

Healthwatch Wandsworth carried out several outreach and engagement sessions to ask service users and carers some of the questions related to the No Rights Ignored, No Voices Unheard Consultation.

We focused on responding to question 2 in the consultation which we believed had many elements within it that could be relevant to the people we spoke to. We broke down the questions so they were easily accessible for the group of service users and carers we were engaging with.

The feedback and the stories we collected are below.

FEEDBACK

1) Visit to local mental health support group

We visited a local mental health support group on 15th May 2015 and discussed the “No voice unheard, no right ignored” consultation with 18 mental health service users.

We asked the following questions and received the following responses;

Your Views & Experience - “Do you think you are being listened to when your care/support is being discussed?”

- “Once a year you meet to receive your support plan, then you don’t see anyone again for another year, no follow ups.”
- “I feel completely supported and my thoughts and needs are taken into account. I have 3 month catch up’s with my GP.”
- 5 service users stated that their care/support plan had already been written up before they met to discuss or added their input.

Do you understand - “Were you provided with clear easy read information helping you to make choices?”

- The group found the document easy to read.

Do you feel Involved - “Do you think you should be involved in making decisions about your own care/support plan?”

- About half of the group felt involved in the decisions being made and the others stated that the plan was already prepared for them.

Can I Change My Mind - “If you’re not happy with the care/support decisions made for you - do you feel able to challenge this?”

- “Things change in a year and there is no opportunity to meet and review your progress or change your plan due to circumstances.”

- “I had to complain that I was not happy with my support worker as I felt that they were not helping me address some of my housing related issues.”
- Half of the group did not want to challenge as it is important to have a good relationship with your social worker and they did not want to rock the boat or tarnish the relationship.
- 12 service users didn’t know that they could change their mind if they were not happy with their support/care plan.

Additional issues that came up:

- “For 1 year I have been left in limbo in regards to my housing issues with no real support, I could not get legal aid due to cut backs.”

2) Visit to local charity

We visited a local charity on 12th May 2015 and discussed the “No voice unheard, no right ignored” consultation with 9 students with learning difficulties.

We asked the following questions and received the following responses;

Your Views & Experience - “Do you think you are being listened to when your care/support is being discussed?”

- “My support plan is about my life and how I want to live it”
- “It’s about things that you want to improve.”

Do you understand - “Were you provided with clear easy read information helping you to make choices?”

- “Not always.”
- “My support worker explains it to me and asks me what I would like to do.”

Do you feel Involved - “Do you think you should be involved in making decisions about your own care/support plan?”

- “I would like to talk about the future and jobs.”
- “Yes.”

Can I Change My Mind - “If you’re not happy with the care/support decisions made for you - do you feel able to challenge this?”

- “I would tell my mother if I’m not happy.”
- I would tell staff at the charity if I am not happy.”

Notes: This was a very difficult group to engage with due to complexity of some of the learning difficulties.

3) Visit to local learning disability group

We visited a local learning disability group on 11th May 2015 and asked 3 service users several questions in response to “No voice unheard, no right ignored” consultation.

We asked the following questions and the following responses are as follows;

Your Views & Experience - “Do you think you are being listened to when your care/support is being discussed?”

- “Yes and No - I had an annual review with my social worker 2 months ago and she put together a care plan for me but it got to the point that I had to accuse my social worker of not listening to me.”
- “I have to keep telling my doctor to stop using medical jargon because I have a learning difficult and I cannot understand it.”

Do you understand - “Were you provided with clear easy read information helping you to make choices?”

- “It is very rare that you are provided with information in easy read. They did not take into account the fact I have cataract.”
- “My social worker gave me my care plan and it was not easy to read - it was very small writing.”

Do you feel Involved - “Do you think you should be involved in making decisions about your own care/support plan?”

- “I am involved in about 50 - 70% of the time when it comes to decisions about my care/support plan.”
- “My mother is my main carer and she gets involved in making the major decisions in my care/support plan and involves me in the decisions.”

Can I Change My Mind - “If you’re not happy with the care/support decisions made for you - do you feel able to challenge this?”

- “Sometimes I feel I can challenge a decision and if I am unhappy with the results I go through all the channels I need to go through to get a decision.”
- “I tell my support worker if I don’t understand something.”
- “I had an appointment with a doctor who spoke too fast and I could not understand him. I was with my support worker and asked if I could have another doctor and I got seen by another doctor who took the time to talk to me and was excellent.”

4) Visit to a local carers' support groups

We visited a local carers' support group on 28th May 2015 and discussed the "No voice unheard, no right ignored" consultation with 13 carers of people with mental health, learning difficulties or autism.

We asked the following questions and received the following responses;

Your Views & Experience - "Is the person(s) you care for being listened to when their care/support plan is being discussed"?

- "Professionals are not listening to carers and carers are being left out of conversations and not being respected as the person's expert."
- "Sometimes discharged without a care/support plan in place."
- "Not checking with service users if they feel able to be discharged."
- "Lots of carers feeding back that they do not have a care/support plan in place for the person they care for."

Do you understand - "Are the person(s) you care for (and you) provided with clear easy read information helping you to make informed choices"?

- "Need the communication to take into account the different needs of the individual and not categorize. Everyone's communication need should be taken to account and they are different."
- "Lack of signposting to organisations that can help when completing care plan."
- "Lots of paperwork to read and you have to spend a lot of time reading to understand it."
- "Sometimes the information provided is not relevant, full of jargon and contradictions."
- "Sometimes there is too much choice and the information isn't clear or out of date."

Do you feel Involved - "Does the person(s) you care for feel involved in the decisions being made in their care/support plan"? "Are you (the carer) involved in any decisions being made in regards to the person(s) care/support plan?"

- "Carer for the person is not able to articulate plan and professionals are not listening to carers as they are trying to give rights to the person."
- "Carer is able to make decisions for service user on a daily basis but are not listened to when it comes to making decisions in annual review meeting of care /support plan."
- "Care plan has to be more flexible - an annual review meeting is not feasible as circumstances change and these changes are not taken to account as no follow up from annual meeting."
- "Didn't ask the service user if they wanted the carer to be involved in decisions being made in the care plan - and they did not understand what that care plan was about."

Can I Change My Mind - “If the person you care for is not happy with their care/support plan do they or you as the carer feel able to challenge”?

- “A carer spotted inaccuracy in medication care/support plan - it was the carer that spotted this and if they had not challenged the inaccuracy would have been repeated.”
- “Service users are not always able to challenge care/support plan so important that carers are listened too and not fobbed off.”
- “There was an issue with having to get the power of attorney involved in order to be involved in carer - which seemed very drastic to have to do.”
- “I have challenge before but seen as a busy buddy and don’t want to make it more difficult for the person caring for.”

Can I Change My Mind - “Does the person(s) you care for know that they have a right to change their mind and their wishes should be acted upon?”

- “No they don’t know they can change their mind nor does the carer - would like this to be made clear.”

STORIES

The following stories relevant to the No Voices Unheard, No rights Ignored, were captured in May 2015, during several outreach and engagement sessions.

- A man with learning difficulties, blind and in a wheel chair who lives in Tooting was asked to attend his annual review meeting, to agree his support plan, out of his designated area and travel alone to Clapham Junction, without care or support or with the assistance of a travel buddy, to save money. He challenged this and now receives £120.00 per month to take him from home to and back from review meetings (which is under review).
- A woman with learning difficulties spoke about a bad experience she had with a doctor who spoke too fast and used jargon that she could not understand. She was happy that she had her support worker with her that day to support her and they asked if she could see another doctor. She was assigned to another doctor who was excellent and took the time to understand her issues and talked things through with her.
- A woman with a learning difficulty spoke about the positive experience she has had with two liaison nurses at St Georges and at a worker at a local Medical Centre who took the time to listen to her concerns and talk her through her options so that she could make an informed decision.
- A woman told us about her son who is 5 years old and has autism; she expressed concerns about the fact that views on her son’s progress are only sought at annual review meetings. She also stated that the writing is too technical, but she has support in reading it. Additionally, she was not happy

with the length of time the school bus was taking but was able to get the help of her caseworker.

- A man stated that whether he felt listened to when his care was being discussed depended on the person he was speaking too. He did not feel able to challenge the decisions about him however he did find that the information he receives are easy to read and helpful in making choices
- A man stated that he does not feel listened to when his care is discussed and he believes that other people do his thinking for him, however he feels sometimes able to challenge the decision taken about him.
- A man who was a support worker talked about how the young man that he supports is really unhappy with the recent closure of a local community centre that he regularly attended. He now has nowhere to go and meet the friends and misses the classes that they used to run.
- One man spoke about how he would like to be able to meet and socialize with people his own age.
- Several people spoke about having opportunities to find jobs and working/volunteering opportunities in their support plans.
- Everyone talked about how important it is to regularly meet up with friends and go out to different places and they wish they could do this more and it is important that this is incorporated into their support plan.
- The group unanimously felt that care in the community is not good as sometimes patients need to be away from the community, family and friends to recover fully.
- One lady wanted to know if there was any activist groups that are challenges the cut backs in mental health support as she does not feel that service users concerns are being listen too.
- Another gentleman stated that he felt vulnerable and worries about the recent cut backs and lack of service and support for people with mental health issues.
- A few service users talked about a lack of support with housing issues and a lack of access to legal aid to be able to challenge this.
- There was much discussion in regards to the new government and what implications this will have on this and other groups, as possible further cuts in mental health support.
- One lady shared how worried she was about the closure of the ward at Queen Mary's hospital and the implications of not having enough beds for people with mental health issues.