

Health Services for people with Learning Disabilities (PWLD)

An update from Brent Mencap

November 2012

Brent Mencap received funding from Brent NHS to organise the Big Health Check Day at the end of May in order to inform Brent NHS Self Assessment Framework (SAF). Workshops/consultation groups were facilitated around the following themes:

- Keeping healthy and safe
- Screening/information
- Consultation/Engagement
- Access to healthcare

In addition there were short presentations about NHS changes, equality and reasonable adjustments, health promotion/prevention, safeguarding as well as feedback from pwld and carers, a number information stalls and exercises to break up the day.

In excess of 88 people attended with a good mix of professionals, carers and pwld. The day was very well received and we have funding to organise another day in 2013.

When validating the SAF with NHS London it was found that there are quite a few red areas. One of the main problems is the lack of exact figures. In order to have the right strategies in place and to deliver the necessary services one needs to know one's population. It is also a safeguarding issue.

Other areas were learning disability commissioning, governance. Robust primary care systems need to be in place to keep pwld out of hospitals.

The Health Action group, a sub group of the Partnership Board, is working jointly with the NHS and other partners. Brent Mencap feels this group is important and has made sure that it continued to meet bi-monthly. We are hoping to get funding to continue this work beyond March 2013.

One learning disability liaison nurse has been in post for about one year but she is still working from an office, now at the Kingswood Centre, rather than being based in one of the hospitals. There are plans for a further acute liaison nurse but more hospitals will need to be covered. The role of the community learning disability nurses is still not quite clear or readily accessible. They are now managed by CNWL and a new service specification is being drawn up with one nurse being attached to each of the CCG localities.

Hospital/health passports are going to be piloted by the acute sector for 3 months.

Funding to continue with a focus group for carers and pwld was granted only recently, therefore the group has not met yet. However, there is now a patient focus group for pwld meeting at Central Middlesex Hospital looking at issues in the hospitals. So far this group has met twice.

Brent Mencap contributed to the JSNA consultation and still participate in the Obesity Strategy group. Members from our Disability Rights and Politics group have been supported to contribute to consultations and attend relevant meetings. Unfortunately this project will end at the end of January 2013. Brent Mencap will represent the voice of pwld on the EDEN committee.

Training for GPs and other health care staff had been put into a bid last November but due to several changes in personnel nothing has been agreed, there is, however, some movement. Also, the Royal College for General Practitioners has developed an online training course. Brent Council also offers in-house learning disability awareness training. 1 councillor, 2 council officers, 6 social workers and 1 NHS staff attended training provided by Brent Mencap in the last 6 months. The acute liaison nurse trained some staff in the acute sector but without the input of service users. One GP practice wanted to send staff to training but we were unable to accommodate them.

We still receive occasional telephone calls from GPs and even more calls from social workers who want to refer someone with a learning disability for either diagnosis or because they need a specific service and are unsure who to refer them to.

Visits to GP practices and a very recent result of mystery shopping at Central Middlesex Hospital found that whilst staff are very helpful and their manner of communication is respectful and warm there is very little accessible information in wards, the diabetic centre or the pharmacy and the signage is still very confusing, hard to understand and impossible to follow for someone who has little or no literacy skills. For example the waiting system for blood tests has no pictorial stimulus, it just says 'please take a ticket and wait' or using words like haematology without the easier to understand 'blood test' alongside it.

The diabetic department had a photocopy of the 'Getting it Right' charter displayed on the notice board.

The talking lift was much appreciated.

We are unable to comment on the work of the Health and Wellbeing Board regarding the acknowledgement of the needs of pwld who would need additional care as we are not involved in those and no information has been passed on to the voluntary sector.

Nor are we privy to safeguarding arrangements for pwld in homes within and outside of Brent and their inspection.