
Meeting	Health and Well-Being Board
Date	20 th March 2014
Subject	Healthwatch Barnet /Barnet Mencap Report “Talk to Me”
Report of	Healthwatch Barnet
Summary of item and decision being sought	This paper provides the Board with the report from Barnet Mencap, charity partner to Healthwatch Barnet, on their research into the needs of people with learning disabilities using health services. The Health and Well-Being Board is requested to consider and comment on the recommendations. A separate meeting will be established with Clinical Commissioning Group Board and staff members, Barnet Mencap and Healthwatch Barnet staff to consider the potential implementation of the recommendations, in detail.

Officer Contributors	Ray Booth, Barnet Mencap Selina Rodrigues, Head of Healthwatch Barnet
Reason for Report	This report provides the Health and Well-Being Board with Barnet Mencap/Healthwatch Barnet’s report, “Talk to Me” which highlights findings and recommendations from the recent research into the needs of people with learning disabilities using health services.
Partnership flexibility being exercised	N/A
Wards Affected	All
Status (public or exempt)	Public
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Appendices	“Talk to me”- A Report on the local healthcare experiences of people with learning disabilities and/ or autism in the London Borough of Barnet

1. RECOMMENDATIONS

- 1.1 That the Health and Well-Being Board notes this update report and provides comments on its recommendations.**
- 1.2 That the CCG representatives provide an update on the posts of Acute Liaison Nurse (currently vacant) and Health Facilitator for Learning Disabilities (contract due to end in May 2014) (see also Section 10.3).**

2. RELEVANT PREVIOUS DISCUSSIONS AND WHERE HELD

- 2.1 At its meeting of 23rd January 2014, the Health and Well-Being Board noted a paper from Healthwatch Barnet and a verbal report from Barnet Mencap on the findings and recommendations of recent research into the health needs of people with learning disabilities. This paper provides the full report.

3. LINK AND IMPLICATIONS FOR STRATEGIC PARTNERSHIP-WIDE GOALS (SUSTAINABLE COMMUNITY STRATEGY; HEALTH AND WELL-BEING STRATEGY; COMMISSIONING STRATEGIES)

- 3.1 There is a specific target in the “How we live” chapter in the Health and Well-Being Strategy to increase year on year the number of people with a learning disability who have had an annual health check.
- 3.2 Through its representation on statutory bodies and its ongoing relationship with health and social care fora and residents, Healthwatch Barnet will contribute to the development and delivery of the Health and Well-Being Strategy and other relevant strategies and initiatives.

4 NEEDS ASSESSMENT AND EQUALITIES IMPLICATIONS

- 4.1 Barnet’s JSNA (2011-15) estimates that there are 6,336 residents aged 18-64 with a learning disability in Barnet. The JSNA states 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. Improved survival, rising birth rates and growth among communities at higher risk of learning disabilities (for example, the South Asian community) all mean that this is likely to be an area of growing need locally”.
- 4.2 The JSNA also states that people with learning disabilities “have much poorer health, shorter life expectancy and a greater risk of early death. Problems are caused by a high incidence of congenital defects, respiratory disease, and epilepsy, but people with learning disabilities also suffer from high levels of incidence of schizophrenia, psychiatric disorders and dementia. In addition, adults with learning disabilities are more likely to be exposed to poverty, unemployment and social disconnectedness. There are also widely reported issues surrounding poor diets and nutrition, obesity and a lack of physical activity”.

- 4.3 One of the core aims of Healthwatch Barnet is to ensure the views and experiences are heard and represented of those groups with protected characteristics under the Equality Act, and with under-represented communities and individuals. Healthwatch Barnet runs targeted activities with people from protected groups (as defined in the Equality Act 2010) and its work is further enriched by our developing engagement programme with children and young people and older adults. As a charity partner, Barnet Mencap provides expertise and engagement with people with learning disabilities to support Healthwatch overall aims and objectives.

5. RISK MANAGEMENT

- 5.1 A risk analysis of the recommendations will be undertaken as part of the meeting of Barnet CCG, Barnet Mencap and Healthwatch Barnet.

6. LEGAL POWERS AND IMPLICATIONS

- 6.1 Section 182 to 184 of the Health and Social Care Act, 2012 and regulations subsequently issued under these sections, govern the establishment of Healthwatch, its functions and the responsibility of local authorities to commission a local Healthwatch.

7. USE OF RESOURCES IMPLICATIONS- FINANCE, STAFFING, IT ETC

- 7.1 As recommended by Dr Debbie Frost, Chair of Barnet Clinical Commissioning Group, a meeting of the CCG, Barnet Mencap and Healthwatch Barnet staff will be established to consider the recommendations and a cost-benefit analysis to determine how the recommendations in this report could be implemented. An update will be provided to the Health and Well-Being Board in due course.

8. COMMUNICATION AND ENGAGEMENT WITH USERS AND STAKEHOLDERS

- 8.1 This report was discussed at the Learning Disability Partnership Board on 18 March 2014. It will also be circulated to other organisations working with people with learning disabilities in the Borough and will be available on the Healthwatch Barnet website.

9. ENGAGEMENT AND INVOLVEMENT WITH PROVIDERS

- 9.1 This report has been forwarded to Barnet CCG and will be sent to other relevant statutory service staff and stakeholders, as advised by Barnet Mencap and the Health and Wellbeing Board partners.

10. DETAILS

- 10.1 Background

A total of sixty-three people, with learning disabilities and autism, were consulted through focus groups, questionnaires and a survey. These 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.

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.

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.

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.

10.2 Key findings

The report provides full details of the findings from the research, including quotes and examples of the positive and poor care received. Some of the key findings are as follows:

- 43% shared a good experience about their healthcare. This included health care professionals ‘willing to go that extra mile’ for the individual, reassuring them and making sure all their health needs were being met.
- 38% of participants stated that they use walk-in centres in the borough, many using the Finchley Memorial Walk-in Centre. 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.

- 55.5% of participants shared a poor experience. Many commented that receptionists were not always sympathetic and patient
- 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.
- 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.
- Many participants did state that they find it difficult to understand what is being said to them (51.5%)

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 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.

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.

10.3 Key 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.
- The Board and Barnet CCG are requested to provide an update on the post of CCG Health Facilitator for Learning Disabilities. This was a one-year post and the period of employment will cease in May 2014. Healthwatch Barnet values the support Barnet CCG has provided in funding the post. We understand there is still outstanding training and actions that can still be delivered, that would help deliver quality and efficient services for people with learning disabilities in the Borough.

10.4 Conclusions

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. 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.

Considering the health needs and health support needs of this community, Barnet Mencap and Healthwatch Barnet would request that members of the Health and Well-Being Board give full consideration and support to the recommendations of this report.

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.

11 BACKGROUND PAPERS

11.1 None