reduced from the higher rate to the lower rate.”



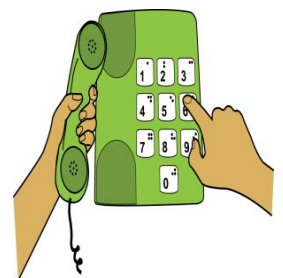
“They don’t listen to people with learning disabilities. They listen to people who haven’t got them, but they don’t listen to people who have got disabilities”.



“About 18 months ago, I moved in with my partner. After 6 weeks a review was done. Before my review, my sister in law helped put together information about the things I needed help with and the things that I did not. I can do some things on my own, but I need help with finances and things at home like cooking.

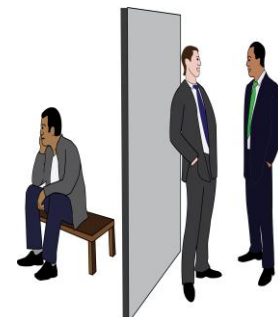


Within 15 minutes of the review I got a phone call saying they would be pulling my support and there would be no appeal process. I have learned to cope because I had to.”



c. Discussion: this means talking about the issues that came out of the research

Because of cuts to local authority funding, social workers do not seem to be able to take on the needs or views of people with learning difficulties. This means that a group of people who are already left out of society are being left out of decisions about their own care and support.



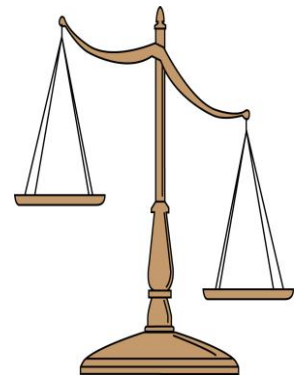
As well as this many people with learning difficulties have communication needs. If they are not given a real chance to say what they think, then they will not be able to give important information that is needed for professionals to make the right decisions in assessments.



It seems that professionals are making decisions without all of the information. This is making assessments as well as the cuts to support and services very difficult for people with learning difficulties. People are not being given the chance to have their say and be listened to.



As well as this, the research has shown that those who have support and those who shout the loudest have a better chance of keeping support and services. This means that reviews and assessments are not fair for many people with learning difficulties. This will lead to less people with learning difficulties getting the support that they need.



The Cuts Vs People's Needs: There seems to be a big problem if health and social care professionals are going into assessments looking to take away support or services from people.



It is clear that professionals are finding it difficult to make cuts and that it is not an easy job. However, if they are looking to make cuts then how can they really be looking at people's needs and the effect that cuts will have on people?



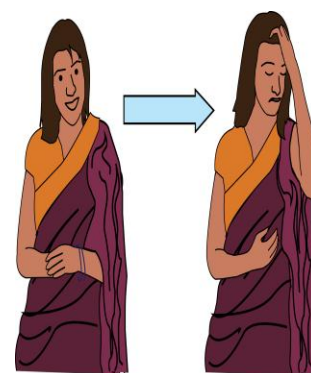
People felt that the main things that affects decisions is how much support and services cost, instead of how people's needs can best be met. How can professionals be fair in meeting the needs of people with learning difficulties and meeting the needs of the local authority in making cuts?



The most important question is, how can cuts and changes to support and services be made without people with learning difficulties being a real part of the decisions being made?



The impact: People felt the difference. They knew what it was like when they had more support and services and what it meant that they could do. People have had to deal with a number of day to day issues as well as dealing with how they have felt around the cuts to support and services.



Is the need to cut how much a local authority spends a good enough reason to take away support and services that people need? It is leaving people more at risk on a number of levels.



The big problem is that the local authority and national Government do not even know what the full impact will be on people with learning difficulties. There has to be a better way of doing this.



Getting by and trying to deal with the cuts and changes is not the same as living an independent life with the support and services that a person needs.



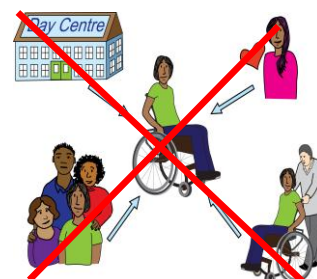
Some people have no one to turn to at a time of crisis. It seems that the local authority has no way of checking whether people are dealing with changes or of making sure that people have access to support in a crisis.



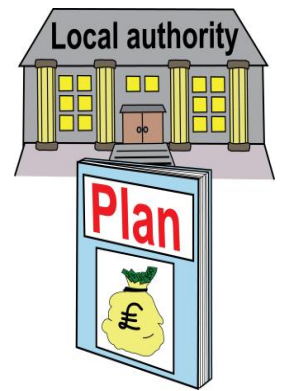
In one case, there was a change to a person's situation and this meant that they had a review of their support. Fifteen minutes after the review a decision had been made to take away all local authority support. This person was left to deal with this change. This person did have the support of their family, but this is not the case for everyone.



Support services now seem to aim to make sure a person is getting by, rather than making sure a person has wellbeing and the right support and services to be as independent as possible.



With less funding, local authorities are saying more and more ‘you don’t need support’. When actually what they should be saying is ‘we don’t have the money to support you in the right way, and we need to work with you to find out how we can best meet your needs with the money that we have got’.



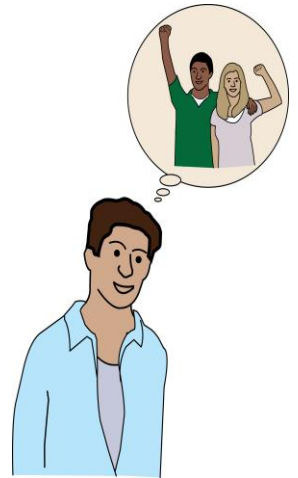
Listening to people: during this research we saw that local authorities are going through big cuts. However, this does not mean that local authorities can put into place cuts to support and services without seeing people’s views as important and listening to what is important to people.



People with learning difficulties are experts about what is important in their own lives. They should be a part of the decisions being made about support and services. The research shows that this has not been happening. People are going into assessments and reviews without having information and support to understand what is being planned.



What happened to Valuing People? This put forward ‘nothing about us without us’ and was an important part of Valuing People Now. It said that things would be put in place to make sure that people’s voices are properly heard and that people can access their rights. The experience of the people that took part in this research that are going through assessments and reviews shows that this is still not happening.



This research has shown that for a person to get their ideas and information across, they need someone who works in an accessible and inclusive way. They need good information about what is happening and what is being planned. They also need independent support to get ready for reviews and assessments, to take part in reviews and assessments and afterwards to deal with any cuts or changes to support and services.



5.3 People do not understand what is happening, are not given information that is then used to make decisions, and are not a real part of the decisions being made

The big feeling that came out of this research was that people did not have very much or enough information to understand what was being planned. They also did not have information about the effect that these plans would have.

They had to rely on the opinions of health and social care professionals about what would be best for them at a time of cuts to the local authority's money.

a. People do not know what is happening

Most of the people who took part in the research, did not have information about the cuts and changes to benefits and local authority support that might affect them. 30% of the people that took part had some general information about cuts and changes; however they did not have information about how it would affect them.



When doing the research there was a feeling that there was a culture of people not having access to information. There was a culture of thinking that people do not need to know what is happening, even when they are able to understand. This can be seen in the examples below:



When one person was asked if their money benefits have changed, they said “no”. The person’s carer said that the person’s parents take care of benefits and money.



When another person was asked the same question they said ‘I don’t know if my benefits have been cut, my carer would know’.



This way of dealing with benefits seems to be the way that assessments and reviews have been done. Not having this information means that people with learning difficulties and their family or carers do not know what is happening and do not understand the effect that changes or planned changes will have.



From service managers

“Parents and carers don’t understand what is happening.”

“Parents don’t understand why they are being charged for the support service for their daughter or son. That is then just referred to the duty social worker.”



Supported by what people with learning difficulties had to say:

When asked about Personal Independence Payments, one person said “I am under the impression that PIP will be better”.



When asked what they knew about how Personal Independence Payments would change things, this person said “I am not aware.”



“I find it hard to understand all the budget cuts; I have had cuts to support service hours as well as my benefits”

Another person was asked if they know about the changes that the Government is making, they said “no, I am not sure”



“I am not sure what will happen if I do not qualify for PIP, my assessment is happening next year.”

b. Trusting health and social care professionals

Many people with learning difficulties have to rely on health and social care professionals to make sure their needs are met. This means that there is a trust placed in them. However there is an issue here because health and social care professionals work for the local authority.



When the local authority has to make cuts to support and services this means that they cannot fully be working to make sure that people have the support and services that they need.



For this reason there is a need for clear, accessible information and independent support, so that there is not a **conflict of interest** for health and social care professionals.



Conflict of interest: this is where a person has two or more roles or jobs. Some decisions or parts of the jobs that a person has might go against each other. It can mean that if a decision needs to be made a person might have to take sides with one of their roles.

60% of the people who had been through local authority assessments had experienced cuts to their services or support, did not agree with the cuts, but did not take any action.



One person was even told that they could not appeal a support review decision. Of the 40% who took further action, this was only done after speaking to one or more independent people about what had happened.



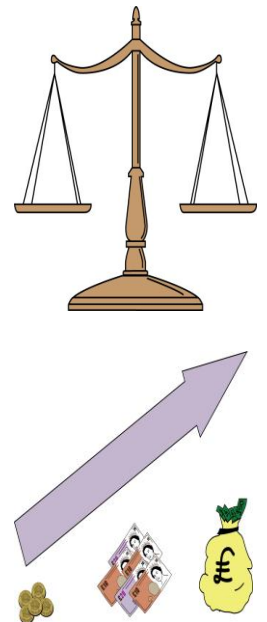
From service managers:

“In terms of perceptions by service users on changes, they just trust professionals; it is what happens in the review and how it impacts. People are not consulted and they accept what they are being told at face value.”



Supported by what people with learning difficulties had to say:

“I was assessed here by Barnet Council, maybe last year or the year before. I was told I have to pay a fairer contribution towards my care (...) It makes a difference that I pay my fairer contributions (towards care), at least that way it has been dealt with. I probably need to pay some more of it, we’ll see.” When this person was asked if they plan that kind of thing, they said “No, no I don’t. If they say I need to pay, then I pay”.



This person did not really understand how 'fairer' was measured, but the person trusted Barnet Council's decision. This meant that this person trusted Barnet Council's view that what this person had been paying before this had been unfair.



Below are some other examples of trust being given to professionals:

A person being told they could not appeal a local authority support decision and therefore taking no further action.



A person being told that a benefit change would be positive, yet having no information about why this would be better.



A person having a cut to national benefits without knowing that they could appeal until speaking about the situation with a number of other independent people.



c. Discussion: this means talking about the issues that came out of the research

Health and social care professionals have a difficult job because of the cuts to the money that local authorities are going through. Many people with learning difficulties trust professionals and think that they are getting independent advice and support.



Professionals may try to make sure that they get the best result for a person, but it is actually not possible to do this. This is because they work for the local authority, which at the moment is going through big cuts in the money that they get from the Government.



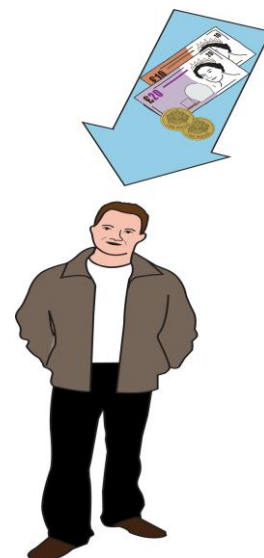
There are also big changes in the way that decisions about support and services for people are made. Less and less people are able to get support from the local authority.



Because of this, it shows that there is a clear need for independent support and advice. This is to make sure that people with learning difficulties know about the support that they are able to get and the different choices that they have.



Many parents and carers are in control of the money and benefits of people with learning difficulties. This can be very supportive and may be something that is needed for some people. The big issue is about whether it is seen as normal that people with learning difficulties rely on people to deal with money and benefits.



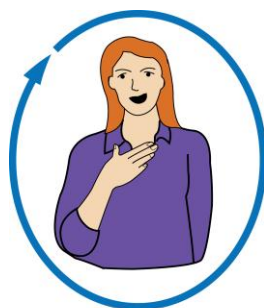
Also whether it is seen as normal that people with learning difficulties do not need information and do not need to have control. This research points to this being quite normal. The problem is that this makes it easier to make changes without people with learning difficulties being a real part of the decisions being made.



None of the people that took part in the research understood the national cuts and changes that were happening. They also did not understand how these cuts and changes might affect them.



People, who were going to have assessments for the new Personal Independence Payments, did not understand the changes to this benefit and what it would mean for them.



People are going into local authority and national benefit assessments without being able to talk about their needs and how this affects their day to day life. People are not being given information that they can understand and people do not have the support that they need.



Even for parents and carers of people with learning difficulties this research shows that they do not fully understand how assessments and reviews work. This then means that they find it hard to support the person that they care for through assessments and reviews.



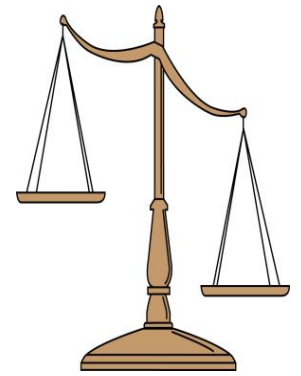
As we can see from this research, it is very important that people with learning difficulties have good information and independent support when they are going through assessments.



People also need support to understand how the cuts and changes will affect them. From the interviews, it was seen that people felt that they did not have any power. The effect that this has on people that are going through a number of assessments needs to be thought about.



The experience that people have had of assessments seems to show that they are not fair or equal. If people are not able to fully take part in the assessments, how can the decisions made in the assessment meet people's needs? This brings up the following questions:



- Are local authorities meeting their Equality Duty to give people accessible information and support to understand these changes?



- Do people with learning difficulties have any power and control in assessments and reviews?

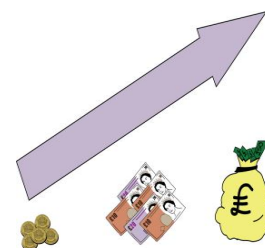


5.4 Cuts to benefits, support and services and charges for support and services going up

Here we look at the effect that cuts to benefits and services have had on people with learning difficulties. It is important to say that many people who took part in the research were waiting to go through assessments and so they did not yet know what was going to happen.



The main things that people were affected by were cuts to support hours and charges for support and services going up.



About 35% of the people with learning difficulties who took part in the research were still waiting for assessments and reviews.

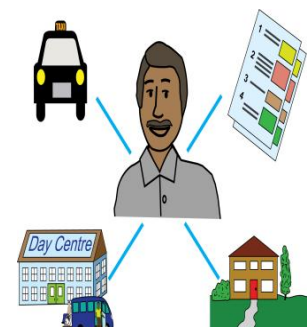


a. More than one change happening at a time

It is not clear whether the local authority or Government departments understood that people were going through a number of cuts and changes at the same time. Of the people that had already been through an assessment, everyone had experienced some kind of cut.



Over half of the people that were interviewed had been through more than one change or cut to services and support. This was a mix of cuts to services, changes to services, or their charges for services and support going up.



Example A

“My support went down from 6 hours to 4 hours per day. They have increased my charges and now give me less money to pay for support.



In the last year my support costs have gone up from £250 to £300 per month. They are creeping up all the time. It makes it difficult as I am left with less money, I can't get out on my own, I get really frustrated when I have to rely on people. My supporter puts extra hours in for me because she really cares about me. I feel frustrated, emotional, and lonely.”



Example B

“My support got reduced from 3 to 2 hours per week. They just said we're cutting your hours, instead of 3 hours we are giving you 2. It's OK, if I need anything, like letters, I take it to my mum.”



“I had a bad assessment for the Employment and Support Allowance; it was reduced to a lower rate. I kept it to myself until a mentor supported an appeal, as well as a doctor, a nurse and my family. We won the appeal, but ESA didn’t know and continued to give less money. In 2014 I got the backdated amount.



I ended up in Barnet General with a viral infection and seizures; I wasn’t able to work because of my health and mental state, I would get really agitated. Before this happened I used to go out to the gym, swimming, afterwards I was just sitting indoors doing nothing.



Now that I have got ESA back I am paying bills and everything, I’m bringing everything up to date and I am happier now.”



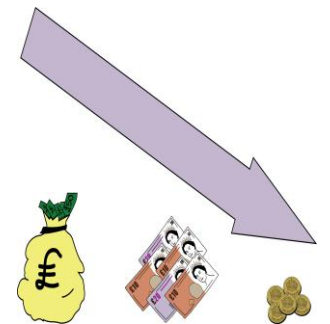
b. Losing out on opportunities and having less independence

This research showed how cuts and changes to services and benefits affect how people with learning difficulties are able to live independently and access opportunities.



From service managers

“Previously people would just go to the service and it was paid for. Now they are being charged for the service. This is having a huge impact on individual disabled people, they are getting a lot less money than they used to get.”



Supported by what people with learning difficulties had to say:

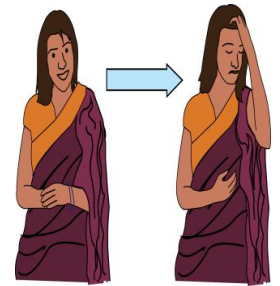
“At X organisation we now have to pay, it used to be free, I have to pay £85 a month and if I want to do a course it costs £145. My sister has to help me and pays for it as I can’t afford to pay for it.”



“I used to volunteer but now there’s no way for me to get there, they don’t arrange transport.” But you would like to volunteer?
“Oh yes.”



“It can be lonely when independence is taken away.”



“Being able to get out whenever you want is important.”

“At the moment I get 10 hours support a week to live independently which is just right, but that is because I haven’t been reassessed yet, I know when they get their act together they’re going to cut it down.”



“I get support from X disability organisation, they have funding for next year, but we are not sure what will happen after that.”



c. Discussion: this means talking about the issues that came out of the research

When more than one cut happens at a time, it can be very hard for people with learning difficulties to deal with the changes. With Example A, the person had a cut to benefits as well as having their local authority support cut.



For this person it meant that they needed their supporter to work hours without getting paid. This person also got support from other people to be able to do things. This person was not able to get out as much as they wanted to. This meant that they felt lonely. This person also felt upset that when they did want to get out, they had to ask other people to support them.



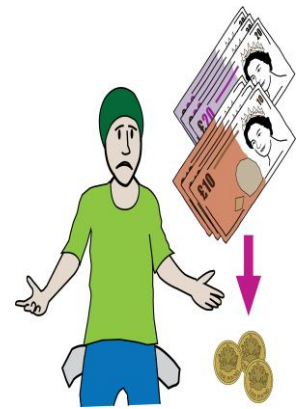
With Example B, having support hours cut did not affect them as much. The person got support from their mother with letters and admin. It is great for this person that they had support from their family.



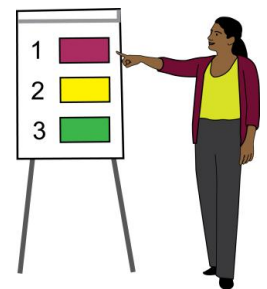
However, for many people they cannot get support from their family. This can be for a number of reasons, such as having difficult relationships with their family or because parents are older and not able to support them.



At the same time as having a cut in support, this person also had their Employment and Support Allowance assessment. The result of this assessment meant that the person was getting less money. This cut meant that the person got sick and ended up in hospital. After this the person was stuck at home, they were not able to work and felt very stressed.



The effect of two or more changes happening at the same time does not seem to have been thought about when decisions were made in assessments. This means that many people are going through two or more changes with each change being looked at on its own.



This shows the need for full impact assessments being done. This should be done either by local authorities or by the Department for Work and Pensions. This is to make sure that changes do not affect people as seen in Example A and Example B.



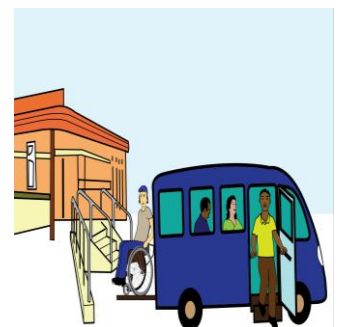
It is also clear that there is no support after a decision has been made to cut or change a person's benefits or support. People then have to find support where they can to make sure that they are ok.



As well as the cuts to benefits and support, charges for services that used to be free are affecting people in a bad way. Organisations that run services do not have the same money as they did before to run their services.



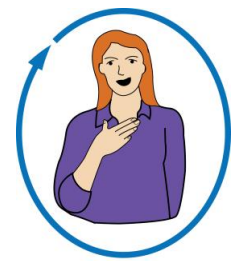
The person in Example A, whose support and benefits had been cut, also had to stop volunteering. This was because the organisation where the person was volunteering could not pay for transport anymore.



Charges are going up and the number of activities that people can take part in are going down. This is affecting people's independence and whether they can get out and do things. This is why when looking at the impact of cuts to benefits and support, they need to be looked at together with the other local services that a person uses.

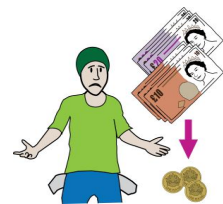


What was found out in this research, shows the need for impact assessments looking at the whole life of a person and all of the things that they do. If this does not happen then the full effect will not be seen.



These changes mean that people:

- Feel lonely
- Feel stressed
- Are not able to get out as much
- Do not have as many things to do
- Have to get by with less money
- Lose their independence
- Have to deal with how all of these things affect their health and their mental health
- Have to get support from family and other people when paying for things and to get out and do things



As these changes are not all happening at the same time, the effect of this may not be seen at first. However, when all of these things are looked at together with less services and services closing, it means that people are less able to cope. This then leads to people losing their independence in a big way.



People who have not yet gone through assessments are worried about what will happen. One person is sure that support hours will be cut and another is worried about what they will do if their benefit is taken away. If this happens there is no support from local authorities to deal with this change and make sure that they have enough money and support to get by.



5.5 What was missing? How important support is when going through assessments and after the assessment to deal with cuts and changes to support and services



Two of the main ways to meet the access needs of people with learning difficulties are having accessible information about what is happening. As well as this, having support to understand and deal with what is happening.



The research has shown that people do not have enough support and that information has not been accessible. This section looks at the support needed to go through an assessment and appeal a decision. It looks at the support needed after a change has happened. It also has examples of people who have not had this support and what that has then meant for them.

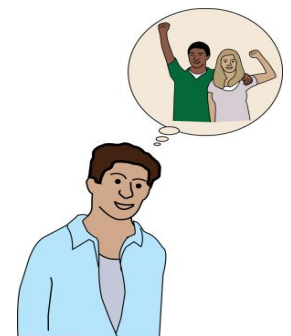


a. Support needed to get ready for an assessment or to appeal a decision

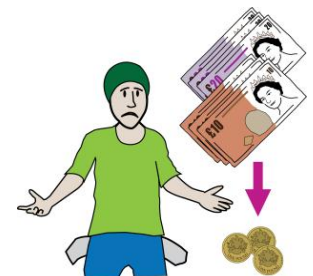
The research showed that there is no way of getting support to get for ready for an assessment or to appeal a decision. People had to find support where they could from anyone who was able to give support.



“At one point they wanted to take my bedroom away and started deducting money and me and my supporter had to fight for it, and now it’s fine.”



“For 2 hours support per week it costs £130 a month. The council asked me to put in £38 per week, but a disability organisation was able to bring this down to £28.”



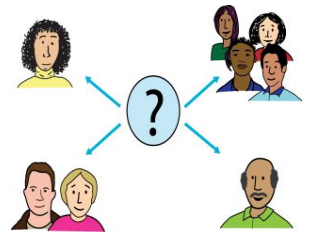
“I was told that Access to Work was being stopped on 31st August, I am trying to appeal the decision. The place I work are supporting me to make an appeal.”



“My parents have supported me to ask for an extra 5 hours support.”



“I got through the appeal by speaking to my community nurse, doctor, family and mentor.”



“Before my review, my sister in law came to help me put together the things I needed.”

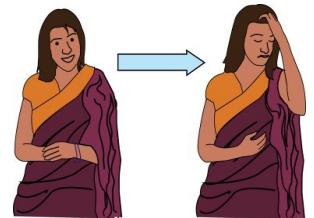


All the service providers that we interviewed, supported parents and carers with: “benefits forms”; “letters”; and “assessments”.



b. Support to deal with a cut or change after a decision has been made

For some people, they could get support from family and friends. In some cases this meant that people felt less independent.



“After the assessment and my support got cut I had contacts in the borough, but what would they do?” I had to learn how to do things on my own, or with the help of family members. My partner’s mum has helped us put together a shopping budget. Now I rely on my parents and my partner’s parents.”



“They just said we’re cutting your hours, instead of 3 hours we are giving you 2. It’s OK, if I need anything, like letters, I take it to my mum.”



But other people did not have access to support

“It is very hard to access an advocate; to get an independent advocate from outside is very hard.”



“It makes a difference that I pay my fairer contributions (towards care), at least that way it has been dealt with. I probably need to pay some more of it, we’ll see.”
When this person was asked if they plan that kind of thing, they said “No, no I don’t. If they say I need to pay, then I pay”.



c. Discussion: this means talking about the issues that came out of the research

When either an assessment is going to happen or when something goes wrong, we can see the number of people and organisations that are needed to support someone through this.



People need support when going through assessments and appeals. However, local authorities and the Department for Work and Pensions do not have anything in place to make sure that people get the support that they need.



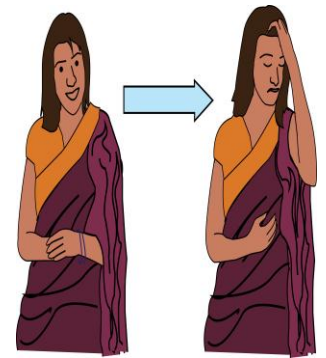
In most cases, where a person had support, they were able to get a good result in assessments and appeals. However, there are many people who do not have this support and therefore did not make appeals when they were not happy with the result of an assessment.



Supporters, organisations that run services, family members, doctors, nurses and other organisations all did everything they could to support these people with learning difficulties. However, this is something that so many people with learning difficulties need. Therefore a service giving independent support should always be there for people with learning difficulties who do not have anyone to support them.



When people did not get a good result in their assessment, most people who had been independent, had to go back to getting support from their family. Some people were ok with this, but other people felt that they had lost their independence. Others who did not have support from family were left on their own.



People talked about how difficult it is to get an independent advocate using their rights under the Care Act 2014. To even make the first steps towards getting an advocate, most people with learning difficulties would need support. Therefore, this is not really an accessible service for people with learning difficulties.



Independent support would help a person to look at what a change means to them and decide whether they are ok with the change. People without support in many cases are not able to try and change decisions made in assessments or make an appeal once an assessment has been done.



Some people may have even seen some changes as good because they do not have accessible information and support to understand the change and the choices that they have.



Most of the people that had support got a good result after making an appeal. The support came from:



- Supporters
- Charities and other organisations
- Organisations that run services
- Family
- Health professionals such as doctors and nurses



But what happens to people who do not have this support?



5.6 People know what independence looks like and what they need

It can be seen from the information above, that people are not listened to or able to take part in decisions made about their lives. However, this section shows that people know what they need and want. People know what independence looks like in their lives and what works for them.



The problem is not about whether a person with learning difficulties knows what they need, the problem is whether they can have a voice and can take part in the decisions being made about their lives.



a. Good support and the right benefits

“I feel valued, I go to (X third sector organisation) whenever I run into problems.”

“When there was more support it was wonderful.”



“Now that I have got ESA back I am paying bills and everything, I’m bringing everything up to date and I am happier now.”



“On hand support is important.”

“My Support Network is important; friends, support workers and family.”



“Living independently needs proper support.”

b. Work, volunteering and getting out and about

“I started volunteering, doing it has kept me going.”



“Getting out whenever I want is important.”

“Volunteering is good.”



“I have got a volunteering job with a charity and I like it. I work in the shop serving customers; I can work any day I want.”



“I work at a supermarket, I love it there, and they are all very friendly.”



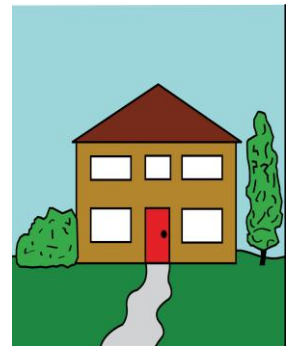
“I want to be doing more things in the day.”

“I am looking for a paid job; I am looking for work experience. I am looking for work, I went to the job centre and they said I am not fit yet, the doctors said I am fit for work but the job centre said I am not fit for work.”



c. The right place to live

“I feel independent and like living on my own.”



“I am very happy, its quiet here, no noise, banging about, it’s very quiet, I want it very quiet and it’s very nice.”

“I live independently. The flat I live in is perfect. I get 10 hours support because I haven’t been reassessed, which is enough. I know when they get their act together they are going to cut it down.”



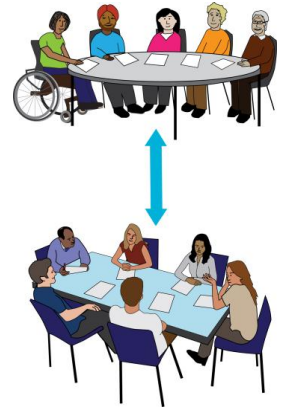
d. Discussion: this means talking about the issues that came out of the research

People know where to go to get good support, what type of support they need and how much support they need. Working or volunteering is an important part of people's lives. Most people who took part in the research who do not work or volunteer, want to start. Having a full life is important.

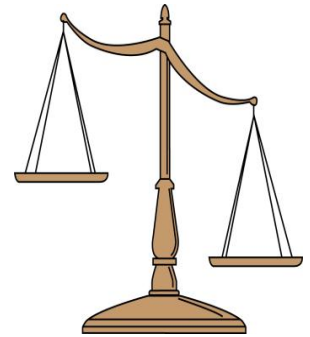


6. Conclusion: summing up what we found out

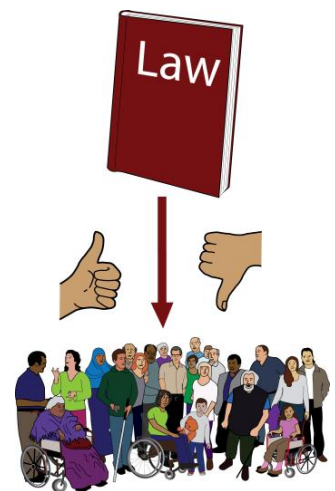
This research project has brought together two user-led Disabled People's Organisations. The national self-advocacy organisation, People First (Self Advocacy), and the local self-advocacy organisation, People's Choice at Barnet Centre for Independent Living.



The Cuts Impact Action Now project has found information which shows that people with learning difficulties are left out of society and are discriminated against. It also shows that they face barriers and do not have equal access to health services, education, work or justice.



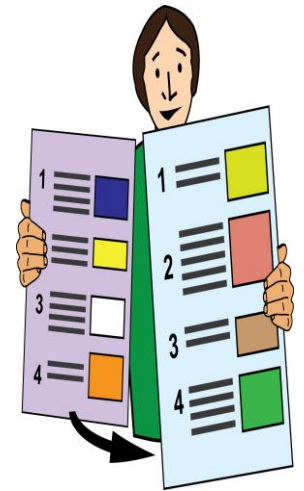
The research looked at the changes to national and local policies and laws and how this might affect disabled people and people with learning difficulties. These changes mean that there are not as many services and that there is not as much money for people to live on. It looked at what this might mean for people with learning difficulties.



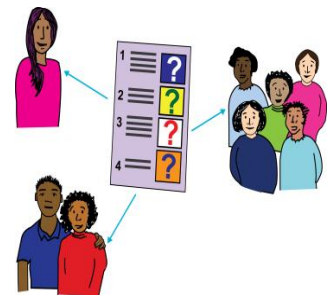
It gives a big picture idea of what is happening and how cuts and changes might affect people with learning difficulties.



It looks at changes such as the Disability Allowance change to Personal Independence Payments, the Independent Living Fund closing, changes to Housing Benefits, the new Employment and Support Allowance; changes to Access to Work, cuts to Legal Aid and cuts to the money that local authorities have to spend on Adult Social Care and local services.



The Cuts Impact Action Now project is a user-led research project. The research was done in the London Borough of Barnet where it is thought that there are 5,874 people with learning difficulties. Of this number, 1,326 people use local authority services.



In this research, information about changes to services and benefits was given by 54 people with learning difficulties. This was done through 35 one to one interviews and 3 focus groups. Information was also given in interviews with 3 service managers.



This was done to understand the views and experiences of people with learning difficulties in Barnet.



From the information that was given we looked at how all of the changes that are happening around benefits, services and support impact on the day to day lives of people with learning difficulties in Barnet. The research found that changes to benefits, services and support did have a bad impact on people's lives.



This affected the support and services that were on offer to people. It affected people's health and mental health. It affected people's wellbeing. It affected whether people were able to take up opportunities. It also affected how much money and independence people had.



People with learning difficulties and service managers also thought that there were big problems with the way that reviews and assessments were done. Both service managers and people with learning difficulties thought that the aim of cutting how much money the local authority was spending was being seen as more important than people's needs.



It was also thought that the people who made decisions in reviews and assessments did not understand that people were being affected by many cuts and changes at the same time. Not having accessible information and independent support when going through assessments, reviews and appeals was also a big problem.



It meant that people could not really take part in decisions being made about their own care and support. There was also no support for people to be able to deal with cuts and changes that affected them in a bad way.



In summary, for most people, reviews and assessments were seen as a very bad experience. People felt that they had power taken away from them, that they could not take part and that they did not have a voice.



The research also showed that people with learning difficulties are clear about what is important to them and what they need. This was shown by people wanting:



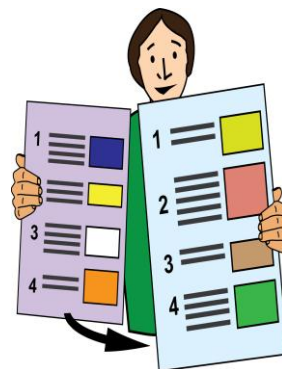
- To stay independent
- To be more independent
- The right amount of money to be independent
- The right support to be independent
- Access to opportunities
- To get out and about
- Access to education, volunteering and work



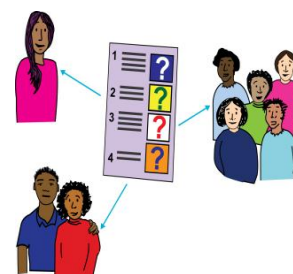
Using what we found out in this research, we have written down 7 things that we think need to happen, these are called recommendations. The recommendations are aimed at policy makers, decision makers, and health and social care professionals.



These recommendations aim to make a number of people and organisations work in a better way. They aim to make reviews and assessments better. They also aim to make sure that cuts and changes to benefits, support and services do not have such a bad impact on the lives of people with learning difficulties.



This pilot 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 collect evidence and campaign in their local areas. It will also mean that they can be part of a national voice to make change happen.



7. Recommendations: what we think should happen based on what we found out

The recommendations below are aimed at Barnet Council and in some cases national Government departments. However, many of the recommendations that talk about Barnet Council can also be used by other local authorities.



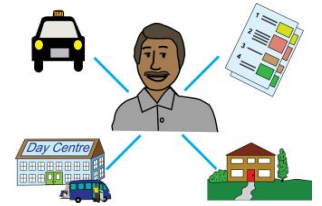
Recommendation 1: Being a part of assessments and reviews

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 local authority support



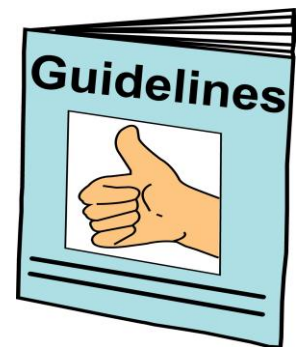
- Why cuts are needed
- When cuts or changes will happen
- What choices each person has



This will mean that people with learning difficulties can be a part of 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 should be done and the information needed to make this accessible for people with learning difficulties.



Recommendation 2: Getting my voice heard

Barnet Council should carry out an assessment looking at the need for an independent support service for people with learning difficulties. It would be a service for all people with learning difficulties that they could use when going through assessments and reviews.



This service should make sure that people can:

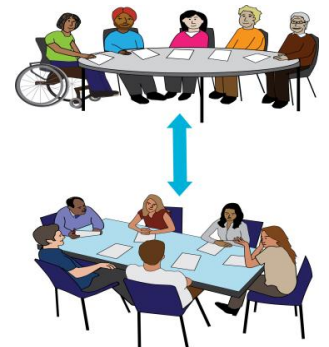
- Get ready for assessments
- Show their needs in an assessment
- Think through the choices that they have
- Talk about their needs and make sure that they have been understood
- Get support after a decision has been made to deal with any cuts or changes to support, services or benefits.



This will make sure that people have an equal voice, choice and control in the decisions being made about their lives. The assessment of the need for this type of service should be done 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 this type of service is set up for people with learning difficulties.



Commissioning Team: this is the team that decides what services are needed in a local area 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

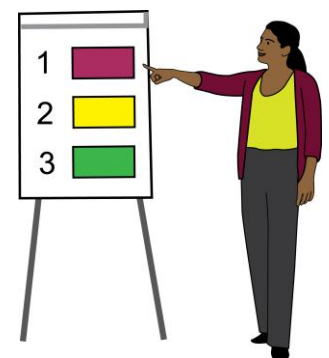
Social workers and other professionals in Barnet that are part of assessments and reviews should have user-led learning difficulty awareness training. This will make sure that professionals understand the needs and life experiences of people with learning difficulties.



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 in an understanding way, such as news about cuts in support.



There should be training for staff who are already working on assessments and reviews and training should 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 and will be put together with a number of people and organisations that have skills and experience of assessments.

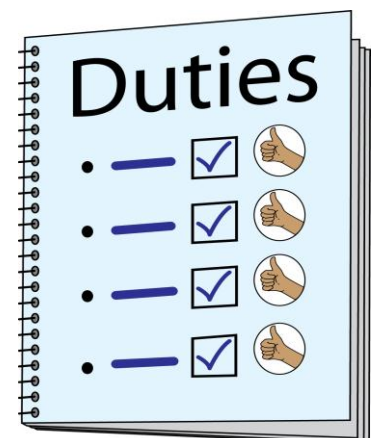


Recommendation 4: What happens after an assessment or review decision has been made

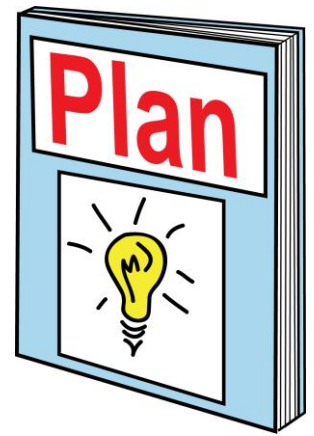
Cuts to the money that local authorities have to spend mean that less and less people are able to get local authority support. However, this does not mean that a person does not need support; it means that the local authority does not have the money to pay for this support.



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.



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 that they feel they need.



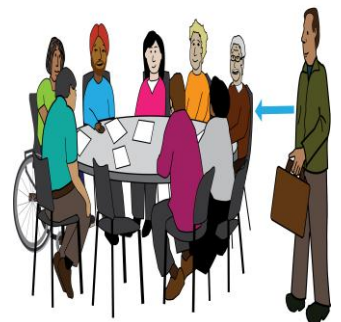
There should be information about organisations that give support in the areas that the person feels that they might need support. There should also be information about activities in Barnet.



They should make sure that each person has the support that they need to make contact with these organisations, whether this is a family member, carer or independent support from a local organisation.



There should also be a meeting after a cut or change to support has happened to find out the impact that this has had on the life of the person with learning difficulties. This should look at national benefit changes, local authority support changes, changes to local services and changes to service charges.



How will we know it has been done? This will be part of the guidelines that will be written with Barnet Council around making assessments 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 making sure that this happens will be started in January 2016.



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



Recommendation 6: Cumulative Impact Assessment

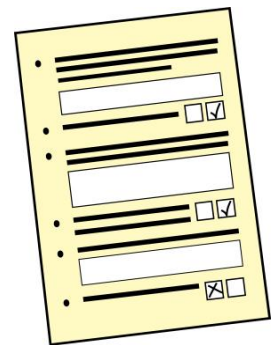
There needs to be a Cumulative Impact Assessment done in general for disabled people. This also needs to be broken down for people with learning difficulties.



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



There needs to be a way of checking this is 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.



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.

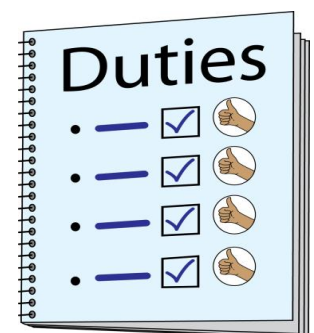


Recommendation 7: Taking part, having choice, control and a voice

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. They 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. How Barnet Council is meeting this duty should be shown by the local authority. This will be asked for at the end of each year.



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 as to how they are meeting the wellbeing principle under the Care Act 2014 for people with learning difficulties.

