**Meet the Care Quality Commission with Shaping Our Lives Wednesday 16th March 2016**

**Notes from the Regional workshop with people with a learning disability**

**In total 19 people with learning difficulties attended.**

There were three additional support workers provided by the organisers plus a transcriber. Five members of CQC staff also attended.

**Introduction**

The event was organised by Shaping Our Lives on behalf of Change. Shaping Our Lives has a close working relationship with People First Lambeth who helped to promote the event. Although the event was well attended with 19 people with learning disabilities taking part with the support of several local services, there was a lot of anxiety from people with learning disabilities that if they attended and made references to services that there would be repercussions. The event was only a success because of the reputation of the organisers and trust that has been built through ongoing partnership work. It should be stressed that ensuring people attend events like this takes several personal approaches and reminders.

One organisation enquired about attending with people who have challenging behaviour. The service worker told us the people could be violent. Unfortunately we were not able to make arrangements for these people to be involved safely in the time and resources available. The worker said they would try and attend on their own but did not come on the day possibly because they were too busy.

**General points**

* There was low awareness of what the CQC does.
* There was cynicism about the action CQC will or can take and how much they listen to people with learning disabilities.
* People find making a complaint difficult for a number of reasons: they do not know the procedure, they are frightened to because of repercussions, they are not listened to and/or taken seriously.
* Independent advocates are important if people need support to make a complaint especially if this is about their supporter, personal assistant or any other person they come in to contact with through services..
* Accessible communication is essential if people with learning difficulties are going to have equal access to health and care services.
* There is poor awareness of the ratings system and no one reported having seen a displayed rating in a service.
* Waiting for appointments and waiting at appointments causes anxiety, distress and sometimes anger.

**Issues raised about what CQC does and their processes**

Participants expected CQC to monitor day centres. The issue of who monitors supporters is also unclear to people. This means people don't know who to go to if they have concerns about these services.

CQC should have easy to read inspection report summaries, information available for people who have visual impairments and should consider making films of CQC findings.

Written words with pictures to illustrate the words are useful for some people.

How does CQC deal with whistle-blowers now, are they faster at acting since Winterbourne View?

How long is CQC prepared to let a service carry on if it is not very good?

**CQC’s inspections**

People felt It is good to do unannounced inspections so services don't know CQC are coming.

CQC need to check that care staff are police checked and that they do not shout at people as this is abuse and leads to traumatic experiences.

**Adult social care**

There is concern about how to complain about support workers and other staff from services and that service users do not know who to go to.

For some people living independently means people don't get enough support. There was an example of a young man who said there were not enough staff supporting people in the flats where he lived - and some people were not ready to be left as much as they were.

The issue of food for people in supported living came up. It was felt people are often not supported enough to learn to cook for themselves and that people are often frightened of using the cooker. It was felt there is great reliance on ready meals - so people are being supported to put ready meals in the oven but not to learn to cook for themselves.

There was a good example of a supported living service who sent a weekly note to their clients with information about the staff rota for the next week and who would be coming to support each person. The list included staff photos. This was very reassuring to the clients so they knew who to expect and if someone they didn't know came to the door they would know not to answer.

**Hospitals**

People thought it was good when hospitals let them know as a reminder that they had an appointment. But they also felt this should be a phone call for people with a learning disability as many people found text messages difficult to understand.

There was a specific example of someone going to St Thomas’s after having two blackouts who was told to clean up her own sick and told ' it's not a hotel you know'.

There was another example of a woman with a learning disability who needed to go to A&E from her doctor’s surgery as she had swollen feet. She had to get to A&E on foot and the bus without assistance which was very difficult for her. No arrangement was made to make this journey easier.

**Primary care**

Accessing GP appointments was generally found difficult. This may be because:

* the telephone rings for a long time and nobody answers and/or you have to keep ringing until you get through;
* there is a first come priority service and people cannot get there early enough (this may be because their support staff are not available);
* using the telephone is not accessible and there is no other accessible method;
* There is a general concern that GP appointments are too short and that people may not be able to see their usual doctor in walk-in clinics. Consistency is often important for people with learning disabilities.

Many people felt it was difficult to get through to their GP practice on the phone and to get an appointment, and it should be easier for people with a learning disability to do this. People also wanted to see the same GP and know they would be able to. This made it harder to get a timely appointment.

There was an example of a GP giving double appointments for people with a learning disability and this was seen as a very good practice.

Some doctors were felt to be impatient and rushing people with a learning disability. People reported that doctors who speak to their supporter or carer rather than them. Good practice is to make eye contact and explain points that are difficult without using jargon or medical terms.

There was a view that receptionists can be rude or lacking in understanding of people with a learning disability, even when nurses and GPs can be very good in the same practice.

The language doctors use is often difficult for people to understand (in GP and hospital settings) and there were several people who felt doctors talked to their supporters rather than them.

There should be more training for doctors and reception staff by people with a learning disability. Several people had been involved in training including a theatre group that preformed to medical students. Training prevents practice that offends unintentionally.

The touch screens in GPs were difficult for people to use and the display boards writing people's names up were also inaccessible for people who find reading difficult. An example was given of a computer check-in system and feedback form at a hospital that were not accessible.

There was an example of someone attending their GP practice with another service user (from the same group home) with one support worker between them, but the practice didn't put the appointments adjacent to each other so they all had to stay at the practice all morning.

One woman described how she liked to get to her GP practice early as if she was late she couldn't be seen. But if she came early the receptionist would tell her to go home and come back again. She found this stressful and explained she just wanted to wait and read her book.

One comment was made that people were not being diagnosed properly or fully (with a particular reference to mental illness) and this can lead to them not getting the right support and care.

There was a good example of a pharmacist who manages someone’s medication with a daily pill sorter which is locked and the pharmacist keeps the key. (This was probably in a service provider).

**Other points:**

There was broad agreement that staff don't listen to people with a learning disability in some services.

It was suggested that the number of young people not getting identified as needing support early enough is increasing.

Staff and support staff should not shout at people with learning disabilities as this makes them frightened and anxious, sometimes leading to embarrassing accidents, a loss of confidence and isolation.

An example was given of people with learning disabilities working together and sharing skills to make them more safe, such as people going out in groups where some have good traffic skills and could support and train others in road safety. If people are continually supervised then they don’t learn to do it by themselves.

There was experience of people working as buddies and supporting other people with learning disabilities to get to services and home again.

Someone reported having to pay to access their care records and waiting 6 months, and it was not possible to complete the request process without help, which could compromise confidentiality.

Transport and support is needed if someone is sent from one appointment to another in different locations.

**Specific service feedback**

A I went to the GP. I was with someone else from the same home. We were sharing a carer, but they didn’t put our appointments together so I ended up waiting the whole morning.

A I went to St Thomas’s hospital and they left me waiting a long time for my appointment. I got angry waiting.

A I had a small operation and they were really nice to me. They kept checking on me.

A Kings College Hospital. They treated me, my mum, and my sisters. It is very clean. The doctors treat me very well. They treated me quickly. I like it there.

Shaping Our Lives promoted this event via Twitter and sent information about it to relevant newsletters: Equality and Diversity Forum, Inclusion, Healthwatch newsletters and Shaping Our Lives noticeboard.

About 20 organisations in London were invited to attend.

People First Lambeth promoted the event to organisations they have contact with and followed up invitations in person.

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