

# Learning Disability Care **in** Barnet

A Report on Quality of Care for Learning Disability Service Users in Barnet



**July 2017**

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## Executive Summary

In aiming to address increasing concerns about the quality of care, service users in Barnet are experiencing; this project revealed a number of areas, which could reasonably be improved.

While many service users reported they were satisfied on an overall level with the support they received, it was clear from the data we collected that their day-to-day experience could be considerably improved, if certain specific areas were targeted for improvement.

We collected many varied opinions about service provision, though many respondents voiced the same concerns. We are confident, therefore, that the recommendations we have made at the end of this report will increase satisfaction across the board.

## Introduction

Healthwatch Barnet is one of a national network of independent local charities that aim to help local people get the best out of their health and social care services. Healthwatch enables residents to contribute to the development of quality health and social care services, and to provide information on local services in Barnet. It was formed in April 2013.

People's Choice is a team of three staff members who have learning disabilities, who are employed by Inclusion Barnet, a peer-led disability organisation which promotes inclusion and independent living so that disabled people can have choice and control over their lives. Inclusion Barnet have worked both with Barnet Council and the NHS to make sure people have a voice in the services they use.

This investigative project first came about because of a concern identified by the 'Learning Disability Parliament' around the quality of support that service users were experiencing, which was not as good as it could be. A growing number of individuals voicing a variety of different concerns led us to believe that the quality of care being received at home and at day centres should be explored. We decided it was important to find out if service providers were giving the right balance of good support and respecting the wishes of the individual with the ultimate aim of discovering how the wellbeing of the service user was affected.

## Background

In the service area this report is concerned with we looked at feedback from people in Barnet with learning disabilities about the quality of care they received. Care could be received through a care agency, from family members or from individually registered carers and we wanted to find out how happy people were with their care and what the challenges were that carers and care agencies themselves faced, while aiming to provide a consistently high level of support.

The expectations of support working are to provide a high quality support service that will allow the person with learning disabilities to learn to make choices in a safe environment. The support worker should support the person by:

- Explaining difficult choices and situations - what the consequences can be, explained clearly using language that is easy to understand. .
- Speak up for the person with learning disabilities, act as an advocate on their behalf but NOT take over
- Not giving their own opinions on situations unless asked by the person with learning disabilities
- Listen and be supportive
- A good support worker will be familiar with Easy read and Makaton - both are forms of communication for people with learning disabilities.

## Methodology

In order to make sure our research was as comprehensive as possible we spoke to 72 service users and 10 support workers as well as talking to 4 relatives of people with learning disabilities to gain their perspective on the care their relatives received. In addition to this, we created flyers to advertise our project and drew up questionnaires for people with learning disabilities and support workers, as attached at the end of this document. We designed and conducted focus groups, gained information from our members and also ran drop-in sessions for people with low communication skills to allow all people with learning disabilities the opportunity to express their views. For clarity, we decided to divide our research into the following information:

- Wellbeing
- Health and Safety
- Socialising
- Admin
- Budgeting

- Personal Care
- Food
- Independence

To begin our information-gathering we attended the Barnet Healthy Eating Day in September 2016 where we conducted 1-1 interviews with 20 service users. We held a group session for individuals with higher support needs at Your Choice Barnet (Local Authority Learning Disability and Autism service provider) which was attended by 15 people. We held two sessions at Inclusion Barnet which were attended by five people (three service users and two support workers). We also held a group session at Dimensions (Learning Disability Service Provider) which was attended by 2 people.

## Findings

Having divided our research into 8 different themes we found that from a service user perspective:

**Wellbeing** - People with Learning Disabilities can feel isolated if their support worker does not have time to make personal conversation with them. People have also felt unhappy and rejected when their support worker reportedly shouts at them or calls them names such as ‘lazy’. One respondent reported: *“My support worker talks bad to me.”*

A major issue that was flagged up by around 20 per cent of respondents was that support workers often make a lot of telephone calls on their mobile phones during work time. Many people with learning disabilities have reported that this makes them feel ignored, and in addition to this, lack the confidence to speak up: *“When my support worker talks a lot on his mobile phone it makes me feel very down but I can’t say anything as they might get rude to me.”*

**Health and Safety** - Because of time restrictions and the fact that a lot of emphasis is placed on going out in the community 10 per cent of respondents said that housework does not get completed. On these occasions the safety of homes is compromised by items left lying around on floors, washing up remaining undone and tables and kitchen worktops uncleaned and therefore unhygienic.

**Socialising** - Around 85 per cent of respondents feel that they are well supported in choosing, planning and accessing their leisure activities such as sport and spending time with families.

**Admin** - Support hours are not always adequately explained, for example, some people do not know what happens to the money or cost when support hours are cancelled and service users are not always sure what happens to their hours when a support worker is away.

**Budgeting** - Most people are happy with the help they receive with budgeting however it was reported that in one instance a service user was left with not enough to live on.

**Personal Care** - Clothing is not always presentable. It is either un-ironed, inappropriate for the weather or outfits are not well put-together. Sometimes clothes are chosen that service users feel do not fit properly anymore. Seven percent of service users feel as though their wishes, in terms of what they wear, are not always respected.

**Food** - Some foods being bought are not what the service users said they wanted to eat. There is also an issue with the fact that support workers don't always use clear, easy-to-read food labels with the best-before-date for limited shelf-life products such as milk, ham and cheese. These are then left to go mouldy. Around 15 per cent of service users said that when out in the community unhealthy meal choices such as burgers and cake were often encouraged even though service users may need to watch their weight or have other health issues that mean that healthy choices are very important.

**Independence** - Around 80 per cent of respondents seemed to be happy with their level of independence. They felt as though they were well-supported in making choices about their care and were being given the right balance of good support while their wishes were being respected.

#### **Support Workers viewpoint:**

While people with learning disabilities were asked questions around the quality of care they received and how much they were supported to make independent choices, Support Workers were questioned on how much they felt supported in their posts, what kinds of daily tasks they performed and what their motivation was to enter the field of support work.

Many entered the profession because they saw it as a compassionate career choice. As one support worker responded:

*“Having spent most of my career working in a large corporation for whom profit was the key driver, I felt I had to do something more meaningful, that might have a real impact on supporting people less able and hopefully to make a difference.”*

Despite being motivated to support people and feeling as though they made a positive difference to people's lives, one of the key challenges support workers reported was in dealing with the benefit system with many experiencing high levels of anxiety around navigating the benefit system of behalf of service users.

As one Support Worker said: *“I have had to fight and had to find out what help there was. The Department of Work and Pensions have been unhelpful and destructive.”*

Another added: *“I have had to be feisty and willing to challenge doctors and the DWP....I have encountered many obstacles and it has been so frustrating....the closure of the Welfare Rights Unit was the beginning of all the problems and difficulties.”*

While the benefit system is seen as being challenging, it is widely recognised as being even more problematic for people with disabilities to steer.

As one respondent summarised: *“The system is very difficult for people to navigate and there is not enough support particularly for people with disabilities.”*

### **Family Carers Viewpoint:**

Carer's can often experience high frustration levels particularly if they are caring for a family member and have assumed the role because no one else is available. As one family carer said: *“I work at home...a carer looking after my husband. I don't enjoy it but I assumed the role because someone had to do it.”*

Another stated that his role caring for a family member meant that his life had *‘completely altered’* and that he had *‘lost his freedom’*. When asked what he had learned from his role as support worker he replied: *“Avoid this situation if humanely possible.”* Particularly problematic are the difficulties associated with ageing with one carer saying that as time got on he became *‘very despondent’*.

While training does not generally seem to be an issue for those who are employed by care agencies, the reverse is true for those who care for family members with many feeling ill-prepared for the work they are called on to do. Family Carers reported they had had insufficient training (First Aid, Basic Life Support, Moving and Handling, Health and Safety, Understanding Dementia) which led to them feeling overwhelmed and unable to cope by many situations they encountered in their caring role: *“I have had no training...only what has been learned from looking after elderly parents.”* Another reported: *“Maintaining a healthy balance between work and home is often impossible to achieve.”*

## **Case Study**

This is a case study of an individual who has high support needs and whose support is provided by Direct Payments.

When the individual moved into supported accommodation, the support worker stayed with him in order to provide continuity. The individual now has more than one support worker to assist with doctor and hospital appointments, food shopping, budgeting, choosing leisure activities and dealing with benefits. When

asked about his relationship with his main support worker he replied that '*she talks bad to me*'.

The support worker has written that they have to be firm for the everyday targets to be achieved: "*He has a very busy routine and his day starts early and he wants to stay in bed so staff have to be firm and consistent.*"

While this individual does feel as though he is in charge of his own money, further comments by his support worker indicate that it is the support worker who is in control of this: "*He is aware that his money is being spent.... He might otherwise just spend the money on burgers and biscuits and KFC.*"

## Conclusions

With our primary project objective to find out the 'happiness' rating of individuals in terms of the support they receive we discovered that broadly, individuals are happy with their support.

Many had been with the same support worker for what they saw as a long time, were adequately supported to engage in daily activities of their choosing and were generally kept informed of their daily timetables.

### Areas that could be improved on were:

- Support workers spending less time on their mobile phones while with service users
- Better support with household tasks, structuring the time spent to ensure that as many of the essential tasks as possible were completed.
- An additional area for improvement was that there could be greater transparency when it comes to contractual agreements between Support Workers and their service users. This is because service users were unsure of what agreements were in place, especially when support workers are not available.

### From a carer's point of view:

It is very clear that happiness levels were not what they could be and that greater support was needed, particularly in terms of accessing benefits advice, which is currently a source of great frustration.

Family carers' wellbeing is also affected by feelings of isolation, a lack of training and feeling as though they are unable to achieve a healthy balance between work and home.

In particular, this is the message that comes through from those who care for family members as they reported high levels of stress and poor well-being because



of having less support and limited coping strategies. Many of these would benefit from respite care.

## Recommendations

- 1) Help for support workers/carers to access benefits advice and to be kept-up-to-date on changes.
- 2) Ensure information is available to family carers about training and support that they can access.
- 3) Greater clarity and information be provided when it comes to the contracts between support workers/carers and the service users with all parties understanding the terms.
- 4) Support workers/carers to exercise discretion when it comes to using their mobile telephones during working hours.
- 5) Support workers to give greater focus to be given to household duties, provided this has been agreed with the service user.
- 6) Ensure that individuals receiving care are provided with details about how to complain or raise concerns about the care they receive where necessary.

## Acknowledgements




Thank you to Benji Lanzkron, Mahmuda Murshed, Emma Hatfield and Michelle Burke from Inclusion Barnet for researching and writing this report.

Thank you to everyone who helped with this project including Inclusion Barnet's members; Kisharon, Barnet Carers, St Joseph's, Mencap, Dimension and Community Space. Thank you also to all those who took the time to talk to us about their experiences of care services.

## Appendices

### Appendix 1 - Extract Service User Questionnaire

For ease of presentation we have only included the questions from the questionnaire.

	<p><b>Who provides your support?</b></p>
	<p><b>How long have they been your support worker?</b></p>
	<p><b>Do you have one person supporting you or do you have lots of support workers?</b></p>



Do your support workers help you with any of these activities:



Doctors and hospital appointments:



Yes



No



Food shopping:



Yes



No



Budgeting money



Yes



No



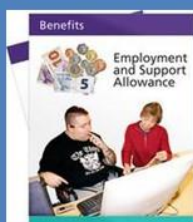
Choosing leisure activities



Yes



No



Benefits



Yes



No



How do your support staff talk to you?



Good



Bad



Did you choose your support worker or Key worker?



Yes



No



When you first had support workers, did they explain:

- What their job is
- What they will support with
- How they will support you?



Yes



No





**Do your support worker's plan sessions with you?**



**Yes**



**No**



**Are you in charge of your money when you go out with your support worker?**



**Yes**



**No**



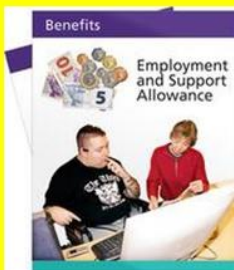
**Do your support workers help you to budget your money?**



**Yes**



**No**



**If you had a problems with your benefits, did your support staff know who to go and get the right advice and help from?**






**Yes**



**No**

	<p><b>Do your support workers support you to choose a healthy lifestyle?</b></p>		
	<p><b>Yes</b></p>		<p><b>No</b></p>

	<p><b>Does your support worker support you to cook meals that you have chosen?</b></p>		
	<p><b>Yes</b></p>		<p><b>No</b></p>

	<p><b>Does your support worker help you to clean your home?</b></p>		
	<p><b>Yes</b></p>		<p><b>No</b></p>



Does your support worker help you to dress nicely?



Yes



No



Does your support worker talk on their mobile phones?



Yes



No



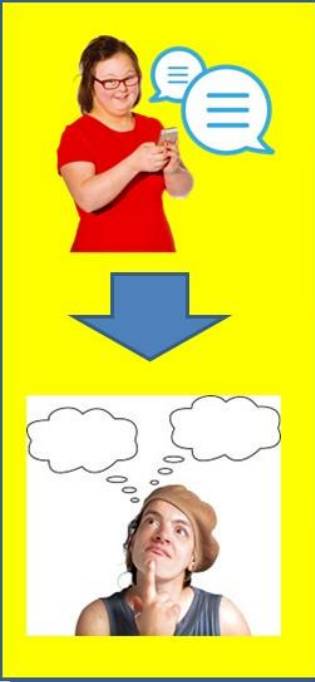
If they do talk on their phone a lot, how does it make you feel?



happy



angry



do your support workers ask you if they can answer their phone?



yes



no

Do you think is ok for your support workers answer the mobile phone if it is to do with work?



yes



no



## Appendix 2 - Extract Carer Questionnaire

For ease of presentation we have only included the questions from the questionnaire.

	<p>Which support organisation do you work for?</p>
	<p>How long have you been a support worker?</p>
	<p>What do you enjoy about being a support worker?</p>
	<p>Why did you want to work as a support worker?</p>
	<p>What personal skills do you have that help you be a support worker?</p>



What training have you had to be a good support worker?



Does the organisation you work for; give you good training for developing your skills to help you to work as a support worker?



What have you learnt from your role as a support worker?



What kind of daily tasks do you have to support people with?



Have you ever had to support a person with learning disabilities to sort out benefit problems



Yes



No

If the answer is yes could you give us more information about what support you had to give:



What do you think is good practice for a support worker?  
(e.g.: using makaton, how you verbally communicate, knowing good support tools to use)



Have you any other information to tell us about being a support worker?



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