

# “Talk to me”

A report on the local  
healthcare experiences  
of people with  
learning disabilities  
and/or autism in the  
London Borough of Barnet

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February 2014

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# Chapter 1

## Introduction

**A** new national network ‘Healthwatch’ was created in 2013 to emphasise the importance of people having a voice in relation to their care. This gives people the opportunity to speak up about the healthcare and social care they receive, with the aim that this data will help to influence local and national policy.

Healthwatch Barnet is part of this network, giving people a more powerful voice locally with regard to the healthcare they receive. Healthwatch Barnet creates opportunities to *‘listen to what residents say about health and social care in the Borough; liaise with the health and social care providers to develop good quality services in Barnet; and provide information to residents about what services are available’*.

Barnet Mencap, as part of Healthwatch Barnet, has been listening to what people with learning disabilities and/or autism have to say about their healthcare experiences.

Barnet Mencap is one of the leading voluntary organisations for children and adults with learning disabilities and their families in the London Borough of Barnet. It is a well-established local charity and is known to many people with learning disabilities and/or autism. Barnet Mencap was asked to research good and poor experiences giving a great opportunity for people with learning disabilities and/or autism to have their say about their doctors, local hospitals and other healthcare provision.

It is estimated that 1.6 million people in the United Kingdom have a learning disability and 700,000 are on the autistic spectrum. The Equality Act (2010) defines someone as having a disability if they have *‘a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal daily activities.’* Similarly autism is described as *‘a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.’* (The National Autistic Society, 2013).

However, a person with autism does not necessarily have a learning disability as autism is a spectrum condition, meaning that the condition affects each individual differently, although people who are autistic may also have an accompanying learning disability.

The NHS and Community Care Act (1990) states that *'services are intended to help people who need care and support to live with dignity and independence in the community and to avoid social isolation'*. Over the past 30 years, the health of people with learning disabilities has improved, though recent government reports such as "Death by Indifference" (Mencap, 2007) and "Government response to the confidential inquiry into premature deaths of people with learning disabilities" (Department of Health, 2013) suggest that they are still vulnerable to receiving inadequate healthcare treatment and shows there is still a high need to improve the services available.

Reports show that people with learning disabilities and/or autism have higher levels of health needs than the wider population. This is because they are at increased risk to certain health conditions, for example epilepsy, diabetes, sensory impairments and obesity.

The Royal College of Nursing produced a report called 'Meeting the health needs of people with learning disabilities' (2006). The report states many reasons behind these increased health risks, for example:

- communication difficulties
- lack of awareness of available health services
- confusion regarding the law on consent

When treating people with learning disabilities, these reasons can lead to delays in treatment. This can result in people with learning disabilities and/or autism dying younger than other people.

The Department of Health's 2001 White Paper, 'Valuing People', which relates to working with people with learning disabilities and/or autism, encourages carers and professionals to discover *'what people want, the support they need and how they can get it'*. It states that this is achieved through promoting four key principles:

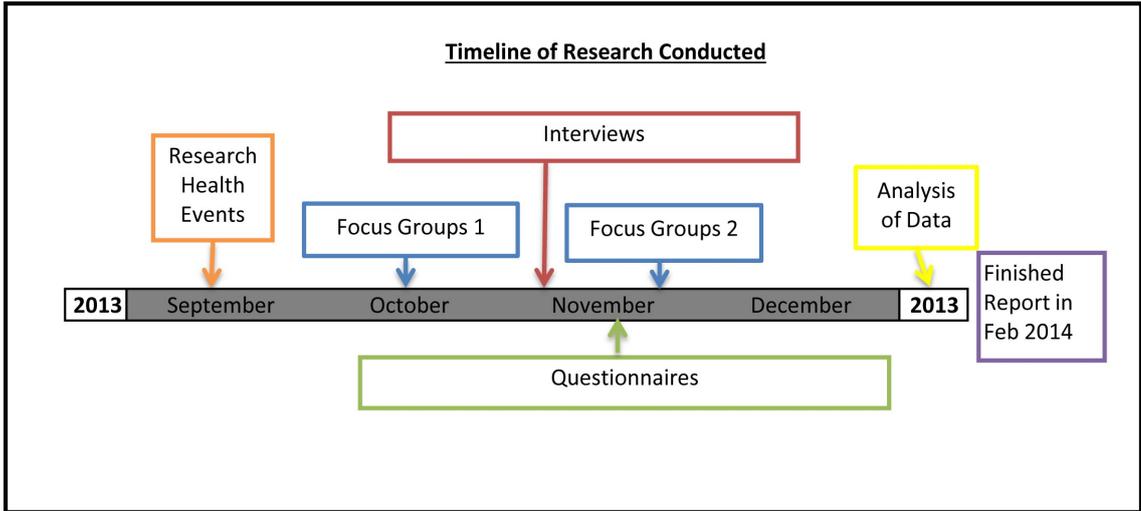
- Rights
- Independence
- Choice
- Inclusion

# Chapter 2

## Methodology

### I Research Approach

The three research tools used were focus groups, questionnaires and interviews. The following timeline chart shows how the various areas of research interconnected.



### II Data Collection Techniques

The tools provided a combination of methods which enabled a multi-perspective analysis approach to the topic question. The majority of the data collection required a qualitative approach; however, some approaches were quantitative. The aim of the project was to capture the detailed experiences of people with learning disabilities and/or autism as they are the main drivers for shaping any perceived improvements and developments within the healthcare services they receive. Consent forms were signed and the data was audio-recorded and transcribed.

#### First Method of data Collection Focus Groups

Focus groups were chosen to create a detailed picture of what people with learning disabilities and/or autism feel about the health services they receive and how it makes an impact on their lives. To try to achieve a representative sampling of people with learning disabilities and/or autism, Barnet Mencap contacted a number of organisations who work directly with people with learning disabilities and/or autism in the borough. In total, five focus groups were held — three at Barnet Mencap, one at Flower Lane Autism Service and another at Hft. A total of 18 people participated.

## Organisations that participated in the HealthWatch Research



### Hft

is a national charity, with offices in High Barnet, supporting adults with learning disabilities to live the life they want. They provide 1-1 and group support to adults with learning disabilities to live in independent housing, in their family home (including respite), to access community facilities and look for employment



### Oak Lodge

is a special school maintained by the London Borough of Barnet



### Barnet Mencap

was established in 1965 and for over 45 years has provided advice, information and support for people with learning disabilities and/or autism and their family carers



### Barnet 'How Are We Doing?' event

was organised to get the views of people with learning disabilities and their families and carers about the services they receive in Barnet including social care and health



### Health4All

is a new partnership project that has been set up by Barnet Mencap and Barnet Learning Disability Service. It offers a monthly event to help adults with learning disabilities aged 18+ find out how they can improve their health and fitness



### Finchley Youth Centre

runs courses and activities throughout the year for young people aged 11-19 (up to 25 for young people with disabilities)

### Barnet Learning Disability Service

is a team of health and social care professionals who aim to help people with learning disabilities to access their local health and community



**Your Choice Barnet** is a specialist social care organisation offering support for hundreds of people with physical and learning disabilities

### Flower Lane Autism Service

provides specialist support to people on the autism spectrum

### Community Space

is a day service offering support for adults with a wide range of learning disabilities

### Rosa Morison Day Service

is a day service for adults with profound and complex learning and physical disabilities

The image opposite shows the organisations that participated. Although Barnet Mencap would have liked to have taken a larger and more representative sample for the focus groups, time constraints and a lack of response from several organisations made this difficult. All focus groups were asked a series of questions from the questionnaire and this enabled the participants to give their true opinions without any subliminal enforced bias.

The 'Tree Of Life' exercise was used as an evaluation within the focus groups. The groups created a colourful tree which symbolised themselves. The trunk of the tree represented their feelings and the vital things they needed to be healthy. The branches and leaves showed what people felt they received and should receive from the health services to achieve all the feelings in the trunk of the tree. On the outside of the tree (symbolising weather elements) were negative experiences people had encountered and how it made them feel.

The idea of this activity was to show the participants that despite the 'bad weather' (negative experiences) trying to impact the branches and leaves (good experiences) the trunk always remains and it is important that all needs within the trunk are maintained.



## Second Method of Data Collection The Questionnaires

Questionnaires are used as a simple research tool which solicits information from participants directly. In this research process they were selected to obtain data from large groups of individuals quickly. There were three different questionnaires that were designed and distributed to retrieve feedback, either electronically or by hand (see Appendix A – Questionnaire 3).

Questionnaires were distributed to people with learning disabilities and/or autism at events such as ‘Health4All’ – a lottery funded project to promote healthy living for people with learning disabilities and/or autism led by Barnet Mencap and Barnet’s Learning Disability Service – and the ‘How Are We Doing?’ day, an event held by the Learning Disability Partnership Board in Barnet which focussed on how health and social care services are performing.

Questionnaires were also given to participants in the focus groups, to local organisations, Oak Lodge School, Flower Lane Autism Service and to parents and carers. Both verbal and non-verbal service users were contacted. Once the data was obtained, it was analysed and used for feedback and evaluation purposes.

The questionnaires were designed using an easy read format to help participants complete them. In total, 39 questionnaires were returned.

*‘Access to information is the key to participating in society, achieving in education and gaining employment. The importance of access to information is reflected in its recognition as a fundamental human right, backed by legislation.’ (RNIB, 2013)*

The easy read format uses a range of techniques such as simple language, pictures and a clear font to enable the participants to understand and access the questionnaires easily. Because the target group was so diverse, trying to cater for everyone was also difficult. Having a questionnaire that was too simple could offend, and having one too complicated could be inaccessible for some participants. A lot of questionnaires were not fully completed with many questions left blank. This was a challenge for the researchers as many services users and families have said in the past that they want their voices to be heard.

### Third Method of Data Collection Interviews

The interviews were chosen to get a detailed insight into individual participants' health matters. Some participants preferred to be interviewed on a one to one basis. It was a key source for retrieving information which benefited the project immensely.

In total, six one to one interviews were conducted over two months. These interviews focused on detailed good and poor experiences of the health care services. They were all very successful. The interviews ranged between 30 and 90 minutes in length and were all conducted at the Barnet Mencap offices. Consent forms were signed by all interviewees.

### Visual Tools

Visuals were used within each research tool. Picture cards were created to help participants explain how they felt. For example, traffic light cards symbolised 'I disagree' (red), 'I don't understand' or 'I have question' (amber) and 'I agree' (green). For less verbal or non-verbal participants these visual techniques enabled them to have their say and aided communication.





### III Issues of a confidential or ethical nature

The nature of the research suggested that issues of a confidential or ethical nature would undoubtedly arise. Some of the participants may have felt embarrassed or uncomfortable when such subjects arose. Therefore, systems were put in place to ensure that there was an environment where the participants felt comfortable and secure discussing their opinions and experiences.

A consent form was created in an easy read format and signed by all participants involved in the project (See Appendix B – Consent Form). The consent form used pictures and words to explain the aims of Healthwatch, the use of data, and the anonymity and confidentiality of the participants. All forms were signed by the researchers and participants and attached to each research instrument. Participants were verbally reassured that they could withdraw at any point. In addition, all names have been changed for the purpose of confidentiality in this report.

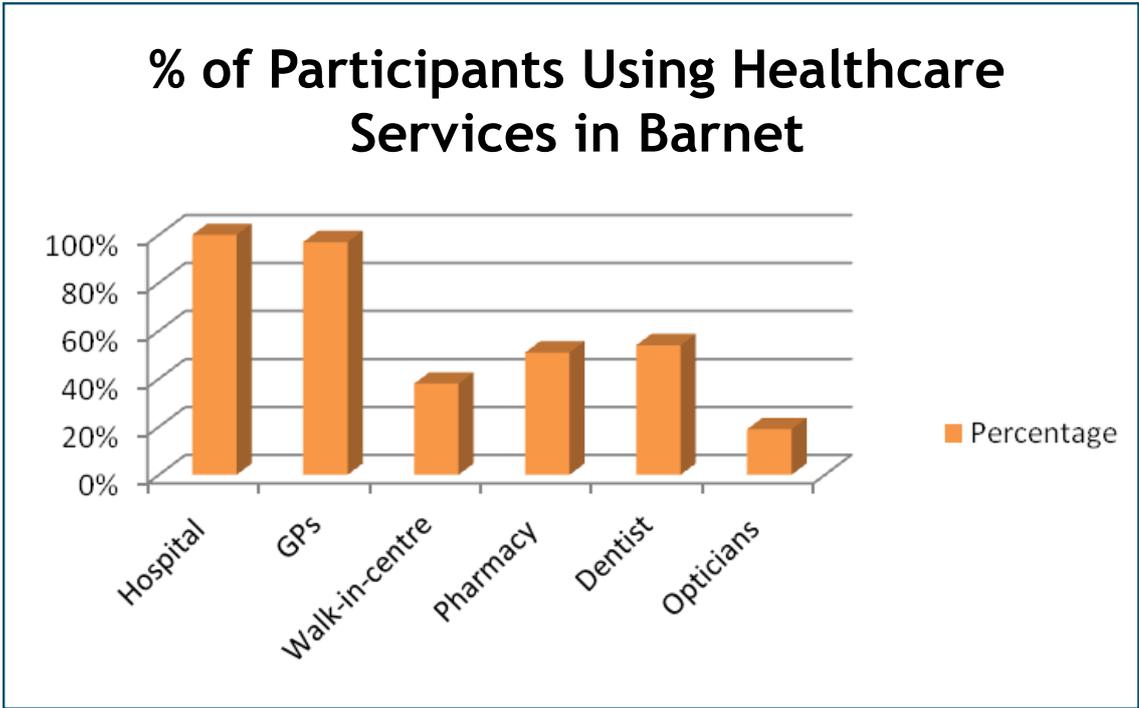
### IV Analysis of methods

Once all the data had been collected it was analysed using an array of techniques. All of the methods have positive and negative aspects when applied to this project. It was found that the interviews and focus groups gathered excessive data, yet it was difficult to gather detailed responses from the questionnaires.

# Chapter 3

## Data Analysis

The data for this research was collected over a period of three months. A total of 63 people with learning disabilities and/or autism participated in this research, of which 52% were male, 46% were female (and 2% not known) and all were aged between 16 and 60 years. To introduce the subject matter to participants, we asked them what healthcare services they use. The chart below shows the percentages of the services used.



From gathering this data, the researchers were then able to ask participants about their experiences within these healthcare services. There was a range of good and poor experiences shared, particularly about hospitals. Edgware Community, Barnet, Finchley Memorial and the Royal Free were all mentioned. These experiences highlighted areas for improvement, as well as positive comments for certain practices.

On a positive note, 43% shared a good experience about their healthcare such as health care professionals ‘willing to go that extra mile’ for the individual, reassuring them and making sure all their health needs were being met. A participant shared an experience of this when her husband, who also had a learning disability, was admitted to Barnet Hospital:

### **Experience 1 Sandra aged 57**

*My husband was very poorly, so I called out the paramedics to our home. They were really lovely to him. They explained everything as well as giving my husband eye to eye contact. A few days later when my husband was on the ward at Barnet Hospital recovering, the same paramedics came to visit my husband to check he was okay. The public service was there when my husband and I needed them and we couldn't have asked for more*

Similar experiences were expressed about doctors and nurses meeting participants' individual needs. Some GPs were very friendly, polite, understanding and sympathetic. For example, a participant's GP went to their home to check they were well as they were unable to attend their appointment at the surgery. Another participant shared her experience following an operation, when frequent visits from health professionals were needed due to an infection. Both found this care invaluable.

Many of the participants commented favourably on the new layout of the Finchley Memorial Hospital as it is now easier for people to find their way around and park. 38% of participants stated that they use walk-in centres in the borough, many using the Finchley Memorial Walk-in Centre. A participant shared her experience about her treatment prior to attending the Tissue Viability Unit at Finchley Memorial Hospital and how her care is now:

### **Experience 2 Rose aged 48**

*I was waiting for my nurse to come to my house to change my dressing on my leg. She was meant to come at 10am and my dad's funeral was at 11am. The nurse did not turn up and I missed my father's funeral. I called five times and only got through to the voicemails. Both myself and my family made a complaint as we were so angry. I had no support or apology from the nurse. My leg dressing did not get changed for two more days and I started to develop maggots. Instead of getting a nurse to come to my home now, I go to the Tissue Viability Unit where I receive fantastic care.*

However, 55.5% of participants shared a poor experience. Many commented that receptionists were not always sympathetic and patient. A participant shared an experience of this nature when he had an allergic reaction to a medicine prescribed by his GP and as a result had to go to A&E as his face had become swollen and covered in spots. Upon arrival, the receptionist commented on his face in an aggressive tone and said, 'Ergh . . . what's wrong with him?'. This made the participant feel embarrassed and scared. Although this was a negative start to his experience, it was turned around when the hospital gave him his own personal room which he referred to as his 'VIP room' and 'like a hotel'. Over the month in which he received care, having his own space made him feel a lot more comfortable.

Many other participants also stated that they had received poor care within certain services, such as staff speaking inappropriately. People gave examples of not feeling comfortable with their healthcare professional so they do not want to speak up.

Some individuals experienced a range of abuse whilst being in care. Edgware General Hospital, closed in 1997, was a service highlighted by participants on several occasions as providing inadequate care. As a result of these past experiences, many of the participants now refuse to attend appointments in the new Edgware Community Hospital, opened in 2005. For example, many years ago a participant was admitted for surgery at Edgware General Hospital. She was a victim of severe physical abuse. From this experience she had to get an Ombudsman to help follow her complaint through and obtain justice. Since then she has not attended any appointments at Edgware Community Hospital, receiving all support such as counselling and psychological help elsewhere.

### **Experience 3 Rob aged 53**

*'I had to stay in the Royal Free Hospital as I had broken my hip. I felt completely lonely, just lying there. I like to be busy. When my support worker and friends came to visit me I enjoyed the time. However staff did not support me very much to help me walk again. If I didn't have my carer I wouldn't be able to walk again, as she helped me. She was able to come and visit me whenever, but my friends had set visiting hours.'*

This experience highlights the need for people with learning disabilities and/or autism to be supported throughout their healthcare experience by their healthcare staff, support workers and families. 94% of participants stated that they are supported by a worker or family member to appointments at their hospital or GP. They said that when someone is with them during appointments or visits them in hospital, they experience the following feelings, taken from the Tree of Life, as shown in the diagram below.



Although the majority of people with learning disabilities and/or autism are supported during appointments, only 21% felt that they are spoken to directly by healthcare professionals. This is a concern as professionals should be speaking to the individual unless told otherwise, i.e. that the individual does not have capacity to make their own decisions. A participant strongly stated that ‘they are not there to see them, they are there to see *me*’, as it causes her distress when healthcare professionals speak to her carer instead of her.

Many participants did state that they find it difficult to understand what is being said to them (51.5%) and appreciated the support their carers/family members give them in appointments.

*‘I find the words the doctors use confusing’*

*‘I don’t feel confident asking doctors to repeat what I don’t understand’*

*‘The language is like an alien language. I get completely confused and it’s annoying’*

*‘Some have ignored me and spoken to my support worker instead’*

This highlights an area of concern, as healthcare professionals are not meeting the communication needs of individuals (100% of participants from the focus group stated this). The use of jargon and complicated language confuses people. They would like healthcare professionals to use objects for reference and pictures to explain if needed. In addition, they feel that they are not listened to in their health appointments and would like healthcare professionals to speak more slowly.

The Disability Discrimination Act 1995 states that '*all service providers must make reasonable adjustments to ensure disabled people can access services*'. This emphasises the need for healthcare professionals to meet the individual communication needs of those with a learning disability and/or autism.

Along with participants not understanding what health professionals are saying to them, many also said that their appointment letters were difficult to understand (40%).

Many expressed the view that they cannot understand their appointment letters and have to rely on a family member or carer to read it to them. This suggests that an easy read format should be used to give those who have difficulties the chance to understand and read the letter for themselves. Many participants stated that having pictures and the use of a large font would be helpful.

The Department of Health (2010) stated in *Making written information easier to understand for people with learning disabilities*, that health care services should try to implement an easy read format within their practices through their appointment letters, medical information about treatments, and tests. The majority would also like healthcare professionals to speak slower and allow longer appointment times, allowing more time for questions and for the healthcare professional to meet individuals' communication needs.

To address and support individuals' communication and health needs, the Department of Health have created an easy read document called a Health Action Plan (HAP) that people with learning disabilities and/or autism can bring along to all health appointments.

*‘A Health Action Plan details the actions needed to maintain and improve the health of an individual and any help needed to accomplish these. It is a mechanism to link the individual and the range of services and support they need if they are to have better health’ (Department of Health, 2002).*

Only 16% of participants mentioned that they have HAPs that they use, but many stated that they forget to bring them along to appointments or need their HAPs updated. Reminders for people to bring their HAP with them to appointments should be included in easy read appointment letters . In addition, professionals need to be made more aware of the availability of HAPs and offered training.

The Barnet Learning Disability Service provides HAP training for carers so that they can create/update the plan without professional help. By providing this HAP training, which addresses the needs of the individual, it is making sure that a high standard of care is delivered.

## Conclusions and Recommendations

The central aim of this research was to determine the good and poor health experiences people with learning disabilities and/or autism have received from local healthcare providers. Overall, 70% of participants expressed in positive terms their experience of healthcare services they had received, but many of these participants also expressed poor experiences.

The research put in place three tools to aid with data gathering from a wide range of services, with the main requirement being that these tools were accessible for people with learning disabilities and/or autism. Information from these various sources was gathered to produce the findings of this report.

This research was designed to develop a better understanding of what people with learning disabilities and/or autism want and need in relation to their healthcare requirements. Breakdown of communication between healthcare professionals and clients was identified, which resulted in participants not understanding their health issues. This can lead into the development of poorer health for people and many reports state that extra support should be provided to give people with learning disabilities and/or autism opportunities to access information.

*'In order to support people with learning disabilities to understand their health issues, GPs and practice staff doing health checks should have good access to **accessible information** and any relevant research. The Easy Health website is an excellent source of accessible information on health, most of which can be downloaded for free. Go to <http://www.easyhealth.org.uk>' (Turner and Robinson, 2010)*

### Recommendations

- Easy read documents should be used.
- People with learning disabilities and/or autism should routinely be given additional time for their appointments.
- Healthcare professionals should create an easy read summary of the appointment that can be given to the individual, so that they can fully understand and remember why they attended, what happened and what the next stage is for them.

- An easy read feedback form should be created and handed out at the end of every appointment to monitor and keep a record of people's good and poor experiences.
- Healthcare professionals need to adopt a person-centred care approach to each individual.
- Some people with learning disabilities and/or autism have communication and understanding difficulties along with their health needs. The use of Health Action Plan training and learning disability and autism awareness training for health professionals would assist with this.
- From the findings of this research and papers used within this report such as *Meeting the health needs of people with learning disabilities* (Royal College of Nursing, 2006), there is a need and demand for a higher standard of care within hospitals and GP surgeries to make the experiences of people with learning disabilities and/or autism more dignified and as comfortable as possible.
- Having an acute liaison nurse within hospitals benefited many individuals and their families and bridged the gaps in the breakdown of communication between health professionals and some people with learning disabilities and/or autism. There were requests from many participants for another acute liaison nurse to be put in place at Barnet Hospital as, at the time of writing, this post is vacant.

### Conclusions

The researchers gave additional help to the participants regarding the issues highlighted within this research, signposting and offering further information and guidance to improve their healthcare needs through Health Action Plan referrals, and advising them on how to make a complaint and confront issues.

The researchers did face some obstacles when gathering the data. Engaging participants from a variety of organisations was a challenge, as was the full completion of questionnaires that were sent out to individuals. Sensitive information disclosed by participants was expected and this was addressed appropriately.

Many people with learning disabilities and/or autism feel they do not get the opportunity to express their voice in relation to their health needs. When people were given the opportunity to talk about their opinions and discuss their experiences through this research, this was not utilised to their full advantage as there was a lack of support from some organisations.

This research has enabled those that took part to have a voice about their health needs, which is a main aim of Healthwatch. Participants have enjoyed being involved and are hoping for an improved experience from healthcare providers.

People with learning disabilities and/or autism have higher health needs than the rest of the population. Therefore, research needs to be ongoing so that relevant issues can be monitored and improvements made in regard to healthcare provision. Many health issues are ongoing so there is a need to enable people with learning disabilities and/or autism to have a say about their healthcare.

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*Barnet Mencap and Healthwatch Barnet would like to thank Flower Lane Autism Service, Hft, Barnet Learning Disability Service, Oak Lodge School, and all the individuals who were involved in and supported this research.*

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**Project Manager:** Shelley Gibbons

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**5. Do you understand what they are saying to you?**

Yes                      Sometimes                      No



**6. Do health professionals do the following to help you understand (please tick):**

- speak slowly
- use pictures
- objects
- role play
- posters
- leaflets
- use language you understand

**7. When health professionals are examining you do they ask you for permission?**



Yes                      No

**8. How do you feel when health professionals are examining you?**

.....

**9. What could make you more comfortable?**

.....

**10. How do you find the overall experience of seeing health professionals?**



Please tell us about a good experience you have had:

.....



Please tell us about a poor experience you have had:

.....

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**Section 5**

This section is about Health Action Plans. A Health Action Plan is a booklet with all your health care needs in easy read for you to understand. You take this booklet to each appointment you go to.



**1. Do you have a health action plan?**

Yes                      No

If you would like a Health Action Plan please complete your details below:

Name: .....

Telephone No: .....

Address: .....

.....

**2. Do you take and use your health action plan?**

Yes                      No

**Section 6**

This section is about your aftercare you receive.

**1. Were you provided with information about the treatments or tests you might need?**

Yes                      No



**2. Did health professionals give you information about your health conditions and medicines?**

Yes                      No

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**3. Were you given a follow up appointment or visited at home by a health professional?**

Yes                      No

**4. How do you find the overall experience of aftercare you have received from health professionals?**

Please tell us about a good experience you have had:

.....

.....

Please tell us about a poor experience you have had:

.....

.....

**4. How would you rate the health care services you receive?**

Very Poor                      Outstanding  
1   2   3   4   5   6   7   8   9   10

**5. Do you have any suggestions for how health services could develop and be made better for people with learning disabilities?**

.....

.....

**6. Is there a healthcare professional you would recommend? If so, please tell us who and why you would recommend them**

.....

.....

Thank you for completing this questionnaire, everything you tell us is private and confidential.

If you tell us anything that may need to be followed up are you happy for us to contact Barnet Learning Disability Service? (please circle)

Yes                      No



If you are happy with the above, please fill in your name below

Name .....

Signature .....

Date .....

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**Section 7**

This is the final section. We would like to hear your views and recommendations of health care services, professionals and buildings.

**1. Please can you share your overall good experiences:**



.....

.....

**2. Please can you share your overall poor experiences**



.....

**3. Do you know how to make a complaint, and who to, if you are unhappy with the services you receive?**

Yes                      No



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# Appendix B – Consent Form





**Healthwatch Project**

Barnet Mencap is getting information for HealthWatch about **what you think about the HealthCare Services** you get.



In the **One to One interview** we will ask you questions about your good and poor experiences of going to the hospital, doctor and dentist.

To remember all the things you tell us, we will use:



Recorder



Written



Photographs



Photographs

Some of the things you tell us **maybe used in the HealthWatch project, reports, articles or presentations.**

Anything you tell us **will be treated in a private and confidential way.** Your name will not appear in any reports, articles or presentations.

Participants Copy





**If you tell us anything that may need to be followed up are you happy for us to contact Barnet Learning Disability Service? (Please tick)**



YES



NO

**If you are happy with all the above and would like to take part please sign below.**

I ..... agree to be part of the Barnet Mencap Healthwatch project.



Your name: \_\_\_\_\_ Date of birth: \_\_\_\_\_



Signed: \_\_\_\_\_ Date: \_\_\_\_\_



Researcher: \_\_\_\_\_

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

Participants Copy
Autumn 2013

All forms are A4 size

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