

Learning Disability Wellbeing Programme Engagement Report

People with a Learning Disabilities (LD) are expected to live on average 20 years younger than the general population. This is partially due to increased risk of coronary heart disease, respiratory disease and epilepsy, however many of these deaths can be prevented with the right support.

Haringey CCG and Islington CCG have carried out lots of engagement work with their respective local communities to find out what people with LD think of NHS health services.

Both Islington and Haringey are diverse boroughs and the CCG utilise good relationships with local voluntary and community sector organisations to hear from a broad range of local residents about their experience of health services.

Haringey and Islington have spoken to LD service users through organisations, such as Centre 404 and Elfrida Society, to gather LD service user's views about their experience of health and care services.

This report describes what LD service users have said about health services. LD service users have highlighted that health and care services are often thought not to be disability friendly. This is largely due to poor communication, difficulties they experience accessing services, long waiting times, complicated referral processes, and services not being properly integrated or meeting people's needs at every stage of their patient journey.

The report lays out some recommendations at the end. The following reports were cited:

- Centre 404 engagement report
- Integrated Care Research report 13/14
- CCG annual Community research 14/15
- Primary Care Extended Hours insight
- NHS 111 and Out of Hours insight
- Care My Way Community engagement 15/16
- HealthVoice Islington data 15/16

Communication

- LD service users have told us their experience of services would be improved if more staff received communication training for working with LD service users. Health and care professionals should be aware of a person's learning disability and make appropriate adjustments, such as offering easy read information, tailoring communication style to suit the person and allowing more time during appointments to explain information in a way that is easy to understand.
- LD patients have said that the difference in communication style from staff who had received specialist training to work with people with autism and other learning disabilities was noticeable.
- LD service users and their carers reported that the current system to call to book an appointment over the phone is very confusing. Managing an automated service and other factors, such as needing to call between certain times, only adds to the confusion. Using the NHS 111 service is similarly

confusing. LD service users reported difficulties understanding complex language, are often misunderstood by telephone handlers, felt pressure to answer questions quickly and to remember a lot of information.

- Patient facing information such as leaflets, websites and posters were said to be difficult to understand for a LD service user.

Access

- LD service users said that accessing appointments is difficult for a number of reasons. Busy waiting areas and long waiting times (in GP practice, A&E and walk in centres) often cause confusion and agitation for LD patients.
- Slow referrals and long waiting times for appointments are stressful for LD patients.
- LD patients living in supported accommodation require adequate support from the staff in community based services to feel safe enough to carry out daily tasks such as shopping or going out. Antisocial behaviour in local areas or fear of falls are said to be reasons LD people feel unsafe.

Integrated services

- LD service users reported that as a whole care does not currently feel integrated. They reported feeling frustrated and overwhelmed by a large system. Toing and froing between different services was described as stressful and it was felt that an integrated system where services are linked, people don't have to repeat their story, where clinicians have a holistic view of health and care needs is a good service.
- It was reported that hospital, GPs / community services and social care services do not communicate well with each other. This meant that LD service users sometimes arrive for their appointments without the adequate support put in place for them, for example information not being in plain English or they are required to repeat their story, which can be stressful and time consuming.
- There were reports of positive experiences of integrated services in early years but when children go to school parents reported a fragmentation of services. For example LD services for people between ages of 0-5 were reported to be excellent, but were thereafter reported to be fragmented. Likewise it was reported that there are difficulties in transitioning from young person's services to adult service. At age of 16 it was felt there is limited support available and having continuity of staff is helpful, but regular changing of staff can be very problematic. Additionally a person's condition may not be deemed severe enough to be referred for a particular service and yet they still have unmet support needs.
- Occupational Therapy services were reported as being really important and useful services for those with LD, however it was felt that as a service it is under resourced. The continuity of service could be improved as there is often no check-up after the initial consultation or if the child is deemed to 'not meet the criteria' no alternative service is offered. Parents/carers reported difficulties having their child or person they care for diagnosed quickly. Often parents are not seen straight away and there can be a long time between the initial consultation and therapy/support/OT sessions.

Recommendations for LD services

- More staff to receive training to improve communication style with LD service users and to increase awareness of how people with LD express themselves differently. As such listening, understanding, patience, empathy and respect are very important attributes that improve the way staff communicate with LD patients. Talking directly to the patient (not the carer), using language the person understands and practicing patience, i.e. not rushing appointments, were raised as key components of good communication by LD patients.
- Improve waiting times for GP and hospital appointments, and for referrals. Longer appointments allow time for communication between clinician and patient so as to better meet the needs of LD service users, who may take longer to explain their condition.
- Provide a more seamless service, particularly transition of services between 0-5 years old and school age, and the transition between young people's and adult services.
- LD patients to be prioritised to avoid extensive waiting time.
- Cancellation of appointments should especially be avoided with LD service users as it can take a lot of effort to prepare for an appointment and can cause confusion if it's cancelled at short notice.
- Better support for LD carers.