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NHS Long Term Plan

Burton Street Foundation Focus Group

17th April 2019

1 Introduction

1.1 Description of the focus group/engagement activity

Burton Street Foundation- A Day Centre for Adults with Learning Disabilities

Healthwatch Sheffield facilitated a two hour focus group with a group of ten adults with learning disabilities. Five support staff employed by Burton Street Foundation were also in attendance. The group was well established and were comfortable discussing their experiences with one another.

An easy read formatted work book, asking three overarching questions related to the Healthwatch local survey for the NHS Long Term Plan was prepared ahead of the focus group.

Participants were given the opportunity to rate the importance of different subjects in their work books and were engaged in discussions about their own experiences.

We used a flipchart with pictures and large text to provide further visual prompts.

1.2 Acknowledgements

Healthwatch Sheffield would like to thank all those who took part in the focus group, as well as Justin and the support staff at Burton Street.

2 What was the purpose of the activity/session?

2.1 Purpose

The aim of the focus group was to hear from adults with learning disabilities about their experiences of healthcare and how they think the NHS should or could provide good care to them in the future - in the context of NHS Long Term Plan.

2.2 What did you do?

Participants were provided with an easy read workbook and had sight of a flip chart which featured images from the workbook.

Three members of the Healthwatch Sheffield team facilitated the focus group. A lead facilitator and two note takers. The team began with introductions and an explanation of the work being carried out by Healthwatch in relation to the long term plan.

The lead facilitator explained the format of the session and group rules were agreed. An ice breaker activity followed.

A matching exercise, involving images of a doctor, dentist and optician and an item linked to them, was completed to scope the group's knowledge so that discussion and facilitation was pitched appropriately.

Discussion was encouraged based on each question in the workbook, and participants indicated their overall view (positive/negative/neutral) with an expressive face sticker.

The group took a short break in the middle of the session.

Participants were tiring towards the end of the session with fewer comments and ratings captured.

The final planned activity was an opportunity for participants to record their own story about a healthcare experience. This exercise - 'Tell Your Story' - was completed by the same group and facilitated by Burton Street support staff at their meeting the following week. Burton Street's Adult Services Manager felt the group would share more if Healthwatch Sheffield Staff were not present. The group were asked to complete a worksheet through which they commented on:

- An annual health check
- A visit to the dentist
- A visit to the doctor

2.3 Results of the activity/session(s)

Discussion Questions

Question 1

How can the NHS help people live longer?



Tally of votes			
9	1	0	Is it important to help people to stop smoking?
9	1	0	Is it important to help people to eat healthy food (preventing diabetes)?
9	1	0	Is it important to help people to exercise and get fresh air?
9	1	0	Is it important to help people to drink alcohol sensibly?

Has anything helped you?

- It's important to me that the NHS support people to stop smoking. It's all about will power.
- It's not right to smoke all the time or your heart will get much worse if you keep smoking.
- If you carry on smoking you will get other illnesses.
- It's important to eat healthily if overweight- it's linked to diabetes.
- You should have everything in moderation.
- A nurse scared me about not stopping smoking. Cigarettes are also too expensive now - it's about health as well as cost.
- I don't get enough exercise and fresh air- I would like more.
- I found an exercise machine in the park and enjoyed using it. It was easy for me. I was hoping I would find one in another park but I couldn't.
- I like fresh air. I enjoy exercise. I stretch my knees. I do athletics every week.
- I go with friends to the cycling at Hillsborough park every Wednesday. I can use the pedals with my hands. (This person used a manual wheelchair).
- I try to walk but it's difficult. I use a powered chair instead of walking if I need to.
- They should help people to know what they're doing.
- It's not right to drink alcohol or your heart won't be healthy.

Question 2

What will help people have healthier and happier lives where they live?



Tally of votes			
9	0	0	Is it important to help people live on their own if they want to?
9	0	0	Is it important to help people to visit family and friends?
9	0	0	Is it important to help people to do things they enjoy (hobbies)?
9	0	0	Is it important to help people to talk to someone if they feel lonely?

Has anything helped you?

- Living on your own depends on the individual.
- It also depends on the circumstances for the person. I live with my parents but have a PA (Personal Assistant). Supported living didn't work out for me. My PA helps do social things and cleaning so I don't always have to rely on my parents. My parents are getting to an age where they can't do everything. I didn't like supported housing last time. I want to keep my PA support. I can do my own washing and cooking and am capable but want supported living to work this time. My parents are in their 70s and 80s.
- (Communicated through carer) Funding has been cut. I live with my parents but in an annexe. Carers come in still but mainly for respite. My transport has been cut down. It's frustrating.
- Government cut things left, right and centre. It's going to be really tough with cuts.
- It's hard to get on the buses.
- I think it's devastating if you can't see family and friends, especially if you still rely on them.
- (Carer) It's hard to get the wheelchairs on trams. The old trams especially have a big step. Trams to Weston Park museum where the group runs every week - the nearest stop is the university and it means a walk all the way up.
- (Carer) Some people get a travel pass with a plus one for the support worker but some people don't, even if they need a support worker to take them out. It depends on their diagnosis what support they get.
- I need someone to look after my money and meds. I would like a ground floor flat. Living with other people didn't work out for me. There was lots of antagonising with staff. The other people there had more needs than me. My mental health deteriorated.

Question 3

How could phones and computers help people be healthy?



Tally of votes			
5	1	0	Is it important to help people to say thank you to carers (people that help you every day)?
7	1	0	Is it important to help people to see their doctor and dentist?
6	0	0	Is it important to help people to get test results quickly?
2	0	0	Is it important to help people to talk about health?

Has anything helped you?

- Hobbies stop you getting bored.
- Hobbies help you to follow your true destiny.
- Hobbies help keep your mind occupied and help take the pressure off my mum and dad.
- If you don't talk to anyone it can make you feel depressed.
- If you talk to people it can stop you feeling frustrated.
- I speak to a psychologist about my problems. That is about my disability and has really helped me out.
- Carers have a thankless task sometimes so I want to thank them.
- You might not have a computer. It might upset a carer if you tell them what they've done wrong.
- (Carer) A phone can be good to keep in touch and not be lonely in hospital.
- It's helpful when doctors and dentists send reminders.
- The reminder texts are good now I can see them in big print but when it was small print on my phone I couldn't read them. I still need help reading what it says.
- (Carer) I got some x-ray results by text and this was really good.
- Sometimes you're told you have to book an appointment in advance but you'd like to do it on the day.
- My PA has helped me going to appointments regularly.

'Tell your Story' Exercise

Support staff members facilitated a conversation about what was good or worked well, what was bad or didn't work, and what could have been done differently by different healthcare providers.

Annual health check



Tally of votes		
4	4	0

Comments:

- I have a health check every twelve months. It was about my COPD. Last week I had a letter sent to my house. It was about having a chest x-ray and breathing test. It was good at the beginning but I was told it was chest x-ray. I take inhalers, two I take and should be on oxygen cylinders. It is hard work walking up hills and flat, sometimes it is the best thing happened to me when I stopped (smoking).
- I have regular health checks for heart beating, weight and measurement. My mother takes me. I found the doctors to be okay; they explained things well to me and my mum.
- Happy with the health check.
- I am really happy with my health checks.
- Yes I had health check. My doctor keeping an eye on me.

A visit to the dentist



Tally of votes		
4	3	0

Comments:

- Mum phones to make appointments and I go for regular check-ups when needed.
- I have only been to the dentist once. I feel nervous going to the dentist but I don't know why. The dentist was friendly. I don't like the dentist putting things in my mouth.
- It's not always easy to get an appointment.
- I haven't been to the dentist recently.
- I go to the dentist for regular check-ups, my teeth are good. I'm happy to go, they are friendly even when I wait.
- My dentist is keeping an eye on me, making appointments and sending them to me. The dentist is really nerve-wracking and scraping makes me cringe, it's like nails down a blackboard. Sometimes my dentist doesn't talk to me, she talks to my mum which really p***s me off. Dentists came to Burton Street Foundation, they called up and made an appointment along with a hygienist. When here they talked to me and not my mum (who wasn't there). They scraped a bit and I told them to stop and they did.
- I like to go to the dentist, they are good to me. My mum supports me, my mum knows when I go, my mum helps (me) not to feel nervous.
- I went to the dentist with my family to check my teeth are nice and squeaky clean. The dentist tells me to put toothpaste on top of my teeth just in case you can't get them to be squeaky clean.
- Don't like going to the dentist, staff are good but I don't like injections.
- The dentist is good; they make sure my teeth are clean. I go once a year.
- I go every 6 months. I don't like to go but I go regular.
- I go to dentist every 6 months; they are very friendly and good with my health condition.
- I go every 6 months, don't mind going but since it has changed to Bupa service it's not as good.

A visit to the doctor



Tally of votes		
6	1	0

Comments:

- Mum phones for appointments for me, doctor speaks to mum and asks what is a matter with me.
- Friendly, helpful, my mum talks to the doctor for me because I don't feel confident. My doctor talks to me - happy.
- Happy with the GP.
- I am happy to go. They are friendly even when I am waiting.
- When I visited my doctor and he felt my chest and my arms and he said, "that's arthritis," and sent me for an x-ray of my chest which found (diagnosis). I felt great during my visit because he listened to my chest and heart and told me to put my arms out and felt my arms and back and looked at my scoliosis. He talked to me like an adult, he explained to me and not my mum. He looked at me which made me feel good. I'm going through the change and am getting good support. When I'm in pain he really cares, so do people at Burton Street. They sent me for a mammogram and that really hurt and it showed I was cancer free. I know I don't have it but it was really scary waiting for the results.
- Find the doctor easy to talk to. I go for a lot of blood tests to check my tablets are working.
- I don't mind going to the doctors but I don't like having injections. The doctors and nurses don't mind me bringing toys in to calm me down. My mum always takes me to the doctors, I wouldn't want to go on my own, I think I will get confused.
- It is a good service but cannot get appointments when required.
- My doctors are okay, can get an appointment when mum phones.
- My doctor gives me a home visit, they are ok.
- My doctors are good.
- My doctors are good; can get in straight away because I have a heart condition.
- Spend a lot of time on the telephone and it's difficult to get an appointment.

Participants also shared their views about optician services:

- Opticians come out to my home because I am in a wheelchair, the service is alright.
- Don't use this service as my eyes are ok.
- Been before for a check-up they are ok.
- Very friendly, go for a check-up when they text me just for a check-up.
- Go every 2 years; this is easier to get an appointment than doctors.

Participants also shared their views about other healthcare services:

- Last time I went to hospital my dad and mum wasn't happy as they wasn't very helpful. Quite friendly.
- Post-surgery check-up went in to talk about returning to work, the physio was NHS person.

Feedback from participants about their experience of the focus group.

Seven participants answered five evaluation questions.

Was the delivery of the session at an appropriate level?

- I found it was easy to understand.
- In my opinion it was well delivered. The ladies were patient and polite and everything I understood, it was well explained.
- Yes it was interesting.
- Yes.
- It was good.
- Yes it was okay.
- It was just right.

Any examples/comments?

- Easy to give answers using smiley faces.
- I liked the way they used pictures of doctors to how you were feeling at the time and enjoyed circling the pictures inside the pamphlet.
- Good at explaining things.
- The pictures were useful.
- Talking and pictures good.
- It was not too quick and not too slow.

What one thing would you change?

- No thought it was good.
- It was my first time in the lesson and I enjoyed every moment. The staff and clients were excellent, I really enjoyed it.
- To use faces instead of dogs (re the warm up exercise, which pug are you).
- I think they should do the session in different work places.
- A little bit shorter.
- Nothing.
- I needed more time to complete the paperwork as I get stressed if it isn't all done.

What was the best thing about today?

- I liked to see people coming into Burton Street to have chats.
- It was my second time in lesson (re Tell your Story). I did not feel nervous of and I enjoyed the two minute challenge (this was facilitated by the support workers).
- The use of the flipchart.
- They were nice people.
- Being part of the group.
- Getting information and meeting people.

- To look at the pictures - what they mean and what they do. I liked the dog photos.

How can we work better with you/your organisation to ensure that the views of people with learning disabilities are heard?

- Quite happy with it was.
- Carry on as we are at Burton Street.
- Do more sessions.
- They could talk to mum and dad.
- Come back again and speak to different people.
- Speak to others sessions.
- Talk to more people. You may need carers to help you understand what some people are saying.

Feedback from staff/volunteers who took part

The adult services manager said the session was pitched at the right level. Feedback was provided by one support worker to the following questions:

Was the delivery of the session at an appropriate level?

- The delivery of the session for our clients was easy for them to understand and explained well.

Any examples/comments?

- Flip chart very good, explained well. Not rushed, very patient.

What one thing would you change?

- All done really well. Lovely ladies, no pressure.

What was the best thing about today?

- Giving our feelings of how we felt about the NHS services, without any pressure and easy to understand.

How can we work better with you/your organisation to ensure that the views of people with learning disabilities are heard?

- Carry on with what you're doing, you did a wonderful job.

2.4 Conclusion

Participants had a good understanding of the importance of healthy living but felt they needed more support to take part in physical exercise and hobbies. This support could include accessible equipment, paid carers and more accessible transport (and better support for physically disabled people using public transport).

Participants were passionate about the importance of hobbies and contact with other people in relation to their health and wellbeing, especially the people they are closest to.

Participants recognised that different people have different needs and wishes when it comes to living independently. This correlates with the move towards more personal centred care, shared decision making and the ‘What Matters to You?’ approach.

2.5 Data and information summary

Date of Focus Group/Engagement Session	17.4.19
Group name	Burton Street Foundation
Description of the group or session	Adults with learning disabilities
Life stage - (Starting Well, Living Well, Ageing Well)	Living well
No. of attendees	10 adults with learning disabilities 5 support staff
Theme area	Mental Wellbeing Choice, Control and Independence Care near where you live
Was it a condition specific session - if so please identify the specific condition	No
What were the key outcomes	The views of a small group of people with learning disabilities were captured and can be used to shape local implementation of the NHS Long Term Plan.