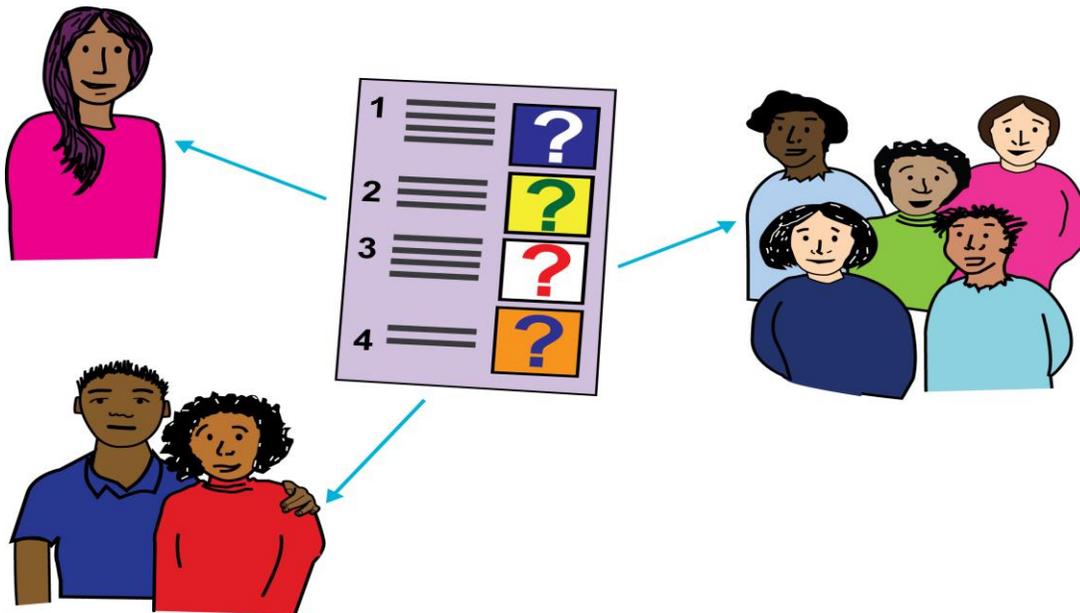


Cuts Impact Action Now

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



Carried out by People First (Self Advocacy) in partnership with People's Choice at Barnet Centre for Independent Living

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Disclaimer

This report is the result of research carried out by the People First (Self Advocacy) Research Team, which was facilitated by People's Choice at Barnet Centre for Independent Living. However this report does not represent the views of the organisations that have carried out or facilitated this research.

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Foreword

When the last Government started making cuts to services we wanted to find out how the cuts were affecting people with learning difficulties and what people knew about the cuts and changes which were happening. We also wanted to create a channel for people with learning difficulties to be able to get their voices heard by decision makers.

From experience we know that often the government, local authorities and services do not give people with learning difficulties information that is accessible. In many cases decisions are made without people's knowledge and that is why the Cuts Impact Action Now project is so important, to show decision makers and professionals what is happening.

We decided to work with People's Choice at Barnet Centre for Independent Living to test run this model for collecting evidence. This group has a history of campaigning and runs the local Learning Disability Parliament which has been a very useful way of getting in touch with individuals, service providers, other organisations and the local authority.

This pilot research project has shown that many decisions are being made from a money point of view rather than being based on a person's needs. There is a gap between what people need and what they are getting, and it has highlighted very clearly the problems with the way that cuts and changes are being put in place. It has shown how important support is for people with learning difficulties, support to make sure they are listened to in assessments and reviews, and support in their day to day life.

As a person with learning difficulties I know the barriers that people have to face and I hope this pilot research project can be the start of more local groups doing the same research. I also hope that decision makers take on board the findings and recommendations in this report and 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
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1. Executive Summary

1.1. Introduction

It is widely accepted that it is very difficult for people with learning difficulties to get their voices heard and take part in society and the decisions that affect their lives. This is as a result of a number of barriers which include inaccessible information, not having enough support or advocacy, and negative attitudes and discrimination against people with learning difficulties. People with learning difficulties are one of the poorest and most marginalised groups in society.

There have been wide ranging cuts and changes to benefits and services, both locally and nationally and they are all happening at the same time. We have quantitative information about cuts at a national level, as well as information from local self-advocacy groups and individuals about cuts and changes to support and services at a local level. However, at no point has any research been done into the combined impact of local and national cuts on the lives of people with learning difficulties. By looking at these changes in a local context it is easier to get an understanding of how both national and local cuts and changes are impacting on the lives of people with learning difficulties. It has been very important that a national and local organisation have been working together on this research. It has enabled the research to use the strengths of both organisations and clearly see how national policy translates into a local reality.

Based on 30 years of experience, People First can say with certainty that people with learning difficulties are often not consulted properly, listened to or given the chance to have a strong voice. By carrying out this research we are recognising that people with learning difficulties need to have their voices heard and their experiences understood.

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

This pilot research project aims to:

1. To enable people with learning difficulties to have a meaningful voice at a local and national policy level about the impact of benefit and service cuts and changes;
2. To collect evidence about the combined impact of national and local service and benefits changes and cuts to people with learning difficulties at a local level;
3. To create a model for evidence collection, enabling other local self-advocacy groups to replicate the Cuts Impact Action Now method of

- research and give a voice to people with learning difficulties locally and create a collective national voice;
4. To increase the awareness of policy makers and service providers of the impact of service and benefit cuts and changes for people with learning difficulties as a driver for change;
 5. To reduce the negative impact that cuts and changes are having on people with learning difficulties.

The key objectives are:

1. To set up inclusive and accessible methods of collecting valid, representative, and reliable information about the impact of cuts and changes to services and benefits on people with learning difficulties;
2. To collect information about how the cuts and changes to services and benefits in a local area are affecting the lives of people with learning difficulties and their families and/or carers;
3. To provide evidence of the impact that service and benefit cuts and changes are having on people with learning difficulties;
4. To enter into meaningful discussion with local and national policy makers and service providers about potential for change and reducing the negative impact;
5. To produce a replicable process for evidence collection at a local level in order to build a national evidence base and voice for people with learning difficulties;
6. To set up channels/networks for giving evidence to policy makers and service providers at a local, regional and national level, creating a collective voice to influence change.

1.2. Background

About the organisations working on this research

People First (Self Advocacy) is a national organisation run and led by people with learning difficulties. As an organisation it aims to raise awareness of the rights of people with learning difficulties, support the development of the skill base of self-advocacy groups and individuals, and make sure that their voices are heard at government policy level. We work at a national level providing support, information, advice and training to individuals and self-advocacy groups.

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. It aims to raise awareness locally of the rights of people with learning difficulties, making sure that their voices are heard. It runs 6 self-advocacy groups and works with people to talk about local and personal issues.

What the big picture looks like for people with learning difficulties

A snapshot of what life looks like.

Life before the cuts and changes started

This covers areas where people did not have equal access even before the cuts and changes to services and benefits began:

Equal access to health: Research shows that as a group, people with learning difficulties have poor health, for reasons such as not having the right housing¹, not having a job and living in poverty². However when needing to use the NHS, as a result of staff not being able to communicate with people with learning difficulties, it has been labelled as 'unsafe'.³

Equal access to education: Many children with learning difficulties do not go to mainstream schools, it is a postcode lottery. The number of children with moderate learning difficulties excluded from mainstream education ranges from 1% to 25% in different local authorities. As well as this permanent exclusions from school are more common for children with learning difficulties.⁴ In higher education people with learning difficulties were four times more likely to be enrolled on 'preparation for independent living' or employment learning programmes rather than on mainstream accredited courses.⁵

Equal opportunities in work: Only 6.6% of people with learning difficulties are in some kind of paid work and most of the people in paid work work part time,⁶ much lower than the 46.3% of disabled people in paid work and 76.4% of non-disabled people in paid work⁷. Getting a job is difficult; the biggest barrier is people thinking that people with learning difficulties cannot work⁸, when actually 65% of people with learning difficulties would like a paid job⁹. Those that are in employment were found to be treated unfairly, facing bigger barriers in the work place.

¹ 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.

² Health Inequalities and people with learning disabilities in the UK, Improving Health and Lives, the Learning Disabilities Observatory, Eric Emerson and Susannah Baines, 2010.

³ <https://www.mencap.org.uk/sites/default/files/documents/Death%20by%20Indifference%20-%2074%20Deaths%20and%20counting.pdf>

⁴ https://www.improvinghealthandlives.org.uk/securefiles/150618_2200/IHAL2013-10%20People%20with%20Learning%20Disabilities%20in%20England%202012v3.pdf

⁵ ALLFIE - Children and Families Bill's Proposed Amendments for consideration at Committee stage (March-April 2013)

⁶ <http://www.learningdisabilities.org.uk/help-information/Learning-Disability-Statistics-/187693/>

⁷ <https://www.gov.uk/government/publications/disability-facts-and-figures/disability-facts-and-figures#employment>

⁸ http://www.ndti.org.uk/uploads/files/3.The_cost_effectiveness_of_Employment_Support_for_People_with_Disabilities,_NDTi,_March_2014_final.pdf

⁹ Valuing Employment Now, HM Government, 2009

Disability hate crime: This has been a problem for a long time, and research done by Mencap found that nearly 90% of people with learning difficulties had experienced hate crime in the previous 12 months.¹⁰ Reporting of hate crime by people with learning difficulties is also very low as a result of communication barriers, not being believed or people not wanting to report these crimes as a result of past experiences with the police.

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

Disabled people are more likely to live in poverty than other people. With only 6.6% of people with learning difficulties in paid work, this means that changes to government and local authority spending on benefits, support and services affect people with learning difficulties more than most other communities of people in society. There have been big changes to benefits, support and services, with some people being affected by up to 6 cuts and changes at the same time.¹¹ Below is some information about the most important changes:

The change from the Disability Living Allowance to the new Personal Independence Payments: Changes to the way that people are assessed for this benefit will result in around 607,000 fewer disabled people getting this benefit and well as 428,000 getting a reduced benefit.¹²

The complete closure of the Independent Living Fund: One third of people who received this fund were people with severe learning difficulties. This money will be passed on to local authorities, however it will not be ring-fenced and therefore does not have to be spent on social care for disabled people.

Overall Benefit Cap and 1% cap on benefit rises: This will mean that 142,500 disabled people will lose around £2 billion by 2018.¹³

The Spare Room Subsidy being taken away: This is sometimes called the Bedroom Tax. People with a 'spare' room, will now have to pay more towards their house. 72% of the houses affected by the change have either a disabled person or someone with a health condition living there.¹⁴

Discretionary Housing Payments: This is a short term payment that can be made to people by a local authority on top of their housing benefits. A local authority decides if this is needed, but it has been found that 41% of disabled

¹⁰ <https://www.mencap.org.uk/blog/four-things-you-probably-didnt-know-about-disability-hate-crime>

¹¹ <http://www.demos.co.uk/blog/destinationunknownapril2013>

¹² (*Personal Independence Payment*) Regulations 2013 . - Parliament www.parliament.uk/briefing-papers/SN06538.pdf

¹³ http://www.demos.co.uk/press_releases/destinationunknownapril2013

¹⁴ <http://inactualfact.org.uk/fact/72-of->

households/<http://www.affinitysutton.com/media/808765/housing-futures-report-final.pdf>

people affected by the Bedroom Tax and Benefit Cap are not being given this payment, even when they cannot find adapted housing.¹⁵

The Incapacity Benefit and some Income Support benefits are being replaced with the Employment and Support Allowance, using the Work Capability Assessment: Work Capability Assessments have been found to be unfair, stressful and do not get the right results. Over half of the Work Capability Assessment appeals are won.¹⁶ However, people with learning difficulties have been found to be at a disadvantage in the appeals process, as a result of finding it difficult to get together evidence for the appeals.¹⁷ There are also harsher rules for people who do not stick to the rules of the Employment and Support Allowance; they can be left without money for a long time.

Universal Credit: This will bring together 6 different benefits and be paid as one benefit payment. Up to 116,000 disabled working adults will lose up to £40 per week.

Access to Work: The Department for Work and Pensions is currently changing its approach to funding support. The current approach is to support as many disabled people as possible without increasing the Access to Work budget.¹⁸ This means that many people with learning difficulties are currently having their funding for Access to Work support cut, as a result of needing “high value” support packages. This approach to funding Access to Work claims is directly excluding people with learning difficulties, who need ‘high value’ support packages to gain access to meaningful employment.

Service Changes

Funding for adult social care has had big cuts in local authorities across the UK: Between April 2011 and March 2013 there have been cuts of £1.89 billion.¹⁹ It was said in June 2013 that there would be funding cuts of 10% to local authority budgets.²⁰ As a result of these cuts 100,000 disabled people are or are at risk of not getting the support that they need.²¹ So far 69,000 disabled people have been pushed out of the social care system.²²

¹⁵ http://www.papworth.org.uk/downloads/makingdiscretionaryhousingpaymentsworkfordisabledpeople_130710181752.pdf

¹⁶ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/411937/esa_wca_summary_Mar15_final.pdf

¹⁷ https://www.learningdisabilitytoday.co.uk/government_loses_appeal_against_esa_benefit_ruling_25769804847.aspx

¹⁸ <http://www.parliament.uk/business/publications/written-questions-answers-statements/written-statement/Commons/2015-03-12/HCWS372/>

¹⁹ <http://www.adass.org.uk/A-new-system-for-care-funding/>

²⁰ <http://www.theguardian.com/politics/2013/jun/26/spending-review-2013-the-key-points>

²¹ <http://www.scope.org.uk/campaigns/social-care-and-support>

²² <http://www.scope.org.uk/news/other-care-crisis>

The new Care Act 2014: This law has brought in a range of standards and rules around social care and the duties of local authorities. However, some organisations believe that it does not go far enough to ensure equal access to social care.

Cuts to organisations supporting people with learning difficulties and increases in service charges: In total, disabled people have been affected by a rise of £77 million in charges for care.²³ 72% of organisations providing support to people with learning difficulties have received cuts in funding. As well as this, nearly half of people with learning difficulties have had their support cut or their charges increased.²⁴

Cuts to Self-Advocacy Groups: This has led to closure or reduced services of local groups that support people with learning difficulties to speak up.

Cuts to Legal Aid support for benefit and welfare cases: This is at a time when the Government is carrying out the biggest welfare reform in 60 years. Legal Aid support has been completely taken away in the area of welfare. However, 58% of the people who use legal aid for welfare benefit cases are disabled people.

Closure of the Equality and Human Rights Commission Helpline: The Equality and Human Rights Commission had a budget cut for the year 2014-2015 of 62% compared to 2007²⁵. As a result of this the Helpline for legal advice on discrimination cases was closed. Many of the legal cases received through the old helpline then went on to be test cases used by the Commission to set a precedent which will no longer happen.

Local changes in Barnet

In Barnet the council have had cuts to funding in all services of 26% totalling £72.5 million, with cuts to adult social care of £23.16 million and further cuts of £12.6 million over the next 5 years.²⁶

Changes to services in Barnet: Barnet Centre for Independent Living lost the contract for its Information, Advice and Advocacy Brokerage service. This service has now been transferred to Barnet Citizens Advice Bureau as of 29th June 2015. It is not yet clear how this service will roll out.²⁷ People's Choice, the partner organisation in this research project came under the umbrella of Barnet Centre for Independent Living and will therefore need to find other funding. The Barnet Learning Disability Parliament, previously run by People's

²³ ADASS budget survey (April/May 2012)

²⁴ Social Care in Crisis: the need for reform, Learning Disability Coalition, 2012

²⁵ <http://www.theguardian.com/society/2012/oct/26/budget-cuts-rights-watchdog-un-status>

²⁶ <http://www.yourchoicebarnet.org/news/2014/09/your-choice-barnet-facts-file-on-the-pay-cut-dispute/>

²⁷ <http://www.barnetcil.org.uk/index.php?id=4&cat=1>

Choice is no longer being funded by the local authority and the organisation is currently seeking funding to continue the Parliament.

Your Choice Barnet: Another big change is that the services run by London Borough of Barnet were transferred to Your Choice in 2012, a Local Authority Trading Company owned by London Borough of Barnet.²⁸ The outsourcing of London Borough of Barnet services to the organisation Your Choice has been the focus of much anger, debate, petitions and even strike action. In 2013 Your Choice was in financial difficulties, staff in its supported living service were downgraded to the role of assistant support worker, and staff numbers, wages and weekend payments were all cut. In March 2015, the Care Quality Commission rated the Barnet Supported Living Service run by Your Choice as 'inadequate', its lowest score.²⁹

Local and national demographics of people with learning difficulties

National demographics: It is estimated in a report called People with Learning Disabilities in England 2012 that there are 1.14 million people with learning difficulties in England, this is around two out of every 100 people.³⁰ More than half of people with learning difficulties are not known to any services.³¹

Barnet demographics: According to a report written by Barnet Council in 2012, by 2015 it was estimated that there would be 5,874 people with learning difficulties in Barnet. Of this total, it was predicted that there would be 1,326 people with severe or moderate learning difficulties, who would therefore be likely to be in receipt of local authority support.

1.3 Research Methods

The Cuts Impact Action Now project is a user-led, user controlled pilot research project carried out by People First (Self Advocacy) and People's Choice at Barnet Centre for Independent Living. We took measures to ensure that the research was carried out in line with good practice. The research was carried out between January 2014 and September 2014. We advertised the project through a range of organisations in Barnet, giving the organisations information to send to their members or users. We found some difficulties in carrying out

²⁸ <http://www.barnetmencap.org.uk/files/Newsletter%202012%20Spring.pdf>

²⁹ [http://www.cqc.org.uk/sites/default/files/posters/20150412_1-](http://www.cqc.org.uk/sites/default/files/posters/20150412_1-112848964_summary_ratings_poster_A4.pdf)

[112848964_summary_ratings_poster_A4.pdf](http://www.cqc.org.uk/sites/default/files/posters/20150412_1-112848964_summary_ratings_poster_A4.pdf)

³⁰ https://www.improvinghealthandlives.org.uk/securefiles/150618_1719//IHAL2013-10%20People%20with%20Learning%20Disabilities%20in%20England%202012v3.pdf

³¹ https://www.improvinghealthandlives.org.uk/securefiles/150618_1715//IHAL2013-10%20People%20with%20Learning%20Disabilities%20in%20England%202012%20-%20Easy%20Read.pdf

the research, for example we needed to get through gate keepers to access people and getting interviews with people was very difficult, in part as a result of people's impairments around memory. We collected diversity information from everyone who attended the interviews and focus groups, using a short questionnaire.

We carried out 35 in depth interviews with people with learning difficulties. The research was carried out with an interview guide that covered topics such as housing, transport, advocacy and support. We introduced each topic and talked around it to see if there was anything that the person wanted to focus on, without asking leading questions. We always asked about changes in a person's life, rather than cuts, to ensure that the interview was not threatening. We also carried out 3 focus groups, and 19 people took part. The same interview guide was used as in the interviews. We made sure everyone could have their say and used pictures to communicate with people with higher support needs. Three service managers were also interviewed to get an overview from their perspective, gaining insight into the experience of carers.

The qualitative data collected was analysed thematically within a quantitative framework, pulling out key themes. We used the method of triangulation. The themes highlighted were supported by example quotes from people who took part. We then discussed some of the points which had been raised and developed recommendations to be considered by Barnet Council, other local authorities, national government departments and health and social care providers.

1.4 Findings and discussion

The assessment and review processes seem to be overriding the needs of people with learning difficulties

Most people with learning difficulties that took part in this research and all service managers interviewed said that reducing funding and making cuts to people's support, now seemed like the main reason for assessments and reviews.

It's all about the money: There was total agreement from service managers and the majority of people with learning difficulties that the need to cut money

from the budget seemed to be overriding the need to make sure appropriate support and services were in place for individuals.

Are you listening to me? 80% of people interviewed, who had experienced cuts in support and services, felt that either important information had been missed, or that they could not get their voices heard. People felt that they were not given the chance to understand what was happening, as a result of not having accessible information and support to say what they thought, be included in the decision making process, or ensure they were listened to.

People do not understand what is happening, are not given information on which decisions are based, and there is a lack of inclusion in the process

The research showed very clearly that people did not have enough information about the planned cuts and changes, nor the impact that they would have. They depended on health and social care professionals' judgments about what would be best for them.

People do not know what is happening: 30% of people interviewed had some general information about cuts and changes. The majority of individuals however did not have any information about cuts and changes to services and benefits. There seemed to be a culture whereby it was assumed that people with learning difficulties did not need this information, and this seems to be paralleled by the way that assessments and reviews were carried out. People are going into national benefit and local authority assessments without good information, or the support to communicate their needs. The research indicates that even parents and carers do not fully understand the assessment and review process and therefore cannot properly support people with learning difficulties.

Trusting health and social care professionals: It was clear that many people with learning difficulties have to rely on health and social care professionals to make sure their needs are met. There was little awareness that health and social care professionals are not independent. This gave a clear indication of the need for accessible information and independent support to avoid a conflict of interest for professionals, and to ensure that individuals can properly access the assessment and review process. Of the people that had an assessment

and did not agree with the outcome, only 40% took further action and this was always with the support of a third party.

Direct cuts to benefits, support and services and increases in charges

Double whammy – more than one change happening at a time: Of those interviewed who had been assessed, everyone had experienced some form of cut, and over half had experienced more than one cut, change to services or increase in charges. There was no post-decision support available, and individuals had to rely on other people's good will to cope with their situation.

Lost opportunities and reduced independence: There was a clear message from the research that the cuts and changes to services and benefits were having an impact on people's ability to lead independent lives and access opportunities. As well as cuts to benefits and support, charges for services that used to be free are adding to the loss of independence experienced. People have had to depend on family and other people to get out and do things, as well as for financial support.

What was missing? The importance of support to go through the process of assessment and after the assessment to cope with reduced support and services

The research showed the high level of support needed for individuals to go through a review and assessment process, appeal a decision and the support needed afterwards to deal with cuts and changes to support and services.

Support needed to prepare for an assessment or to appeal a decision: In order to support people with learning difficulties a range of people stepped in to provide support during the assessment and review process, as well as when difficulties arose as a result of review and assessment outcomes. In the majority of cases, where a person had support, they were successful in getting a positive outcome. However, there were many people without support who did not appeal a decision, even when they did not agree with the outcome. Some people did not realise that they could appeal a decision. Support through the assessment and appeal process was provided by service providers, family members, doctors, nurses, mentors and third sector organisations.

Support to cope after a decision has been made: In most cases, where the outcome was a reduction or complete withdrawal of benefits or support, people had to go back to relying on family members. Some people were accepting of this, others felt a loss of independence and some were left on their own.

People know what independence looks like and what they need

This research shows that people with learning difficulties have not been properly listened to or included in decisions that are being made about their lives. However, it was clear that people know what they need; know what independence looks like in their life; and what works for them in areas such as support, benefits, work, volunteering and getting out and about, and having the right place to live. People know what they need, but the barriers highlighted in this research are making it ever more difficult for people to have meaningful input into assessment and review processes, and thus get their needs met.

1.5 Conclusion

This pilot research project has brought together two user-led Disabled People's Organisations, the national self-advocacy organisation, People First (Self Advocacy); and a local self-advocacy organisation, People's Choice at Barnet Centre for Independent Living. The Cuts Impact Action Now project has documented research which demonstrates that people with learning difficulties, who it is acknowledged are routinely excluded and discriminated against at a range of levels in society, face barriers and a lack of equality in health services, education provision, work opportunities, and access to justice.

The research also analysed the theoretical impact that recent national and local policy and legislation changes, which have resulted in a decrease in service provision and financial support, could have on the lives of people with learning difficulties. It profiles cuts and changes which will condition the experience of people with learning difficulties and potentially worsen their position in relation to income, access to services and support, encompassed specifically in: Disability Living Allowance changing to Personal Independence Payments; the closure of the Independent Living Fund; the Overall Benefit Cap; the Spare Room Subsidy; changes to Housing Benefits ;Incapacity Benefits and Support Benefits being replaced by Employment and Support Allowance; Universal Credit; apparent changes in Access to Work criteria for people with learning difficulties; cuts to Legal Aid, the Equality and Human Rights Commission

helpline closure; and cuts to local authority budgets leading to reduced spending in Adult Social Care and local service provision.

The Cuts Impact Action Now project is a user-led, pilot research project. The research took place in the London Borough of Barnet, where it is estimated that there are 5,874 people with learning difficulties, of which 1,326 are in receipt of local authority services. Information, in relation to changes to services and benefits, was gathered from 54 people with learning difficulties via 35 individual interviews and 3 focus groups; and from 3 service managers. This was in order to gain an insight into the views and experiences of people with learning difficulties in Barnet.

From the evidence collected, how do the multiple policy and legislation changes, which point to a reduction in benefits, services and support for people with learning difficulties, impact on people's day to day lives in Barnet. The research found that changes to benefits, services and support, did have a major and negative impact on people's lives in terms of: support and services available; physical and mental health, and wellbeing; ability to take up a range of opportunities; independence; and personal finances. People with learning difficulties and service managers also thought that the review and assessment process to implement these cuts and changes was a major issue. There was agreement from both sources that the aim of reducing local authority spending was overriding meeting people's needs. It was also thought that there was a lack of understanding by the people who made decisions and carried out reviews and assessments of the cumulative impact of the cuts and changes. In addition, the lack of accessible information and independent support throughout the review and assessment process, including making appeals, meant that people felt that they could not have proper input into decisions about their own care and support. There was also no formal process in place to enable people to cope with and manage the negative changes. Overall, the review and assessment process itself was felt to be an extremely negative experience. People felt disempowered, that they were not included, 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 can be encapsulated in people wanting to: retain the level of independence they have, and become more independent, with adequate income to do this; have the right support; access opportunities and get out and about; and access education, volunteering and employment opportunities. The following recommendations aim to improve the practice of a range of stakeholders, including: policy makers, decision makers, and health and social care professionals, in relation to the

process of reviews and assessments; and alleviation of the negative impact of cuts and changes to benefits, support and services on the lives of people with learning difficulties.

This pilot research project has established a model for collecting evidence from people with learning difficulties at a local level. This model will be replicated in other local areas to enable people with learning difficulties to collect evidence and campaign at a local level, and be part of a national voice to influence change.

1.6 Recommendations

The following recommendations are aimed at Barnet Council and in some cases central government departments. However, many of the recommendations referring to Barnet Council can also be applied to other local authorities.

Recommendation 1: Being included in the process

Barnet Council needs to review their assessment and review processes. They need to ensure that throughout the process, there is accessible information about when assessments and reviews will happen, what each part of the process is about, how much the local authority is looking to cut from each person's local authority support, why this is needed, when it will happen and what the individual's options are. This will therefore give people with learning difficulties the ability to be included in this decision. This review should start by April 2016 and be complete by March 2017.

How will we know it has been done? We will work with Barnet Council to produce guidelines and training around how assessments should take place and the information needed to make this process accessible for people with learning difficulties.

Recommendation 2: Getting my voice heard

Barnet Council should carry out a needs assessment around commissioning an appropriate independent support service which would be available to all people with learning difficulties throughout the assessment and review process. This service should make sure that people can prepare for assessments, demonstrate their needs, think through the options that they have, communicate this effectively during the process, and receive support after an outcome has been decided to deal with any agreed changes in support, services or charges. This will ensure that people have an equal voice, choice and control in the decisions which have a big impact on their lives. The needs

assessment should be completed by 30th June 2016. The commissioned service should be in place by April 2017.

How will we know it has been done? We will work closely with Barnet Council and the Commissioning Team to ensure an inclusive and all-encompassing service is commissioned specifically for people with learning difficulties.

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

Social Workers and other professionals in Barnet involved in the assessment and review process should attend obligatory user-led learning difficulty awareness training. This will ensure that professionals have a better understanding of the needs and life experience of people with learning difficulties. This training will also include information on informing people with learning difficulties about the outcomes of assessment and reviews, especially with regard to compassion when delivering negative news. There should be a rolling training programme for staff already in post, and the training should be incorporated into the induction period for new staff. This should commence in April 2016.

How will we know it has been done? This will be discussed with Barnet Council and developed with a range of other stakeholders.

Recommendation 4: what happens after the outcome has been decided

In the light of local authority budget cuts and increased assessment eligibility criteria, a reduction in local authority support for an individual does not necessarily mean that a person does not need this support, only that the local authority does not have the resources to finance it. The local authority still has a duty of care to make sure that a person with learning difficulties can access other support even if it will not be directly paid for by the local authority. Therefore, this recommendation is about what happens after a person has had a reduction in support or complete withdrawal.

For people with learning difficulties who have experienced a reduction or complete withdrawal of support, Barnet Council should make sure that part of the review process includes a plan for each person, including information about where they can go to get any extra support that they feel they need. This should include signposting to organisations that offer support in the areas needed by each person and services and activities that are available in Barnet. They should also ensure that each person has the support that they need to make contact with these organisations, whether this is a family member, carers or independent support from a local organisation. This should also include a post-change impact follow-up meeting with each person who has been through

the review or assessment process, recording and taking account of 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 included in guidelines produced with Barnet Council around making assessments accessible. An impact report at the end of each financial year should be produced by Barnet Council.

Recommendation 5: Accessible written information

All written information and communication from national government departments and Barnet Council should be in an accessible format depending on the access needs of each person. A People First (Self Advocacy) campaign focusing on this will be started in January 2016.

How will we know it has been done? This will be included in assessment guidelines and Learning Difficulty Awareness training co-produced with Barnet Council. Through national campaigning work, People First (Self Advocacy) will ensure that this stays on the agenda for national government departments.

Recommendation 6: Cumulative Impact Assessment

There needs to be a Cumulative Impact Assessment done in general for disabled people, as well as specifically broken down for people with learning difficulties. This needs to take into account national welfare reform, local authority spending cuts and the impact this has had on local services and activities, service charges, as well as local authority support. There needs to be a monitoring process in place to ensure that disabled people and people with learning difficulties are not being unfairly affected by welfare reform, which our report highlights is happening. This will ensure that all local authority and national government decisions are more effective and based on the principles of equality. This will begin once phase two of the Cuts Impact Action Now Project has been carried out, supporting other user-led self-advocacy groups to carry out research in their own local authority around the UK.

How will we know it has been done? People First (Self Advocacy) will collaborate with national partner organisations to campaign for a Cumulative Impact Assessment.

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

It should not be assumed that people do not have views and cannot make decisions; every opportunity should be taken to ensure that each individual can

participate as fully as possible in decisions about their support and get the information and support needed to do so, as highlighted in the wellbeing principle in the Care Act 2014. How Barnet Council is meeting this requirement should be demonstrated by the local authority. This will be requested at the end of each financial year.

How will we know it has been done? From the information in this report, this is obviously not happening; therefore information will be requested from the Council as to how they are meeting this requirement under the Care Act 2014 for people with learning difficulties.

2. Introduction

Here is a summary of why we decided to carry out the research, the importance of national and local organisations working together, and the aims of the research.

2.1 Why we decided to carry out this pilot research project

2.1.1 Barriers: It is widely accepted that it can be very difficult for people with learning difficulties to get their voices heard. There are a number of barriers that can stop people with learning difficulties from being a full part of society and being included in the decisions that influence their lives. These barriers include: lack of accessible information, not having any or enough support or advocacy, negative attitudes and discrimination towards people with learning difficulties. People with learning difficulties are one of the poorest and most marginalised groups in society. Many people are left out of society and do not have the correct support or information to take part. This can be very disempowering leading to people not being able to speak up and get their voices heard.

2.1.2 Cuts and changes to services and benefits: There have been wide-ranging and numerous cuts and changes taking place at both a national and local level. They are all happening at the same time and having a cumulative effect on people receiving services and benefits. However, there has been no research or evidence collected specifically about what impact this may have on people with learning difficulties. Through People First's national policy work and links with other national disabled people's organisations we have quantitative information about cuts at a national level. However, there is a lack of information about the collective impact of these cuts on people with learning difficulties.

Through People First's work with People's Choice and other local self-advocacy groups and individuals we have been made aware of changes to services and support at a local level, as a result of cuts to local authority funding. However, at no point have both national and local cuts and changes been combined and looked at in terms of their double effect on the lives of people with learning difficulties.

2.1.3 What is happening locally: By looking at these cuts and changes in a local context it is possible to gain a clearer indication and a better understanding of the cumulative impact of national and local cuts and changes to benefits and services on the lives of people with learning difficulties. This would then enable decision makers to look at national policies and how they are translated into reality for people with learning difficulties at a local level.

2.1.4 Being consulted and listened to: Based on almost 30 years of working at a policy level People First can say with certainty that people with learning difficulties are often not consulted properly, listened to, or given the opportunity to have a strong voice, and we have had increasing concerns about what the real life impact of cumulative cuts and changes are having on the lives of people with learning difficulties. People First, in carrying out this research, is giving recognition to the fact that people with learning difficulties need to have a chance to have their voices heard, and their experiences understood. As a pilot research project we are also creating a channel that can then be applied in other local areas, and joined together at a national level to make sure that the voices of people with learning difficulties are heard, and are acted upon.

2.2 The importance of a national and a local organisation working together

This collaborative approach to research is effective, as it proposes a way of collecting evidence using the resources and knowledge of both a national and local organisation. Both organisations bring different strengths to the table.

The key assets that People First (Self Advocacy) brings to this pilot research project include: contacts and working relationships with other national organisations; contacts within national government departments; with ministers and; with non-governmental organisations such as the Equality and Human Rights Commission. In addition, People First (Self Advocacy) has expert knowledge of national policy and an extensive understanding of local policy changes that are taking place and the many barriers and issues faced all over the country by people with learning difficulties.

The key assets that People's Choice at Barnet Centre for Independent Living brings to this pilot research project include: links with local people with learning difficulties; Barnet Council; service providers; and organisations that work with disabled people in Barnet, which it has been built up over the last 15 years. As well as this People's Choice is the organisation overseeing the Barnet Learning Disability Parliament. The team leader of People's Choice, Mahmuda Murshed, who has a learning difficulty, is a Co-Chair of the Learning Disability Partnership Board. People's Choice is also the Chair of the Speaking Up sub-group that has a seat on the Learning Disability Partnership Board.

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

This pilot research project aims:

1. To enable people with learning difficulties to have a meaningful voice at a local and national policy level about the impact of benefit and service cuts and changes;
2. To collect evidence about the combined impact of national and local service and benefits changes and cuts to people with learning difficulties at a local level;
3. To create a model for evidence collection, enabling other local self-advocacy groups to replicate the CIAN method of research and give a voice to people with learning difficulties locally, and to create a collective national voice;
4. To increase the awareness of policy makers and service providers of the impact of service and benefit cuts and changes for people with learning difficulties as a driver for change;
5. To reduce the negative impact that cuts and changes are having on people with learning difficulties.

The key objectives are:

1. To set up inclusive and accessible methods of collecting valid, representative and reliable information about the impact of cuts and changes to services and benefits on people with learning difficulties;
2. To collect information about how the cuts and changes to services and benefits in a local area are affecting the lives of people with learning difficulties and their families and/or carers;

3. To provide evidence of the impact that service and benefit cuts and changes are having on people with learning difficulties;
4. To enter into meaningful discussion with local and national policy makers and service providers about potential for change and reducing the negative impact;
5. To produce a replicable process for evidence collection at a local level in order to build a national evidence base and voice for people with learning difficulties;
6. To set up channels/networks for giving evidence to policy makers and service providers at a local, regional and national level, creating a collective voice to influence change.

3. Background

This includes information about the organisations working on the Cuts Impact Action Now project; the cuts and changes happening locally and nationally that may impact on people with learning difficulties; the local and national social demographics; and the different services available 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. Our Management Committee members (6) are people with learning difficulties from different parts of the country, who have support in their governance work. As an organisation we aim to raise awareness of the rights of people with learning difficulties, support development of the skill base of self-advocacy groups and individuals, and make sure that their voices are heard at government policy level. We work at a national level providing support, information, advice and training to individuals and self-advocacy groups run by people with learning difficulties.

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 also aim to raise awareness locally of the rights of people with learning difficulties, making sure that their voices are heard.

They run 6 self-advocacy groups: Learning Disability Parliament, Speaking Up, Advocacy and 3 drop-in groups across Barnet for people with low, moderate and high levels of learning difficulties.

In these groups they talk about issues that Barnet Council and the NHS have asked them to raise and also issues that their service users would like them to raise, for example, bedroom tax/benefits, transport challenges, good and bad support workers, and carer support.

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

This section aims to give the reader a snapshot 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.

Much of the existing information available is about disabled people in general, especially with regard to current cuts and changes to benefits and support, however, where possible information specifically about people with learning difficulties has been included. Some of the changes to benefits, for example Universal Credit, cover more than one benefit. This means that the figures given about these changes may overlap with figures given in relation to other changes.

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

This section covers a number of areas in which people did not have equal access even before cuts and changes to services and benefits. It is likely that these things will get worse because of the 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 'unsafe' for people with learning difficulties.³² There are a number of problems that have been found in research done in this area. Some of the reasons that people with learning difficulties cannot access good quality health care are:

- Bad communication
- Staff taking a long time to find out why a person is not well
- Staff not always being able to tell when a person is in pain³³

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

- Not having the right housing³⁴
- Not having a job
- Living in poverty
- Being discriminated against and excluded from society³⁵

³² <https://www.mencap.org.uk/sites/default/files/documents/Death%20by%20Indifference%20-%2074%20Deaths%20and%20counting.pdf>

³³ <https://www.mencap.org.uk/sites/default/files/documents/Death%20by%20Indifference%20-%2074%20Deaths%20and%20counting.pdf>

³⁴ 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, MRCGP, Anna Marriott, MSc, Lesley Russ, RNMH, The Lancet 2014.

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

Equal access to education is not a reality for most people with learning difficulties. A big number of children with learning difficulties do not go to mainstream schools. The latest figures from 2011/12 put this number at 12% of children with moderate learning difficulties, rising to 77% of children with severe learning difficulties and 82% of children with profound and multiple learning difficulties. This percentage is going up for children with severe learning difficulties. As with many public services, there is also a postcode lottery when it comes to accessing mainstream education. In some local authorities only 1% of children with moderate learning difficulties are excluded from mainstream education, but in other local authorities over 25% of children are excluded from mainstream education. Children with special educational needs associated with learning difficulties do not get as good results as other children. They are also more likely to be absent from school. As well as this, fixed term and permanent exclusions from school are more common for children with learning difficulties.³⁶

In higher education, disabled young people are twice as likely as their non-disabled peers not to be in employment, education or training by the age of 18. In 2008 the Learning and Skills Council found that students with learning difficulties were four times more likely to be enrolled on 'preparation for independent living' or employment learning programmes rather than on mainstream accredited courses. In addition, changes to the Standard Apprenticeships Framework requiring apprentices to have gained literacy and numeracy qualifications at GCSE level have led to a decrease in people with learning difficulties undertaking apprenticeships. In 2005/6, 11.1% of apprentices were people with learning difficulties, falling to 8% in 2010/11.³⁷

Equal opportunities in work are still out of reach. Only 6.6% of people with learning difficulties are in some kind of paid work and most of the

³⁵ Health Inequalities and people with learning disabilities in the UK, Improving Health and Lives, the Learning Disabilities Observatory, Eric Emerson and Susannah Baines, 2010.

³⁶ https://www.improvinghealthandlives.org.uk/securefiles/150618_2200//IHAL2013-10%20People%20with%20Learning%20Disabilities%20in%20England%202012v3.pdf

³⁷ ALLFIE - Children and Families Bill's Proposed Amendments for consideration at Committee stage (March-April 2013)

people in paid work, work part time.³⁸ This is much lower than the 46.3% of disabled people in general in paid work and the 76.4% of non-disabled people in paid work.³⁹ Getting a job is difficult and people come up against many barriers. The biggest barrier is people thinking that people with learning difficulties cannot work⁴⁰, when actually 65% of people with learning difficulties would like a paid job.⁴¹ The services that support people with learning difficulties to find a job are not as good as they could be. This is because these services need to work better to change the way that employers see people with learning difficulties, raise awareness of support on offer for disabled people, as well as developing more opportunities for people with learning difficulties to work.⁴² For those people with learning difficulties who are in employment, research based on disabled people's experience in the work place found that people with learning difficulties and people with mental health issues are more likely to be treated unfairly and face bigger barriers in the work place.⁴³

As a result of there being so few people with learning difficulties in employment, it means that 93.4% of people are likely to rely on some form of support from the welfare system. This means that they are one of the groups most affected by cuts and changes to benefits and services and changes to local authority assessment rules.

Disability Hate Crime has been a problem for disabled people for a long time, only in 2003 did it come to be a part of law as part of the Criminal Justice Act.⁴⁴ Research done by Mencap found that 88% of people with learning difficulties who took part had been victims of hate crime in the previous 12 months.⁴⁵ Even though the level of hate crime is high, only 3% of these crimes are recorded 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, like the police not being able to talk to them in a way they can understand or the police ignoring them.

³⁸ <http://www.learningdisabilities.org.uk/help-information/Learning-Disability-Statistics-/187693/>

³⁹ <https://www.gov.uk/government/publications/disability-facts-and-figures/disability-facts-and-figures#employment>

⁴⁰ http://www.ndti.org.uk/uploads/files/3.The_cost_effectiveness_of_Employment_Support_for_People_with_Disabilities,_NDTi,_March_2014_final.pdf

⁴¹ Valuing Employment Now, HM Government, 2009

⁴² http://www.ndti.org.uk/uploads/files/3.The_cost_effectiveness_of_Employment_Support_for_People_with_Disabilities,_NDTi,_March_2014_final.pdf

⁴³ 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).

⁴⁴ <https://www.mencap.org.uk/blog/four-things-you-probably-didnt-know-about-disability-hate-crime>

⁴⁵ <https://www.mencap.org.uk/blog/four-things-you-probably-didnt-know-about-disability-hate-crime>

Even with the cases where crimes are recorded as hate crimes, many do not make it to court because the system questions whether a person with learning difficulties can be believed. These barriers mean that a person does not have the same access to the police and cannot get justice through 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 key issues for people with learning difficulties is poverty; families that include disabled people are more likely to live in poverty⁴⁶, this could be as high as one third of disabled people.⁴⁷ With only 6.6% of people with learning difficulties in paid work⁴⁸ changes to government and local authority spending on benefits, support and services affect people with learning difficulties more than most other communities of people in society.

In 2013 the Centre for Welfare reform calculated that disabled people, who make up 8% of the population, will bear 29% of the cuts to services and welfare benefits losing an average of £4,410 per person each year; this is nine times the burden placed on most other citizens. The most severely disabled who are eligible for social care from their local authority, who make up 2% of the population, will bear 15% of the cuts losing an average of £8,832 per person each year; this is a staggering 19 times greater than the burden placed on most other citizens.⁴⁹

There have been big changes to benefits, support and services, with some people being affected by up to 6 cuts and changes at the same time.⁵⁰ Below is some information about the most important changes that will affect people with learning difficulties:

The change from the Disability Living Allowance to the new Personal Independence Payments will lead to 28% less disabled people getting this benefit, totaling around 607,000 disabled people.⁵¹ This benefit started in 1992 to support the extra costs of being disabled.

⁴⁶ <https://www.gov.uk/government/publications/disability-facts-and-figures/disability-facts-and-figures>

⁴⁷ <http://www.disabilitynewsservice.com/report-finds-nearly-a-third-of-disabled-people-in-poverty/>

⁴⁸ <http://www.learningdisabilities.org.uk/help-information/Learning-Disability-Statistics-/187693/>

⁴⁹ <http://www.centreforwelfarereform.org/uploads/attachment/354/a-fair-society.pdf>

⁵⁰ <http://www.demos.co.uk/blog/destinationunknownapril2013>

⁵¹ *(Personal Independence Payment) Regulations 2013 ... - Parliament* www.parliament.uk/briefing-papers/SN06538.pdf

The amount each person gets is between £21.80 and £139.75 per week.⁵² The extra cost of being disabled is said to be on average £550 per month.⁵³ However with the new Personal Independence Payments the assessment criteria has been changed, which has meant that a large number of people who did get the Disability Living Allowance will not be eligible for Personalised Independence Payments. As well as this, 428,000 people will no longer be able to get the enhanced mobility component under the new rules and will therefore get less money.⁵⁴

The complete closure of the Independent Living Fund was decided in March 2014, after two court cases taken by disabled people using this fund. One third of the people that currently receive this support are people with severe learning difficulties. It was decided that in June 2015 this fund would be closed to its 21,000 disabled users.⁵⁵ This money will now be passed on to local authorities. The problem is that this money is not protected meaning that local authorities do not have to spend this money on disabled people, they can spend it on anything. In all cases this will mean that each person who used the fund will have their independence taken away from them.⁵⁶

Overall Benefit Cap and 1% cap on benefit rises will affect 142,500 disabled people who will lose around £2 billion by 2018.⁵⁷ This cap does not apply to Disability Living Allowance, Personal Independence Payments or the support part of the Employment and Support Allowance.

The Spare Room Subsidy being taken away which is sometimes called the Bedroom Tax. People with one 'extra' bedroom will now have 14% less money in their housing benefit and people with two or more extra rooms will have 25% less housing benefit. This is having a big impact on some of the poorest people in society. 72% of houses affected by the change have either a disabled person or someone with a health condition living there.⁵⁸ This change, which was part of the Welfare Reform Act 2012, does not take account of how difficult it is to move house for disabled people. It also does not take on board that some people need

⁵² <https://www.gov.uk/disability-living-allowance-dla-rates>

⁵³ <http://www.scope.org.uk/Scope/media/Documents/Publication%20Directory/Scope-report-Better-living,-higher-standards.pdf>

⁵⁴ (Personal Independence Payment) Regulations 2013 - Parliament www.parliament.uk/briefing-papers/SN06538.pdf

⁵⁵ <http://www.dwp.gov.uk/ilf/news/>

⁵⁶ <http://www.theguardian.com/commentisfree/2014/mar/31/independent-living-fund-disabled>

⁵⁷ http://www.demos.co.uk/press_releases/destinationunknownapril2013

⁵⁸ [http://inactualfact.org.uk/fact/72-of-](http://inactualfact.org.uk/fact/72-of-households/http://www.affinitysutton.com/media/808765/housing-futures-report-final.pdf)

<http://www.affinitysutton.com/media/808765/housing-futures-report-final.pdf>

an extra room for equipment that they need as part of their disability or for a carer to sleep in.

Firstly, there are not enough houses that are adapted to the needs of disabled people, and many disabled people have spent time and money adapting their houses to their needs. Secondly, people with learning difficulties need to find support to find a new place to live, and support to actually move. Thirdly, settling into a new area, making new links, and setting up a new support structure and social network are very difficult to do. Finally, if a person moves to a different local authority in order to find the right house then the disabled person will have to be reassessed for local authority support and run the risk of getting less support in a different local authority. Therefore, moving is actually a very difficult, stressful and worrying process and often not an option for many disabled people. This then means that they pay the extra money to stay where they are. People are then left with less money to live on.

Discretionary Housing Payments have been brought in which is a short term payment that can be made to people by a local authority on top of their Housing Benefits, if the local authority decides that this is needed. 41% of disabled people affected by the Bedroom Tax and the Benefit Cap are not being given this payment when they apply. Some local authorities have not given this payment to disabled people even when they cannot find adapted housing.⁵⁹ To cover these extra costs 9 out of 10 disabled people are cutting back on food, bills, nearly 4 in 10 disabled people are cutting back on getting out and transport, and more than 1 out of 4 are spending less on medication and therapies in order to cover their housing costs.⁶⁰ The changes to the Local Housing Allowance will lead to 827,000 disabled people losing £2.43 billion by 2018.⁶¹

The Incapacity Benefit and some Income Support benefits are being replaced with the Employment and Support Allowance, using the Work Capability Assessment to find out if a person is fit to work. At the moment 2.53 million people get these benefits.⁶² The assessments are found to be unfair, stressful and do not get the right results. The British Medical Association called for an end to this assessment because there

⁵⁹http://www.papworth.org.uk/downloads/makingdiscretionaryhousingpaymentsworkfordisabledpeople_130710181752.pdf

⁶⁰ <http://www.housing.org.uk/media/press-releases/disabled-people-cutting-back-on-food-and-bills-to-pay-bedroom-tax>

⁶¹ <http://www.demos.co.uk/files/Table1-headline.pdf>

⁶² https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/421992/stats-summary-apr-2015.pdf

were so many problems with it.⁶³ People are being put into the wrong groups, and some people are being found fit for work when they are not. Some people are found to be ready for work in a year and are put into the work-related activity groups, when actually they should be going to the support groups which have no time limit. Nearly 51% of Work Capability Assessment appeals are won.⁶⁴ This means that more than half of the people who think that the result of their assessment was wrong and decide to make an appeal, win and get extra support when their application is looked at again. It has also been found that when appealing decisions people with learning difficulties, mental health issues and autism are at a disadvantage; they are less likely to win appeals as a result of finding it difficult to put together evidence for the appeals.⁶⁵ The one year time limit on Work Related Activity Groups will affect 700,000⁶⁶ disabled people and will cost disabled people around £4.4billion.⁶⁷

For people who do not stick to the Employment and Support Allowance rules, the punishment is much worse than before which can leave people without money for long periods of time. However, when people are going through appeals, the Department for Work and Pensions does not have a time limit to carry out another assessment or make a decision. In the meantime disabled people have to choose to either go without money whilst they wait or apply for Job Seekers Allowance, which gives the idea that they are fit for work.

This means that making an appeal can be very long and stressful, and over three quarters of disabled people said that their health got worse because of the stress of their assessment for the Employment and Support Allowance.⁶⁸

Universal Credit will bring together 6 different benefits and be paid as one benefit payment. The benefits that will come under Universal Credit are: income-based Job Seekers Allowance; income-related Employment

⁶³ <http://bma.org.uk/news-views-analysis/news/2012/june/scrap-work-capability-assessment-doctors-demand>

⁶⁴ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/411937/esa_wca_summary_Mar15_final.pdf

⁶⁵ https://www.learningdisabilitytoday.co.uk/government_loses_appeal_against_esa_benefit_ruling_25769804847.aspx

⁶⁶ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/220181/esa-time-limit-wr2011-ia-revised-apr2011.pdf

⁶⁷ http://www.demos.co.uk/press_releases/destinationunknownapril2013

⁶⁸ <https://www.mencap.org.uk/news/article/disabled-people-reach-tipping-point>

and Support Allowance; Income Support; Working Tax Credit; Child Tax Credit; and Housing Benefit. Up to 116,000 disabled working adults will lose up to £40 per week, 230,000 severely disabled people who live alone or have a young carer (in many cases lone parents with children) will lose between £28 and £58 each week.⁶⁹ In total disabled people stand to lose £2.2 billion by 2018 as a result of Universal Credit.⁷⁰

There are other things that are worrying such as the fact that this will be done by computer and for many disabled people, especially people with learning difficulties, this is not accessible. As well as this, the benefit will be paid monthly rather than weekly and people will need support to budget for this longer period of time. With cuts to local services this support may not be there.

Access to Work, which supports many disabled people in work, is currently changing its approach to support. The current approach is to support as many disabled people as possible, however they are doing this without increasing the Access to Work budget.⁷¹ In fact, last year's budget was underspent by £3 million. This means that many people with learning difficulties are currently having their funding for Access to Work support cut, as a result of needing "high value" support packages. This has not been directly stated by the Department for Work and Pensions; however this has been experienced by People First (Self Advocacy) staff, as well as staff from other local self-advocacy groups. Two members of staff with learning difficulties at People First (Self Advocacy), who have had a reassessment, and who have been receiving support for over 10 years, with no change in their impairments, have had to fight for months to maintain the same level of support, one having their support reduced to 20% of the previous amount. This approach to funding Access to Work claims is directly excluding people with learning difficulties who need 'high value' support packages to gain access to employment. It shows a lack of understanding of the support needs of people with learning difficulties in the work place, a group that is already highly discriminated against in employment.

⁶⁹ http://www.citizensadvice.org.uk/holes_safety_net.htm

⁷⁰ http://www.demos.co.uk/press_releases/destinationunknownapril2013

⁷¹ <http://www.parliament.uk/business/publications/written-questions-answers-statements/written-statement/Commons/2015-03-12/HCWS372/>

3.2.3 Service Changes

Funding for adult social care has had big cuts in local authorities across the UK. There have been cuts between April 2011 and March 2013 of £1.89 billion.⁷² This is at a time when there are growing numbers of older and disabled adults needing support, a number which is going up by 3% per year. The biggest increases include older people and people with learning difficulties.⁷³ As well as this, it was said in June 2013 that there would be funding cuts of 10% to local authority budgets⁷⁴. As a result of these cuts 100,000 disabled people are or are at risk of not getting the support that they need.⁷⁵ So far 69,000 disabled people have been pushed out of the social care system.⁷⁶

Research by the charity Leonard Cheshire shows more 15 minute visits are being used by councils in their community services that support people in their home. The number of visits which lasted 15 minutes or less has risen by 15% over the past five years. Some local authorities give more than three-quarters of their care visits in 15 minutes.⁷⁷ Eligibility criteria have gone up and now 83% of councils only fund people with high support needs (DPAC, 2012).⁷⁸

This is putting pressure on the National Health Service and community and mental health services. When people do not have the right care and support at home they are going to hospitals to get support. As well as this, people who were in hospital had to stay longer because they did not have social care support at home. People also now use community health and mental health services, GP services and hospitals more because they do not have care and support at home.⁷⁹

The Care Act 2014 is a new law put in place to bring together all other laws around adult social care and local authority responsibilities. The Care Act 2014 introduced portability of assessments which is a positive step; however, there is no portability of care packages. This is worrying in light of the Bedroom Tax which means people may need to move to

⁷² <http://www.adass.org.uk/A-new-system-for-care-funding/>

⁷³ ADASS Budget Survey (April/May 2012)

⁷⁴ <http://www.theguardian.com/politics/2013/jun/26/spending-review-2013-the-key-points>

⁷⁵ <http://www.scope.org.uk/campaigns/social-care-and-support>

⁷⁶ <http://www.scope.org.uk/news/other-care-crisis>

⁷⁷ <http://www.leonardcheshire.org/sites/default/files/15%20min%20care%20report%20final.pdf>

⁷⁸ <http://dpac.uk.net/2012/07/ilf-consultation-how-are-local-authorities-doing-providing-care-and-support-funding-badly-of-course/>

⁷⁹ <http://www.theguardian.com/healthcare-network/2015/jun/02/nhs-no-more-cuts-to-social-care>

smaller properties in different local authorities, yet they may not get the same care package and may in fact get a reduced package.

The Care Act does include the right to advocacy in assessments and care plans which at first was thought to be a positive step. However, it is not easy to get and if there is a family member or friend that can do this then a person does not get this advocacy support. The problem with this is that, when going through the assessment and care planning process, most family and friends do not have the expertise to make sure that they get the best outcome for the person that they are supporting; it is a very specialist area. As well as this, many people would need support to access advocacy support in the first place and therefore it is not very accessible to people with learning difficulties.

The Care Act introduced a national minimum eligibility standard; however this is set at substantial. This means that even with cuts to local authority budgets, people with a 'substantial' level of care will be able to maintain their local authority support. Campaigners had tried to get the minimum eligibility standard to be set at 'moderate', however they were not successful.

The Care Act brought in the well-being principle; everything the local authority does must promote the well-being of the individual. This includes:

- Personal dignity and treating you with respect;
- Physical and mental health and emotional well-being;
- Protection from abuse and neglect;
- Control over day to day life including care and support and the way in which it is provided;
- Participation in work, education, training or recreation;
- Social and economic well-being;
- Domestic, family and personal relationships;
- Suitability of living accommodation;
- Contribution to society.

However, according to campaigners this does not go as far as the right to independent living, which is Article 19 of the United Nations Convention on the Rights of Persons with Disabilities. The Government and other national charities decided that it did, however campaigners managed to get the right to independent living included in the Statutory Guidance of

the Care Act. This means that Article 19 can be used as grounds for a judicial review if people feel that their right to independent living has been breached.

Cuts to organisations supporting people with learning difficulties and increases in service charges are happening all over the UK. In total disabled people have been affected by a rise of £77million in charges for care⁸⁰, a 20% increase in meals on wheels charges⁸¹, and transport fees have almost doubled.⁸² 72% of organisations providing support to people with learning difficulties have received cuts in funding, as well as this nearly half of people with learning difficulties have had their support cut or their charges increased.⁸³

Cuts to self-advocacy groups that give support to help people with learning difficulties speak up and deal with things that are going on in their lives. Local self-advocacy groups are key to ensuring that people with learning difficulties can use their rights. They are also a big part of the support structure for people with learning difficulties. In the past people might have looked for support and advice from their local self-advocacy group. However, nationally, self-advocacy groups are having local authority funding cut.⁸⁴ Since the report *Staying Strong*⁸⁵ there are no recent national figures for the number of groups that have closed or had reductions in funding. However, from information given by member groups, we know that this is an ongoing trend. People First (Self Advocacy) is currently investigating further the extent of this. Closures and reductions in funding mean that groups cannot give people as much support at a time when they are going through big cuts and changes to benefits, support and services.

Getting rid of free Legal Aid support for benefit and welfare cases at a time when the Government is carrying out the biggest welfare reform in 60 years.⁸⁶ There have been cuts to legal aid and support has been completely taken away in the area of welfare. It has been said by the Government that this is to try and make sure money is spent where it matters the most. However, 58% of the people that use legal aid for welfare benefit cases are disabled people. This is more than 78,000

⁸⁰ ADASS budget survey (April/May 2012).

⁸¹ <http://press.labour.org.uk/post/70178119271/care-charges-soar-by-740-a-year-since-election>

⁸² <http://press.labour.org.uk/post/70178119271/care-charges-soar-by-740-a-year-since-election>

⁸³ Social Care in Crisis: the need for reform, Learning Disability Coalition, 2012

⁸⁴ http://www.ndti.org.uk/uploads/files/IHAL-ev-_2012-01.pdf

⁸⁵ *Staying Strong – but for how long?* The National Forum of People with Learning Difficulties, 2011

⁸⁶ <https://www.gov.uk/government/news/iain-duncan-smith-welfare-reforms-realised>

cases each year.⁸⁷ The benefit and welfare system is going through a big change and from the changes that we have looked at in this section it is obvious that the Government is getting things wrong. Without legal aid, most disabled people will not have the money or time to be able to take legal action against these decisions. When things go wrong disabled people will not be able to access the support to challenge these decisions.

The Equality and Human Rights Commission Helpline has closed and big cuts have been made to their budget. The Equality and Human Rights Commission had a budget cut for the year 2014-2015 of 62% compared to 2007.⁸⁸ As a result of this the Helpline for legal advice on discrimination cases was closed. This was replaced with an advice and information helpline which is run by Sitel and Disability Rights UK. This new service supports people to get advocacy, information and advice. Many of the legal cases received through the old helpline then went on to be test cases used by the Commission to set a precedent; this means set a legal example that everyone must then follow. So although advocacy support is there, support for people wanting to take a legal case is not. With cuts to the capacity of the Equality and Human Rights Commission as well as Legal Aid, what chance do disabled people have of challenging inequality?

3.2.4 Local changes in Barnet

In Barnet the council have had cuts to funding in all services of 26%, this totals £72.5 million, with cuts to adult social care of £23.16 million and further cuts of £12.6 million scheduled over the next 5 years.⁸⁹

The council plans to save £500,000 by joining parts of the adult social care assessment process with the local authority customer service role. It plans to save millions of pounds by renegotiating contracts with external service providers and well as learning disability packages.⁹⁰

⁸⁷ <http://www.theguardian.com/society/joepublic/2011/dec/22/legal-aid-cuts>

⁸⁸ <http://www.theguardian.com/society/2012/oct/26/budget-cuts-rights-watchdog-un-status>

⁸⁹ <http://www.yourchoicebarnet.org/news/2014/09/your-choice-barnet-facts-file-on-the-pay-cut-dispute/>

⁹⁰ <http://www.communitycare.co.uk/2014/04/09/10-ways-councils-targeting-savings-adult-social-care-2014-15/>

Changes to services in Barnet

In April 2012, Barnet Centre for Independent Living launched its Information, Advice and Advocacy Brokerage service.⁹¹ However Barnet Centre for Independent Living lost this contract and these services have now been transferred to Barnet Citizens Advice Bureau as of 29th June 2015, it is not yet clear how this service will roll out.⁹² People's Choice, the partner organisation in this research project, came under the umbrella of Barnet Centre for Independent Living, and will therefore need to find other funding. As well as this, the highly praised Learning Disability Parliament, organised and run by People's Choice, will need to find other funding. The Parliament is a very good way of allowing local people with learning difficulties to get their voices heard and reach decision makers. .

Your Choice in Barnet

Another big change is that the services run by the London Borough of Barnet were transferred to Your Choice in 2012, a Local Authority Trading Company owned by London Borough of Barnet.⁹³

The outsourcing of London Borough of Barnet services to the organisation Your Choice has been the focus of much anger, debate, petitions and even strike action. The outsourcing plans were challenged in the High Court by Barnet resident Maria Nash, but although the judge found that the Local Authority had not consulted service users, her legal challenge had come too late.⁹⁴ Barnet Unison also wrote a report about the plans, which found that the way that this decision had been made was not based on good evidence and that any profits from Your Choice were intended to subsidise Barnet Homes, its sister company in the Barnet Group; that there was no democratic accountability; and that the plans would have a significant impact on staff and service users.⁹⁵

By 2013, Your Choice was experiencing serious financial difficulties and had to receive a £1m bailout from its sister company Barnet Homes.⁹⁶ 170 staff members were consulted about redundancy, and staff in its supported living service were downgraded to the role of assistant support

⁹¹ <http://www.barnetmencap.org.uk/files/Newsletter%202012%20Spring.pdf>

⁹² <http://www.barnetcil.org.uk/index.php?id=4&cat=1>

⁹³ <http://www.barnetmencap.org.uk/files/Newsletter%202012%20Spring.pdf>

⁹⁴ <http://www.theguardian.com/society/2013/apr/29/high-court-challenge-barnet-easycouncil>

⁹⁵ <http://www.european-services-strategy.org.uk/news/2012/local-authority-trading-company-latc-for-adult/latc-analysis-2012.pdf>

⁹⁶ <https://you.38degrees.org.uk/petitions/stop-the-ongoing-destruction-of-services-for-adults-with-disabilities-in-barnet>

worker. Staff numbers, wages and weekend payments were all slashed. In May 2013, the Board of Directors of Your Choice refused to hear families' concerns about the proposed cuts to staff and services at their board meeting. After the threat of legal action by carer John Sullivan, the Board of Your Choice conceded that they needed to consult with service users and carers before making any changes.⁹⁷

In November 2013, service users and carers attended a meeting of London Borough of Barnet's safeguarding committee, who were discussing a report from a Task and Finish group looking into the financial and staffing issues with Your Choice. However, the scope of this report was extremely narrow, and the group did not consult with any service users or carers, or accept any input from Barnet Unison. This resulted in the Task and Finish group's report failing to recommend any effective response to the issues investigated.⁹⁸ In 2014 Your Choice was forced to cut £400,000 from its budget, prompting a petition asking London Borough of Barnet to put savings made through its whole outsourcing programme back into Your Choice.⁹⁹

In March 2015, the Care Quality Commission rated Barnet Supported Living Service run by Your Choice as 'inadequate', its lowest score,¹⁰⁰ and in May 2015, staff at Your Choice staged a three day strike after being told their wages would be cut by 9.5%. This followed restructuring in 2013 resulting in cuts to staff numbers of 30%. The uncertainty led to many staff opting to leave the organisation, resulting in higher usage of agency staff and a lack of continuity of care for service users, contributing to its poor Care Quality Commission rating.¹⁰¹

⁹⁷ <http://www.newstatesman.com/politics/2013/05/secret-cuts-part-one-social-care>

⁹⁸ <http://www.brokenbarnet.blogspot.co.uk/2013/11/i-dont-have-problem-with-making-profit.html>

⁹⁹ <https://you.38degrees.org.uk/petitions/stop-the-ongoing-destruction-of-services-for-adults-with-disabilities-in-barnet>

¹⁰⁰ http://www.cqc.org.uk/sites/default/files/posters/20150412_1-112848964_summary_ratings_poster_A4.pdf

¹⁰¹

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

3.3 Local and national demographics of people with learning difficulties

3.3.1 National demographics

It is estimated in a report called People with Learning Disabilities in England 2012 that there are 1.14 million people with learning difficulties in England, this is around two out of every 100 people. There are:

- 236,000 children
- 908,000 adults over the age of 18 years old¹⁰²

Of these people 22% are known to GP's as people with learning difficulties and 44% were receiving the Disability Living Allowance when this research was done. More than half of the people with learning difficulties are not known to any services¹⁰³.

3.3.2 Barnet Demographics

According to a report written by Barnet Council in 2012, it was estimated that by 2015 there would be 5,874 people with learning difficulties in Barnet. Of this total, it was predicted that there would be 1,326 people with severe or moderate learning difficulties, who would therefore be likely to be in receipt of local authority support. By 2016, it is predicted that 35% of the population in Barnet will be from Black Minority Ethnic groups.¹⁰⁴

According to the Barnet Joint Strategic Needs Assessment (2011), it was stated that 'people with learning disabilities are much more likely to have significant health risks and major health problems, and are more likely to be exposed to poverty, poor housing conditions, unemployment, social disconnectedness and discrimination.' It also stated that as a result of 'improved survival, rising birth rates and growth among communities at higher risk of learning disabilities (for example, the South Asian community)', there is likely to be a growing need locally.¹⁰⁵

¹⁰² https://www.improvinghealthandlives.org.uk/securefiles/150618_1719//IHAL2013-10%20People%20with%20Learning%20Disabilities%20in%20England%202012v3.pdf

¹⁰³ https://www.improvinghealthandlives.org.uk/securefiles/150618_1715//IHAL2013-10%20People%20with%20Learning%20Disabilities%20in%20England%202012%20-%20Easy%20Read.pdf

¹⁰⁴ Barnet's Market Position Statement; Adults and Communities, Barnet Council, 2013

¹⁰⁵ http://www.barnetccg.nhs.uk/Downloads/Document%20Library/JSNA_2011_-_Release_version.pdf

Every year Public Health England put together a report, to give a health profile of people with learning difficulties in each local authority area. The report then compares the local area to the average of what is happening in the whole of the country.

It tries to show:

- How many people have learning difficulties;
- How healthy they are;
- How much health care they get;
- How well social services are looking out for them.

Below is a summary of the health profile of people with learning difficulties in Barnet for 2013-2014, compared to the rest of the country.

Barnet is doing better than the average compared to the rest of the country in the following areas:

- Proportion of eligible adults with a learning disability having a GP health check;
- Adults with learning disabilities living in severely unsatisfactory accommodation (there was no one in this category);
- Adults with learning disabilities in employment;
- Adults with learning disabilities receiving direct payments.

Barnet is doing about the same as the average compared to the rest of the country in the following areas:

- Adults receiving community services supported by local authorities

Barnet is doing worse than the average compared to the rest of the country in the following areas:

- Adults (18 to 64) with learning disability known to Local Authorities;
- Adults using day care services supported by the LA (although this may be because of direct payments being higher than average)?

3.4 Different services available in Barnet for people with learning difficulties

London Borough of Barnet works with Central London Community Healthcare NHS Trust to offer a number of services to people with learning difficulties, following assessment by a healthcare professional and a social worker. These services include social care support to enable people to live independently, physiotherapy, communication support and

speech and language therapy, mental health support, home adaptations, respite care, carers' assessments and signposting or referrals to local organisations offering services such as supported housing, social clubs and benefits advice.¹⁰⁶ London Borough of Barnet also runs one residential care home for people with learning difficulties, Agatha House.¹⁰⁷

Many of London Borough of Barnet's services for people with learning difficulties are outsourced to Your Choice, part of the Barnet Group, which is 100% owned by London Borough of Barnet.¹⁰⁸ Your Choice offer time-limited rehabilitation and enablement services, a supported living service, day services in the community, respite services and specialist services for people on the autistic spectrum and people with complex learning difficulties.¹⁰⁹

There are a number of residential care homes for people with learning difficulties located in Barnet, run by a mix of voluntary sector and private providers. There are specialist care homes for older people, Asian women, Jewish people and people with sensory impairments or physical impairments as well as learning difficulties. There are also organisations running supported housing schemes, such as Origin Housing who run Speedwell Court, a specialist service for adults with autism or Asperger's syndrome which opened in 2013.¹¹⁰

The main voluntary sector organisation offering services to people with learning difficulties in Barnet is Barnet Mencap, who run three supported housing projects, an outreach service supporting people in their own homes, welfare advice drop ins, short breaks, holidays and respite for children, young people and adults, social, sport and learning activities for people over 16, and support for carers of people with learning difficulties.¹¹¹ The learning disability team called People's Choice at Barnet Centre for Independent Living run self-advocacy groups for people with learning difficulties.¹¹² At the time of the research the Peer Support Brokerage team also provided support planning and brokerage to

¹⁰⁶ https://www.barnet.gov.uk/dam/jcr:449fae8a-3b3b-4226-9f31-53cca194aac1/017943_Barnet_LD_WEB.pdf

¹⁰⁷ <http://www.cqc.org.uk/location/1-112848946>

¹⁰⁸ <http://www.barnethomes.org/about-us/our-board/>

¹⁰⁹ <http://www.yourchoicebarnet.org/services/>

¹¹⁰ <http://www.autismdailynewscast.com/origin-housings-speedwell-court-for-autistic-adults-opens-in-barnet-north-finchley-uk/5565/snapshot/>

¹¹¹ http://www.barnetmencap.org.uk/About_us.htm

¹¹² <http://www.barnetcil.org.uk/index.php?id=4>

disabled people receiving self-directed support payments, including people with learning difficulties.¹¹³ As well as this there is also a support service offered by Dimensions, for people who live in their own homes enabling them to develop skills and networks in the community, HFT, a national charity that support people to work in a creative way to achieve what they want and Norwood, a Jewish organisation that offers services for people with learning difficulties.

¹¹³ <http://www.barnetcil.org.uk/index.php?id=4&cat=2>

4. Research Methods

The Cuts Impact Action Now project is a user-led, user controlled pilot research project carried out by People First (Self Advocacy) and People's Choice at Barnet Centre for Independent Living.

4.1 Good practice 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 assured people that none of the information they would give to the research project would mention their name;
- 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 the information down correctly;
- We made sure that people felt comfortable 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 took a gradual approach, and did not risk scaring people about the cuts;
- We worked to People First Lone Working Policy.

4.2 Time period of data collection

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

4.3 How did we advertise the project and attract people to give information both for the interviews and in the 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. This included:
 - The Partnership Board (Barnet Council)
 - The organisations involved 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 contact with residential homes and supported living schemes
- People's Choice membership
- We made flyers which told people what the project is about and how to get involved
- Often we needed to speak to the person with support to set up the interview

4.4 Some of the problems we encountered

- We had to go through gate keepers to access people;
- The fact that it was self-referral raises the question about whether people came forward because they had had a negative experience;
- Securing and getting interviews was very difficult, this was actually as a result of people's learning difficulty impairments around memory, especially as it was a one-off meeting. There were many failed appointments because people had forgotten even with multiple reminders. In some cases this took 2 to 3 interview appointments.

4.5 How we collected the information

- Individual In depth interviews were carried out with 35 people with learning difficulties. We informed people that they could bring a supporter with them. An interview guide was prepared covering 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 carrying out the interviews we used the following approach:
 - We introduced a topic and we talked around it to see if there was anything that the person wanted to focus on
 - We did not ask leading questions
 - We asked about any changes not cuts as we did not want the interview to feel threatening
 - We were patient and encouraging if people were struggling to express themselves

- Focus Groups: Three focus groups were carried out, and 19 people took part in these. The same interview guide was used as in the individual interviews. We used pictures to communicate with people with higher support needs. We made sure that everyone could have their say, including people who did not feel confident at speaking up.

- Service Managers: Three service managers were interviewed to get an overview from their perspective, and to gain an insight into the experience of carers. Prior to the interview we sent an outline of the project and told service managers that the aim of the interview was to find out if they had seen any changes as a result of reduced local authority funding.

4.6 About the people with learning difficulties who gave information

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

- Gender: 43% women, 57% men
- Age: the majority of people were aged between 30 and 59, however, younger and older people were represented.
- Ethnic background: 24% of respondents were from BME communities
- LGBT communities: this was not disclosed by many people
- Complex needs: this was wide ranging and included people with mild, moderate and high support needs
- Residential status: there was a mix of residential statuses, 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 settings.

- Type of support used: people used a range of support, ranging from full time support to people who used 2 hours per week for admin.
- The main benefits received by participants were: Disability Living Allowance, Employment and Support Allowance, Housing Benefits, Job Seekers Allowance, Council Tax Benefits.

4.7 How did we analyse the data?

We typed out all the information from the recordings, and analysed the qualitative data thematically within a quantitative framework, pulling out key themes which came from the individual interviews, focus groups and service managers.

The themes we highlighted were supported by quotes from the individual interviews, focus groups and service managers.

We used example quotes to support our findings, discussed some of the points which had been raised, and developed recommendations to be considered by Barnet Local Authority, other local authorities, national government departments, and health and social care providers.

4.8 How confident are we that our results are accurate?

We used the method of triangulation, this means getting our information from more than one source; service managers, individual people with learning difficulties and focus groups of people with learning difficulties in Barnet. The idea is that one can be more confident with a result if different methods lead to the same result.

Triangulation is a powerful technique that facilitates validation of data through cross verification from two or more sources. In particular, it refers to the application and combination of several research methods in the study of the same phenomenon.

5. Findings and discussion

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 carry out this research we had expected the main information given by people to be about how the cuts and changes to services and benefits had impacted on people's lives. We were therefore very surprised that how the cuts and changes to benefits and services were carried out was itself a major issue for people, and had a very powerful impact.

It was reported by service managers that the need to save money seemed to be overriding people's needs, and this was supported by what people with learning difficulties themselves were saying. In addition, there was a sense that people's views were not being listened to in reviews and assessments and important information was being missed.

In addition, there was a lack of information about the cuts and changes that were being made, and what they would mean for people. People did not really understand what was happening, and what impact the cuts and changes would have on their lives, meaning a lack of inclusion in the process, leading to a lack of control. People with learning difficulties were placing their trust in health and social care professionals to act in their best interest, without being aware that these professionals were not fully independent given their duty to the local authority.

There was also a lack of understanding by both central government and the local authority that many people are going through more than one cut or change at a time, and this combined impact is not being monitored at either a local or national level. As well as this, reduced services and increased charges were impacting on people's ability to take up opportunities, leading to reduced independence.

Another important issue was around support. It was very clear that a lot of support was needed to go through an assessment, appeal a decision and to cope with the changes or cuts being made. There is no acknowledgement by decision makers of the level of support needed. People were finding support where possible to go through this process, but for many, support was not available.

Finally, the research showed that although people with learning difficulties do not have fair access to assessment and review processes as a result of support and information barriers, they do know what they need. People know what is important to them and what support and services they need to be independent. The key issue is that as a result of barriers they are not fully a part of the decisions being made about their lives.

In each section of the findings below there is a selection of quotes from participants to highlight the key issues found in this research.

5.2 Assessment and review processes seem to be overriding 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.

Most people with learning difficulties and all service managers interviewed agreed on one thing; reducing funding and making cuts to people's support now seemed to be a key reason for assessment and reviews. The research gives a very negative view of both the cuts in general and people's experience of the process of assessments and reviews.

Of those who had not been through an assessment or review, 30% of the people interviewed were worried 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, the majority could not understand why their particular support or services had been cut or charges for services increased, but most felt that it was about saving money.

There was absolute agreement from service managers and the majority of people with learning difficulties that the need to cut money from the budget seemed to be overriding the need to ensure appropriate support and services were in place for individuals.

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 individuals 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?

As a result of the focus on cutting costs, it would appear from what both service managers and individual people with learning difficulties said, that decisions had already been made about which support and services would be kept, and which would go. 80% of the people interviewed, who had experienced 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 the chance to understand what was happening, as there was a lack of good information and independent support to say what they thought, be

included in the decision making process, or ensure they were listened to.

If people with learning difficulties are entering into the assessment and review process without good information and support, how can professionals understand and then include their views and needs?

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 individuals 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

Due to cuts to local authority funding, social workers do not seem to be properly taking account of the needs or views of the people with learning

difficulties who they are assessing. This means that this group of people, who are already marginalised by society, is being left out of decisions about their own care. It is also likely that because people with learning difficulties often have specific communication needs, if they are not given a real opportunity to say what they think, they will not be able to give information that is important in terms of assessing their needs, when reviews and assessments are taking place. Professionals seem to be making decisions without all of the information, putting pressure on people with learning difficulties, both at the time of the assessment, and as a result of support and service cuts, and not giving people the opportunity to have their say or be listened to. If you add into this the fact that those who have support and can shout the loudest seem to have more of a chance of keeping their existing support and services, it would appear that the review and assessment procedure is not an equitable process, and that fewer people with learning difficulties are getting the support and services that they need.

Cuts vs need: There is a big problem if health and social care professionals are going into assessments with the main focus being on looking to take away support or services from people. There is no doubt that professionals are under pressure to put in place local authority budget cuts, however if they are looking to make cuts then how can they really be focusing on the needs of people with learning difficulties, and the impact that this will have on them? People felt that the main thing that affects decisions is how much the support and services cost, rather than on making sure that the needs of people are being met. How can professionals fairly balance the need to make cuts with the need to make sure people have appropriate services? Most importantly, how can any changes to support and services be made without properly including the people that it will affect the most?

The impact: People felt the difference. They knew what it was like when they had more support and services and what it enabled them to do, and have had to cope with a range of practical and emotional issues due to reduction in support and services. Is lack of local authority funding something that can justify taking away support and services, and leaving people feeling more vulnerable on a number of levels, without being fully aware of the consequences or taking the time to find out? Surely there has to be a better way?

Coping and struggling by are not the same as leading an independent life with the support and services that a person needs. Some people

have no one to turn to at times of crisis, but it does not appear that the local authority had any way of assessing this or of making sure people have easy access to support in a crisis situation.

In one case, there was a change to a person's situation; this led to a review of the person's needs. Fifteen minutes after the review a decision had been made to take away support completely. This person was left to cope, luckily they had the support of their family, but this will not be the case for everyone, and it does not appear that this was built into the equation. This raises the issue that support and services seem to be being downgraded from ensuring wellbeing with adequate support and services in place, to "just coping".

With less funding available, local authorities are saying more and more often 'you don't need support', when, perhaps what they should be saying is 'we can't afford to support you properly, and we need to work with you to find out how we can best meet your needs and ensure your wellbeing'.

Listening to people: During this research we have become very aware of the cuts to funding faced by local authorities, but this does not justify the way that putting in place the cuts to support and services has been taken forward, in terms of an unwillingness to value people's views or listen to what is important to people, with decisions seeming to be made almost entirely on a financial basis.

People with learning difficulties are the experts about what is important in their own lives, and should be included in decisions being made about support and services. The research shows that this has not been the case, and that assessments are not being carried out in an inclusive way, as people go into assessments without having the information and support to understand what is being proposed. What happened to Valuing People? It was promised that "The Valuing People commitment of 'nothing about us without us', remains at the heart of Valuing People Now", and that mechanisms would be put in place to ensure that people's voices are properly heard and their rights are respected. The experience of people we interviewed, going through assessments and reviews does not seem to support this.

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, with good information about what is happening and being proposed, and independent support.

5.3 People do not understand what is happening, are not given information on which decisions are based, and there is a lack of inclusion in the process

The overwhelming sense gained from the research was that people did not have very much or enough information to understand what was being proposed, nor the impact that the proposed cuts would have. They were very dependent on health and social care professionals' judgments about what would be best for them in the context of the reduced budgets.

a. People do not know what is happening

The majority of people who were interviewed did not have information about the changes and cuts to benefits and local authority support that might affect them; 30% of the people interviewed had general information about cuts and changes however not specifically about how it would affect them.

When carrying out the research there was definitely the sense that there was a culture of people not having access to information, of assuming that people do not need to know, even when they have the capacity to understand, as shown 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 finances.

When asked have any of your benefits been cut? One person said, "I don't know if my benefits have been cut, my carer would know."

This approach seems to be mirrored in the way the assessments and reviews have been carried out, in relation to both individual people with learning difficulties, and their parents and carers. This lack of information means that people do not know what is happening or understand the impact of changes or proposed changes.

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 individuals 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, therefore there is a trust placed in them. However, when health and social care professionals have to also represent the interests of the local authority, there has to be awareness that professionals may have more than one agenda, and it is for this reason that clear, accessible information and independent support are needed so that there is not a conflict of interest for professionals.

60% of the people who had been through local authority assessments, and had had cuts to services and/or support, did not agree with the cuts, but did not take any further 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 as a result of speaking to one or multiple independent third parties.

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 individuals 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, trusted Barnet Council’s judgment, and took at face value that what they had been paying previously, was not fair.

Other examples of trust being placed in professionals include:

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 as to why this would be better.

A person having a reduction in a national benefit without knowing they could appeal until speaking about the situation with a number of third parties.

c. Discussion

Health and social care professionals have a difficult job in the light of the cuts to local authority budgets and services. Many people with learning difficulties trust professionals assuming that they are giving independent advice and support, and that they have the person’s best interests as their priority. Whilst professionals may try to do this, it is actually not possible as they have a duty and responsibility to the local authority, which is currently experiencing big cuts in funding, and criteria for support is ever rising. Given this conflict of interest, it points directly to the need for independent support and advice. This is to ensure that people with learning difficulties know what they are entitled to, and the options 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 indeed be necessary for some people, but it raises the question of how firmly established the culture of dependency, lack of information and

lack of control is for people with learning difficulties. This makes it easier to make changes without properly including people with learning difficulties.

None of the individuals that we spoke to fully understood the national cuts and changes that were happening, nor how they might be affected. In particular, with the move from the Disability Living Allowance to Personal Independence Payments, people who were due for assessments did not understand what this change would mean for them. People are going into local authority and national benefit assessments, without being able to communicate their needs and how their impairment affects their daily life. People are not being given information that they can understand, nor is there a system of support in place for people. Even for parents and carers of people with learning difficulties, the research seems to indicate that they do not have a good understanding of the assessment and review process, and therefore cannot give adequate support. As we can see from this research, it is critical that people with learning difficulties have good information and independent support when they are going through assessments.

People also need support to understand the impact that the cuts and changes to benefits and support will have. Overall, from the interviews, there was a sense that people were experiencing a feeling of powerlessness, and the impact that this may have on people going through multiple assessments needs to be taken into account.

People's experience of the assessment process seems to suggest a sense of unfairness and a lack of equality, because without people's informed input, how can the outcome of the assessment meet people's needs? This raises the following questions:

- Are local authorities meeting their Equality Duty around providing accessible information and support to understand these changes?
- Do people with learning difficulties have any power and control in the assessment and review process?

5.4 Direct cuts to benefits, support and services and increases in charges

Here we look at the impact of cuts to benefits and services and how this has affected people with learning difficulties. It is important to say that many people that we interviewed were waiting to go through

assessments and therefore they did not yet know what was going to happen. The main impact felt was around reduced support hours and increased charges.

About 35% of the people who were interviewed were still awaiting assessments and reviews.

a. Double whammy – more than one change happening at a time

It is unclear if there was any understanding by the local authority and government departments that people were undergoing cuts and changes in services and benefits at a number of levels. Of those who had been assessed, everyone had experienced some form of cut. Over half of the people interviewed had experienced more than one cut, change to services or increase in charges.

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. Lost opportunities and reduced independence

An important finding to come out of the research is the impact that the cuts and changes to services and benefits have had on people with learning difficulties' ability 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 individuals 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

When more than one cut happens at a time it can be very hard for people with learning difficulties to cope. With Example A, they had a cut to benefits as well as a reduction in local authority support. For this person it meant that they had to rely on their supporter to put in unpaid hours and rely on other people to be able to do things. Because this person was unable to get out as much as they would like, and had to

rely on other people to do so, they felt lonely and frustrated, and when this person did want to get out, they had to rely on other people.

With Example B, a reduction in support hours was not felt as strongly because this person was able to rely on their mother to support with letters and general admin. It is great that for this person that family support was a possibility, however for many this is not possible due to difficult relationships with family members or because their parents are elderly and not in a position to support them. At the same time this person also had an Employment and Support Allowance assessment which resulted in a reduction in the money that they received. This led to health issues with this person ending up in hospital, then afterwards stuck at home, not able to work and feeling very agitated.

The impact of two or more changes happening at the same time does not seem to have been taken into account when assessments and decisions are being made by health and social care professionals. This means that many people are going through two or more changes with each being looked at individually. This demonstrates the need for full impact assessments being done, either by local authorities or the Department for Work and Pensions, to ensure that the multiple impacts of changes do not have the kind of effect seen in these cases.

It is also apparent that there is no post-decision support for people once cuts or changes have been made, and they need to rely on other people's good will to get by, that is if they have other people in their lives to provide support.

On top of cuts to benefits and support being cut, charges for services that used to be free are adding to the negative impact on people's lives. Service providers no longer have the same funds to offer certain activities or provide transport. The person in Example A, who had received a decrease in benefits and support, also had to stop volunteering as a result of the organisation no longer providing transport.

The combined decrease in activities available and increase in charges for services is having a big impact on people's ability to be independent, and to get out and do things. This is why when looking at the impact of reducing benefits or support they need to be looked at together with the other local services that a person uses. This evidence points to the need for impact assessments, looking at a person as a whole and all of

the things that they do. If this does not happen then the true impact cannot be seen.

These changes lead to people feeling lonely, frustrated, being able to get out less, a reduction in activities, having to manage on less money, a loss of independence, and the stress impacting on physical and mental health. It also means that people are depending on family and other people to support them to both get out and do things, and for financial support. As these changes are not all happening at the same time, the impact may not seem as bad at first. However, when service closures or reductions are then factored in, the ability to cope and the impact on independence is felt acutely by people with learning difficulties.

People who have not yet been assessed are worried about what will happen when they do get reassessed. One person is sure that support hours will be cut and another is worried about what they will do if their benefit does get cut. If this happens there is not support from local authorities to deal with this change and make sure that they have enough support and money to get by.

5.5 What was missing? The importance of support to go through the process of assessment and after the assessment to cope with reduced support and services

The access needs of people with learning difficulties are met by having accessible information about what is happening, which we have seen has not been available, and having support to understand and deal with situations. The research shows that people with learning difficulties did not have access to independent support during or after assessments. This section looks at the level of support needed to go through an assessment, appeal a decision and the support needed after a change has been made. It also highlights examples where people do not have this support and what impact that has.

a. Support needed to prepare for an assessment or to appeal a decision

The whole process of getting support to prepare for an assessment, or appeal a decision shows a lack of available support and that it is all

completely ad hoc; people had to scramble about getting support from anyone who was prepared to give it.

“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 cope after a decision has been made

For some people this was available through family and friends, but obviously this has an impact on people’s independence.

“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

In relation to support, when either an assessment is to take place or something goes wrong with an assessment or change, we can see the range of people and organisations that have been involved at every stage of this process. People need support to find their way through assessment and appeal processes, it is not easy. Despite this, local authorities and the Department for Work and Pensions do not acknowledge the level of support needed.

In the majority of cases where a person had support, they were successful in getting a positive outcome. However, there are many people who do not have this support on hand and therefore did not appeal decisions, even when they were not happy with the outcome. Supporters, service providers, family members, doctors, nurses, mentors and third sector organisations all went above and beyond to support these people with learning difficulties. However, as this is such a common theme for people with learning difficulties, it would appear that a service offering this type of independent support should always be on hand for people with learning difficulties who do not have anyone to support them.

As a result of a negative outcome, the majority of people who had previously been independent had to go back to relying on family members. Some people were fine with this, however other people felt they had lost independence and others who did not have this option were left on their own.

People have described how difficult it is to get an independent advocate, which is a right, for some, under the Care Act 2014. However, to even start the process of getting an independent advocate most people with learning difficulties would need support, this is therefore not really an accessible option.

Independent support would help a person to look at what a change means to them and decide whether they were OK with that change. People without support tended not to challenge a decision. They may

even have considered it a positive change, without full independent support and accessible information.

Those who had support tended to win appeals and ensure positive changes were made. This support came from:

- Supporters
- Third sector organisations
- Service providers
- Family
- Health professionals

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

5.6 People know what independence looks like and what they need

As can be seen in findings above, people are not being properly listened to or included in decisions that are being made about their lives. However the section below demonstrates that people know what they need and want; know what independence looks like in their lives and what works for them. The issue is not about a person with learning difficulties knowing what they need, it is more about ensuring that they can have a voice and are included in decisions 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

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. The majority of people interviewed who are not currently working or volunteering want to be doing so. Having fulfilling lives is important. When a person is living in a place that they like, with the right support, they value the independence.

6. Conclusion

This pilot research project has brought together two user-led Disabled People's Organisations, the national self-advocacy organisation, People First (Self Advocacy); and a local self-advocacy organisation, People's Choice at Barnet Centre for Independent Living. The Cuts Impact Action Now project has documented research which demonstrates that people with learning difficulties, who it is acknowledged are routinely excluded and discriminated against at a range of levels in society, face barriers and a lack of equality in health services, education provision, work opportunities, and access to justice.

The research also analysed the theoretical impact that recent national and local policy and legislation changes, which have resulted in a decrease in service provision and financial support, could have on the lives of people with learning difficulties. It profiles cuts and changes which will condition the experience of people with learning difficulties and potentially worsen their position in relation to income, access to services and support, encompassed specifically in: Disability Living Allowance changing to Personal Independence Payments; the closure of the Independent Living Fund; the Overall Benefit Cap; the Spare Room Subsidy; changes to Housing Benefits; Incapacity Benefits and Support Benefits being replaced by Employment and Support Allowance; Universal Credit; apparent changes in Access to Work criteria for people with learning difficulties; cuts to Legal Aid, the Equality and Human Rights Commission helpline closure; and cuts to local authority budgets leading to reduced spending in Adult Social Care and local service provision.

The Cuts Impact Action Now project is a user-led, pilot research project. The research took place in the London Borough of Barnet, where it is estimated that there are 5,874 people with learning difficulties, of which 1,326 are in receipt of local authority services. Information, in relation to changes to services and benefits, was gathered from 54 people with learning difficulties via 35 individual interviews and 3 focus groups; and from 3 service managers. This was in order to gain an insight into the views and experiences of people with learning difficulties in Barnet.

From the evidence collected, how do the multiple policy and legislation changes, which point to a reduction in benefits, services and support for people with learning difficulties, impact on people's day to day lives in Barnet. The research found that changes to benefits, services and support, did have a major and negative impact on people's lives in terms of: support and services available; physical and mental health, and wellbeing; ability to take up a range of opportunities; independence; and personal finances. People with learning difficulties and service managers also thought that the review and assessment process to implement these cuts and

changes was a major issue. There was agreement from both sources that the aim of reducing local authority spending was overriding meeting people's needs. It was also thought that there was a lack of understanding by the people who made decisions and carried out reviews and assessments of the cumulative impact of the cuts and changes. In addition, the lack of accessible information and independent support throughout the review and assessment process, including making appeals, meant that people felt that they could not have proper input into decisions about their own care and support. There was also no formal process in place to enable people to cope with and manage the negative changes. Overall, the review and assessment process itself was felt to be an extremely negative experience. People felt disempowered, that they were not included, 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 can be encapsulated in people wanting to: retain the level of independence they have, and become more independent, with adequate income to do this; have the right support; access opportunities and get out and about; and access education, volunteering and employment opportunities. The following recommendations aim to improve the practice of a range of stakeholders, including: policy makers, decision makers, and health and social care professionals, in relation to the process of reviews and assessments; and alleviation of the negative impact of cuts and changes to benefits, support and services on the lives of people with learning difficulties.

This pilot research project has established a model for collecting evidence from people with learning difficulties at a local level. This model will be replicated in other local areas to enable people with learning difficulties to collect evidence and campaign at a local level, and be part of a national voice to influence change.

7. Recommendations

The following recommendations are aimed at Barnet Council and in some cases central government departments. However, many of the recommendations referring to Barnet Council can also be applied to other local authorities.

Recommendation 1: Being included in the process

Barnet Council needs to review their assessment and review processes. They need to ensure that throughout the process, there is accessible information about when assessments and reviews will happen, what each part of the process is about, how much the local authority is looking to cut from each person's local authority support, why this is needed, when it will happen and what the individual's options are. This will therefore give people with learning difficulties the ability to be included in this decision. This review should start by April 2016 and be complete by March 2017.

How will we know it has been done? We will work with Barnet Council to produce guidelines and training around how assessments should take place and the information needed to make this process accessible for people with learning difficulties.

Recommendation 2: Getting my voice heard

Barnet Council should carry out a needs assessment around commissioning an appropriate independent support service which would be available to all people with learning difficulties throughout the assessment and review process. This service should make sure that people can prepare for assessments, demonstrate their needs, think through the options that they have, communicate this effectively during the process, and receive support after an outcome has been decided to deal with any agreed changes in support, services or charges. This will ensure that people have an equal voice, choice and control in the decisions which have a big impact on their lives. The needs assessment should be completed by 30th June 2016. The commissioned service should be in place by April 2017.

How will we know it has been done? We will work closely with Barnet Council and the Commissioning Team to ensure an inclusive and all-encompassing service is commissioned specifically for people with learning difficulties.

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

Social Workers and other professionals in Barnet involved in the assessment and review process should attend obligatory user-led learning difficulty awareness training. This will ensure that professionals have a better understanding of the needs and life experiences of people with learning difficulties. This training will also include information on informing people with learning difficulties about the outcomes of assessment and reviews, especially with regard to compassion when delivering negative news. There should be a rolling training programme for staff already in post, and the training should be incorporated into the induction period for new staff. This should commence in April 2016.

How will we know it has been done? This will be discussed with Barnet Council and developed with a range of other stakeholders.

Recommendation 4: What happens after the outcome has been decided

In the light of local authority budget cuts and increased assessment eligibility criteria a reduction in local authority support for an individual does not necessarily mean that a person does not need this support, only that the local authority does not have the resources to finance it. The local authority still has a duty of care to make sure that a person with learning difficulties can access other support even if it will not be directly paid for by the local authority. Therefore, this recommendation is about what happens after a person has had a reduction in support or complete withdrawal.

For people with learning difficulties who have experienced a reduction or complete withdrawal of support, Barnet Council should make sure that part of the review process includes a plan for each person, including information about where they can go to get any extra support that they feel they need. This should include signposting to organisations that offer support in the areas needed by each person and services and activities that are available in Barnet. They should also ensure that each person has the support that they need to make contact with these organisations, whether this is a family member, carers or independent support from a local organisation. There should also include a post-change impact follow-up meeting with each person who has been through the review or assessment process, recording and taking account of 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 included in guidelines produced with Barnet Council around making assessments accessible. An impact report at the end of each financial year should be produced by Barnet Council.

Recommendation 5: Accessible written information

All written information and communication from national government departments and Barnet Council should be in an accessible format depending on the access needs of each person. A People First (Self Advocacy) campaign focusing on this will be started in January 2016.

How will we know it has been done? This will be included in assessment guidelines and Learning Difficulty Awareness training co-produced with Barnet Council. Through national campaigning work, People First (Self Advocacy) will ensure that this stays on the agenda for national government departments.

Recommendation 6: Cumulative Impact Assessment

There needs to be a Cumulative Impact Assessment done in general for disabled people, as well as specifically broken down for people with learning difficulties. This needs to take into account national welfare reform, local authority spending cuts and the impact this has had on local services and activities, service charges, as well as local authority support. There needs to be a monitoring process in place to ensure that disabled people and people with learning difficulties are not being unfairly affected by welfare reform, which our report highlights is happening. This will ensure that all local authority and national government decisions are more effective and based on the principles of equality. This will begin once phase two of the Cuts Impact Action Now Project has been carried out, supporting other user-led self-advocacy groups to carry out research in their own local authority around the UK.

How will we know it has been done? People First (Self Advocacy) will collaborate with national partner organisations to campaign for a Cumulative Impact Assessment.

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

It should not be assumed that people do not have views and cannot make decisions; every opportunity should be taken to ensure that each individual can participate as fully as possible in decisions about their support and get the

information and support needed to do so, as highlighted in the wellbeing principle in the Care Act 2014. How Barnet Council is meeting this requirement should be demonstrated by the local authority. This will be requested at the end of each financial year.

How will we know it has been done? From the information in this report, this is obviously not happening; therefore information will be requested from the Council as to how they are meeting this requirement under the Care Act 2014 for people with learning difficulties.