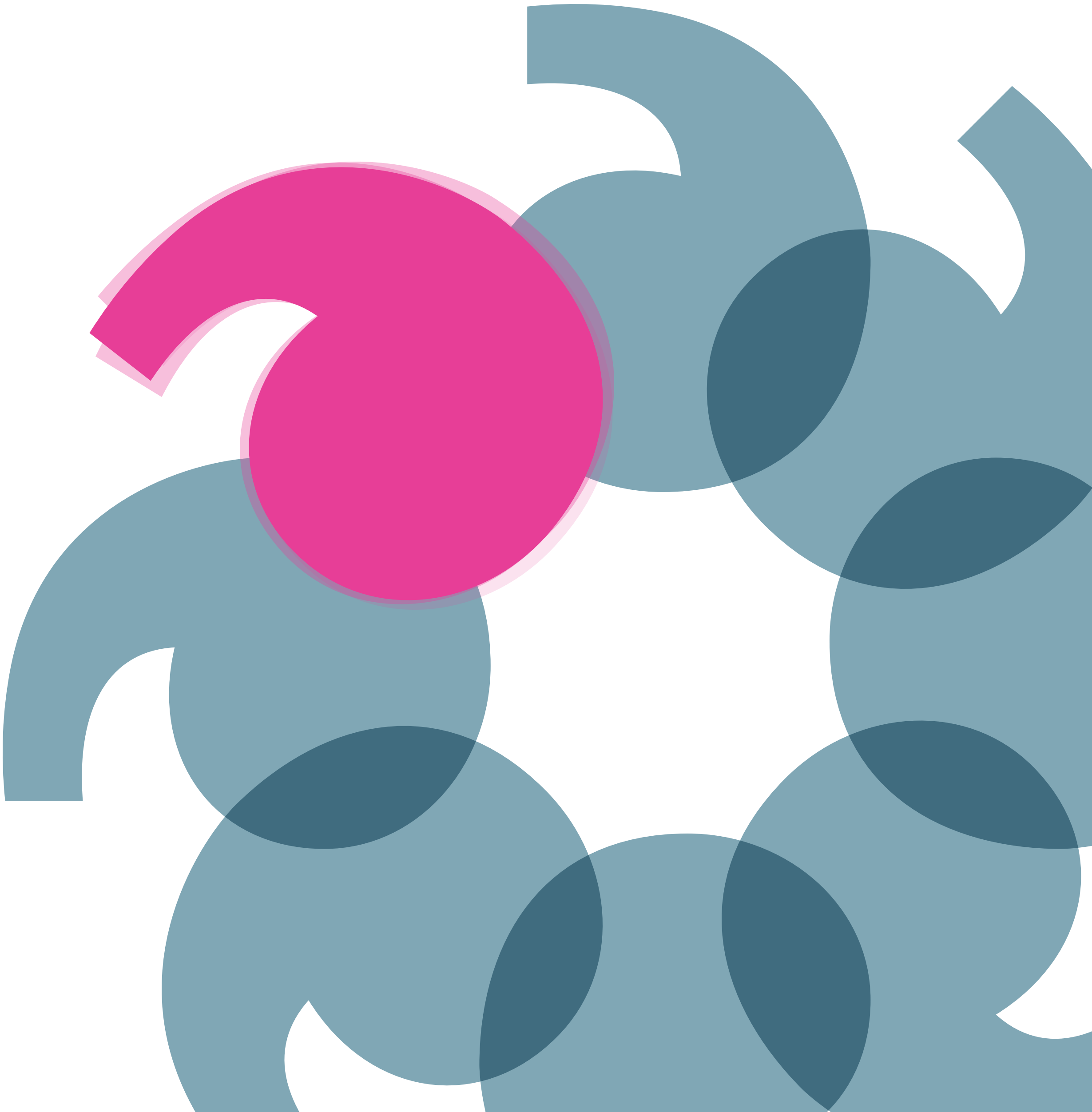
THE Elfrida SOCIETY

healthwatch Islington

Experiences of services provided by Whittington Health

Focus groups with residents with learning disabilities



Healthwatch Islington is an independent organisation led by volunteers from the local community. It is part of a national network of Healthwatch organisations that involve people of all ages and all sections of the community.

We gather local people's views on the health and social care services that they use. We make sure those views are taken into account when decisions are taken on how services will look in the future, and how they can be improved.

https://healthwatchislington.co.uk

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Introduction

Whittington Health commissioned Healthwatch Islington to deliver a series of discussion groups during May 2019. The Trust were interested to learn about residents' experiences of some of their services, and about the ways in which people liked to access services.

In order to make sure that the views of residents with a learning disability were represented, we worked with the Power and Control Group at the Elfrida Society.

The Elfrida Society facilitated two focus groups with Islington residents with a learning disability. Specialist materials, including photos and show-cards were provided and support workers were on hand to provide guidance and help to enable participants to engage. The questions that were used can be seen in the appendix.

The issues we explored on behalf of Whittington Health were as follows:

1. Urgent and Emergency Care services
2. The use of digital technology in healthcare, and what affects people's attitudes to this
3. Whether people prefer services closer to home or closer to a hospital and what affects that choice

The two sessions held were supported by the same lead facilitator, but the format of the session varied according to the needs of the service users, and this report reflects this.

The individual comments are numbered so that it is possible to identify multiple comments from a single participant. Wherever possible, direct quotes have been included to bring out the voice of people with learning disabilities.

Feedback we received from residents with a learning disability has also been included in a separate report on the entire engagement exercise, which has been shared with Whittington Health and can be accessed from our website.

The first focus group

Daylight Resource Centre, 15 May 2019

Participants: 8 people with Learning Disabilities and 2 support staff

All of the service user participants had had some experience of using the Whittington Hospital as an emergency and had something to say about it. The meeting lasted 2 hours.

Urgent and Emergency Care at the Whittington

Participants had been at the Whittington for a variety of issues, mainly from falls, sustaining broken bones, cuts and with a variety of other symptoms. Many described their experiences of being taken in an ambulance.

- About their experience on arrival, there were a couple of comments:
  Long waits in A&E (1)
  'I froze at the front desk, but I didn't have to wait long' (3)

- Nearly all made positive comments about the medical staff:
  'All doctors and nurses good' (2)
  'Doctors and nurses were nice' (4)
  'Doctors and nurses were good' (6)
  'They talked to me, told me what was going to happen' (6)
  'The doctors took care of me. They were kind' (6)
  'They looked at you when talking to you' (2)
  'The doctor sat in front of me. He was very funny and I told him all about Daylight' (3)
  'The nurse was great, very engaging and I was impressed' (3)
  'The doctors spoke to me and my mum together' (4)
  'Told me I was going to the ward on a wheelchair' (4)
  'They helped me fill in the form' (7)
  'They stayed while I had my x-ray'
  'Doctors were good and friendly' (8)
  All spoke to her [the service user], very happy and very calm (staff 1)

- What was good about the visit?
  'They understood my autism and anxiety' (1)
  'Good being discharged quickly' (2)
  'I was in hospital for less than an hour [with cut on hand]' (3)
  'They put in me in a quiet room … I was swearing 'cos it hurt' (7)
  'Really good' (staff 1)
  'My ex-boyfriend went because of a mini stroke – they were good at talking to him' (7)

- What wasn't so good?
  'Had to wait a long time' (1)
  'Don't' know what was bad about it … I was sick and didn't like it' (5)
  'Difficult to find [as staff] – better signposting or maps would be good' (staff 1)

- What could be improved?
  ‘The food is terrible, small and doesn’t taste good’ (2)
  Signposting, as above (staff 1), only one mentioned the wait.

Summary: what was most important to respondents

There was most comment about the attitude of staff, which was very positive. The participants talked about what happened to them, the reception they received as well as treatment, about requiring x-rays, scans and injections, and that these had been explained to them (2,4,5,6,7)

They also had positive experiences that impacted on them:
‘I gave up smoking after it’ (1)
‘I know if I get an infection I have to go back straight away’

Using technology to access healthcare

A few of the participants had views on using technology and understood how it could be used to support their healthcare. One commented that they ‘get text about appointments, it’s good, I like it’ (1).
However, there were mixed feelings about video GP consultations:
‘I like to see my doctors in person, not over the phone’ (2)
‘My mum uses the phone, I like to see them face to face’ (3)
Though as one acknowledged in this discussion, ‘I hate waiting a long time for appointments’ and ‘I would like to see the doctor sooner’(4).
One respondent stated that ‘I like them using computers to look at my records’.

Summary: what was most important to respondents

Five people were involved in this part of the discussion, but their views were quite limited. Those who did contribute placed value on seeing their doctor in person; for example:
‘I went last week and it was good – the doctor talked and listened to me’. (5)

The responses suggest that further discussion is needed with people with learning disabilities and their carers/relatives to explain and respond to concerns as new systems are implemented.

Health centres and care closer to home

Five people took part, having used local centres, and one member of staff.

The participants valued the following about them:
‘Explains and helps me with my tablets’ (2)
‘Made you feel better’ (2)
‘Won’t let me leave until I’m calm’ (2)
‘When I have to have blood taken, I see the same nurse, because they don’t hurt me’ (2)
‘Feel much better, the doctors talk to me’ (3)
‘It’s good when I go’ (4)
‘I like to see a lady doctor’ (4)
‘I like to go’

But the staff member commented:
‘Lots of family have said long waits for appointments … too long if not an emergency.’

Summary: what was most important to respondents

The participants reported positive experiences at their local health centres. Seeing the same member of staff was one factor and being known by the practice. This may prove reassuring to patients with learning disabilities, but further exploration of how this could be achieved may be required, as the discussion was not able to probe the detail.

The second focus group

Leigh Road Supported Housing, 17 May 2019

Participants: Over the course of the session, there were 12 service user participants, most of whom were residents at Leigh Road, but who also included two members of the Power and Control Group who helped to facilitate the session. There were three support staff and a member of staff from Centre 404 who also contributed to the discussion at the end of the session.

The focus group lasted for two hours in total, although not all of the participants were present throughout. Some had very limited verbal skills and their support workers were on hand to talk about the service user's experience in those instances. All three of the key topics were covered.

Urgent and Emergency Care at the Whittington

There were a range of experiences from the participants, a 'mixed bag' of good and not so good stories:

'I fell out of bed, I was bleeding, and went in the ambulance. It wasn't a long wait, and I saw a doctor. They were friendly and kind and nothing bad about it.' (3)

'I broke my leg. It was so painful, I was crying. But they were very nice. I was so scared with the needle. I hate those needles.' (10)

'111 [NHS urgent care phone service] said I had to go to hospital. Was there 7 pm to 3 am. They didn't know about me.' (5 with support worker)

'I've been a couple of times, one was more of an emergency than the other [diabetic hyper]. It was a long, long time. They were kind to me, they did their best to help us. I did not see the LD (learning disability) nurse at the hospital.' (4)

'Because they knew about his situation we were seen faster – but there was two hours until we were seen still. There was nowhere quiet to wait in the meantime.' (support worker)

'The learning disability nurses don't work at weekends and public holidays, and people may not know the names of the person anyway. I have had treatment for cancer, and have found that the learning disability nurse has moved on and I haven't met the replacement yet.' (6)

'I went a long time ago – maybe six years? It was alright though, not bad.' (8)

'I don't want to talk about it. It wasn't good. It was upsetting. But the doctor was nice.' (12)

'My experience is that the triage people can be very rude to people. We need the LD nurse – perhaps pictures of them up for everyone to see. We have been working with the LD nurses to provide easy-read info, like hospital healthcare passports.' (7)

‘I always thought people with learning disabilities got seen as soon as possible – but you’re telling me this is not the case. We really need to use the hospital passports [all service users at the session had one], so that we are not sitting there with everyone asking for our details all the time – should be on the system in the first place, so they know all about it.’

‘My experience of taking people with learning disabilities to hospital has been poor. For example, the GP said the service user would be seen straight away, but after a seven hour wait we were told to come back the next day. Why does this happen? There is a lack of communication between the GP and the hospital and maybe within the hospital as well.’ (Centre 404 worker)

‘[Service user 12] has PTSD from her stay in hospital. She now has an advocate who might be able to say more about this.’ (support worker)

Summary: what was most important to respondents

It is clear that experiences could be positive, negative, or both, and might depend on the circumstances of the specific visit. It was important that hospital staff were aware of the healthcare passports, and – as far as possible – ensured that patients with learning disabilities were seen quickly and handled sensitively. There were some very long waits, and it is argued that there should be a degree of priority for those with learning disabilities, e.g. a quiet room available while waiting. The hospital learning disability nurse (if in post) would seem to be pivotal, and who they are should be widely communicated.

Using technology to access healthcare

Service users at the session had varied access to mobile and digital technologies. A number had their own tablet and phones which they used for text messaging (1 with support) but others said they just used the ‘house phone’ (2, 3). Others would use a laptop or desktop computer to keep a calendar, for example (4). Support workers noted that people with autism don’t have their own phones.

Support workers used a variety of these devices, both for their work and in their work with the service users. Everything to do with the service user’s care would be logged electronically, so that others could see what’s happened, including medication, food and fluid charts. However, support workers generally used computers rather than apps on their mobile devices, which limited opportunities for booking (medical and other) appointments on line, ordering prescriptions etc.

One of the support workers said they would like to see all service users with personal access to a computer. But others said that the computers available were too old and not able to keep up with technological developments, and so mobile devices would be better.

- In terms of video calling with their GP, there were just a couple of comments, as most did not know about how this would work:
  'I would use this.' (4)
  'Didn't know it was a thing. Yes, I would definitely use it with my service users.' (support worker 1)
  'Yes, I would.' (support worker 2)
  'I would if it worked. What happens if you run out of battery, and you can't record important information because of that? I am not sure what would help people to use it.' (support worker 4)
  'It could be good, but not with current systems.' (support worker 3)

- In terms of sharing records, one service user (2) said they would be ok with it, another (6) was concerned about data protection for people.

- Support workers were split between those who were keen, and those who were wary of the idea:
  'It sounds a really good idea to keep everyone up to date.' (support worker 1)
  'I would for myself, but not for the service user. I am a bit worried about it.' (Support worker 2).
  'It all depends on who they share them with, and why, and what it's used for. Need to know more about this.' (support worker 4)

Summary: what was most important to respondents

From the discussion, which was limited in terms of input from service users directly, it was clear that access to new technologies could benefit those caring for people with LD, perhaps more so (at this point) than service users themselves. A lot would depend on the cost of adoption and having the right equipment in a fast-changing technological environment. In terms of sharing records, what this would mean in theory and practice would need to be examined further and fully communicated to convince people to rely on it.

Health centres and care closer to home

The participants made a range of comments about their experience of local health centres and GP surgeries [all the Leigh Road residents used the same practice]:

'The support worker takes me to the doctor. The doctor asks me questions and they do listen to me. All good.' (3)

'They can't give you an appointment for two weeks.' (7)

'I don't like to go to the doctor. But they are very nice. It might be better if they came here.' (2)

'The doctors are very good, they talk to the staff and to me, both of us. They do listen to me yes, if I want to say something. But you have to wait a long time sometimes.' (4)

‘I don’t want to talk about it, because needles make me feel bad.’ (10)

‘Most people don’t want to go. It’s not always easy, and it’s always very busy. They need to see them on time.’ (support worker 1)

‘It’s difficult with injections like the flu jab – they can refuse at first, but the doctors do offer the spray. With [service user 1] we worked it out in the end, but it’s not always easy. Both her mum and support worker need to be there.’ (support worker 1)

‘The doctors really listen to the service users and their carers. One agreed that the Cardiff Health Check is too long. Some doctors handle people well, some not so well. Service users can get very upset and refuse to do it. We could do with more help with the Cardiff form.’ (support worker 2)

‘The doctors do come out for those that are wheelchair based. The doctors are very kind and the usual doctor knows [the service user] so it works better. (support worker 3). It can be quite a long wait when you go there 20-30 minutes, and it’s always very busy. And you are always in the main waiting area, nowhere quiet to go.’

‘It was very good, now it is not so good. Old GP would come out to them, and see them very quickly. The current GP doesn’t know them very well, and doesn’t give them enough time for their appointments. They need more training in learning disability issues and a better understanding of what people need.’ (support worker 4)

‘It would be better if the doctors could come here (Leigh Road), where there are lots of people with learning disability. The service user would be at home and feel safe and the environment would be better for everyone.’ (support workers 1, 2 and 3)

‘Not having to wait so long is the key thing. How can you make this happen? Maybe the surgery could call ahead and let us know the exact time, because it is good to have a private space, e.g. when service user needs suction – there is currently no room and we have to go to the toilets to do this.’ (support worker 3)

Summary: what was most important to respondents

Going to the local health centre could clearly be stressful for all involved, and there was a well-supported suggestion that the GP could visit the setting instead where service users would feel more comfortable. There were concerns about waiting times and there being no privacy or alternative (quiet/private) space.

The service users who contributed seemed to like their doctors, but not necessarily the procedures. Some doctors appeared to deal with people with learning disabilities better than others and more training was suggested so that all doctors better understood the needs of people with learning disabilities and would be able to put in place (often simple) measures to support them accessing care.

Conclusion

Service users and their support workers were able to engage in the discussion at both sessions, and cover all the topics, to a greater or lesser degree. Unfortunately, it was not possible to obtain the perspective of family carers which would have been useful.

As set out above, there were a number of issues of importance which suggests further work in this area is needed. The subject matter was perhaps too wide ranging and needs to be broken down into the different elements to obtain more nuanced responses. There was some consensus across the two groups on what was important, and people with learning disabilities would need to be included in any further engagement on proposed changes because of their specific needs.

Many of the participants in the groups had profound disabilities and some were non-verbal, so the value of support workers in augmenting the contributions was essential. Given the fluid nature of the sessions, with participants dipping in and out, and some with limited communication skills, it was not possible to conduct equality monitoring with them (which has been requested but not yet received from the services concerned).

All, however, were local to Islington, had a learning disability, and some had additional physical disabilities and health conditions. There was a mix of ages, from young to older adults, and of ethnicities and genders. While, therefore, the focus groups should not necessarily be seen as representative of all people with learning disability in the Borough, they were diverse in all key characteristics. The facilitators were not aware of any of them being parents with childcare responsibilities.

Appendix

Accident and Emergency

1. Have you been to Whittington in an emergency?

2. What happened when you got there?

3. Did you see a nurse or doctor?

4. Did they tell you what was going to happen?

5. What was good about your visit?

6. What was bad about it?

7. What could have been better?

Technology and digital

1. Do you use technology like a phone, tablet or computer?

2. Do you use it to look after your health?

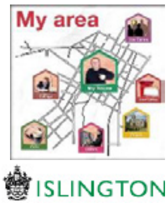
3. If you don't use technology, would you like to use it?

4. What would help you use it?

5. Would you talk to a nurse or doctor on video call?

6. Would you like nurses and doctors to share your records using a computer?

Health centres



1. Do you live in Islington?

2. Do you got to a health centre?

3. What is good about it?

4. What is bad about it?

5. What could be better it?

6. Anything else?

Equality and diversity

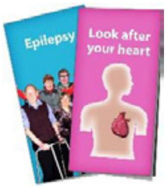
1. Name

2. Borough

3. Age

4. Gender

5. Disability



6. Health condition

7. Ethnic origin

8. Caring responsibilities

healthwatch
Islington

200a Pentonville Road, London N1 9JP
020 7832 5814
info@healthwatchislington.co.uk
www.healthwatchislington.co.uk
@hwislington