‘Our Rights, Our Voice’: Workshop on NHS Constitution for people aged16-25

Summary and Evaluation

Acknowledgements

- We would like to thank all of the young people who attended the workshop.
- We would also like to thank the National Children's Bureau and Council for Disabled Children for producing the workshop materials, as well as Sara Callarman from Speak Your Mind Young People's Advocacy Project, Alex Garner, Engagement Worker and Phil Stevens, LGBT - TAPA (Teen to Adult Personal Advisor) from Sussex Partnership NHS Foundation Trust for helping us to organise and deliver sessions.
- Finally, we would like to thank David Pritchard and Paul Goodwin from the Child and Adolescent Mental Health Service (CAMHS) for providing an overview of local community CAMHS services.

Background

What is the NHS Constitution?

The NHS belongs to us all. The NHS Constitution brings together in one place for the first time in the history of the NHS, and what staff, patients and public can expect from the NHS.

The NHS Constitution was first published on 21st January 2009. As well as capturing the purpose, principles and values of the NHS, the Constitution brings together a number of rights, pledges and responsibilities for staff and patients alike. These rights and responsibilities are the result of extensive discussions and consultations with staff, patients and public and they reflect what matters to them.

It was one of a number of recommendations in Lord Darzi's report 'High Quality Care for All'[1] which was published on the 60th anniversary of the NHS and set out a ten-year plan to provide the highest quality of care and service for patients in England.

All NHS bodies and private and third sector providers supplying NHS services in England are required by law to take account of the Constitution in their decisions and actions. The Government has a legal duty to renew the Constitution every 10 years. No Government will be able to change the Constitution, without the full involvement of staff, patients and the public.

Accompanying the constitution is a handbook which gives more detailed information to patients and staff. Both the constitution and handbook are available by clicking: http://bit.ly/18v22j4.

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[1] For more details see: http://bit.ly/1PvJV0x

Origin of 'Our Rights Our Voice: NHS Constitution project'

Back in 2013 the National Children's Bureau (NCB)[2] consulted children and young people and found that while they wanted to know more about their rights as patients, few of them had any awareness of the NHS Constitution, the key document where those rights are set out.

Therefore, as part of the project exploring how the rights in the NHS Constitution can be promoted to children and young people, the National Children's Bureau and Council for Disabled Children (CDC)[3] have developed and piloted a session plan and set of resources that introduces the rights in the NHS Constitution, alongside other key standards, to children, young people and health professionals. These resources were then tested by the project partners during workshops run in their local areas.

This resource is aimed at a wide range of children and young people with various health needs.

Locally, following the recommendations of a Healthwatch Brighton and Hove report[4], which found that there is a need to raise awareness about rights among CAMHS services users, it was decided to deliver 2 sessions for young people aged 16-25 years old with mental health needs. The workshops were delivered in collaboration with Sara Callarman from Speak Your Mind Young People's Advocacy Project, Alex Garner, Engagement Worker, and Phil Stevens, LGBT - TAPA (Teen to Adult Personal Advisor) from Sussex Partnership NHS Foundation Trust.

During the workshops the following resources were used:

1 Set of 6 jigsaw pieces: Each one is an area that young people may have problems with

- Using the NHS: getting the best care from the NHS
- Being treated well: treating you and your information with respect

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[2] The NCB is a leading research and development charity working to improve the lives of children and young people, especially the most vulnerable. They work with children and for children to reduce the impact of inequalities, by influencing government policy, being the voice for 200,000 front-line professionals, and inspiring practical solutions on a range of social issues including health, education and youth justice, through its extensive research and evidence work. Find out more at: www.ncb.org.uk

[3] The CDC is the umbrella body for the disabled children's sector in England, with links to other UK nations. They bring together a diverse range of organisations that work with and for disabled children to support the development and implementation of policy and practice. Their work impacts on over 800,000 disabled children and their families. Find out more at www.councilfordisabledchildren.org.uk.

[4] 'Putting the Pieces Together: An overview of people's experiences of CAMHS services in Brighton and Hove' (2014) available at: http://bit.ly/1KynrpU

- Making decisions about your care
- Getting involved: making things better where you live
- Staying healthy in adulthood: promoting healthy lifestyles and transition to adulthood
- Putting things right: feedback and complaints

NHS Rights and Pledges Cards: These cards present the rights and pledges in the NHS Constitution

Scenario Cards: These are the types of situations children and young people may find themselves in. There are also blank cards to use for their own scenarios.

Workshop evaluation

Demographical profile of workshop attendees

The first workshop was delivered on 4th August and was attended by 5 young people (2 female and 3 male). 3 out of 5 were mental health services users and 2 are currently working for one of the mental health services. The age range was 20-24 and they all declared to be White English/Welsh/Scottish/Northern Irish/British. 2 of them were heterosexual, 2 bisexual and 1 gay man. The majority of them had complex health needs: 1 on the autistic spectrum and learning disability, 1 with a mental health condition and learning disability, 1 with a physical impairment, sensory impairment, learning disability, long-standing illness, mental health condition and currently awaiting autistic spectrum diagnosis. 1 person declared being a carer for a member of their family.

The second workshop was delivered on 14th September and was attended by 2 young people (2 female); members of Mind Me Up, a young people's mental health participation group run by Mind in Brighton and Hove. One of them was 19 and the other 24 years old. They both declared to be White English/Welsh/Scottish/Northern Irish/British and bisexual. They both had mental health issues, one had also learning disability. Finally, they both reported to be carers, one for parent and other for sibling with special needs.

What happened during the workshops?

Activity 1

The sessions started with true/false statements about rights. The sessions led to lively discussions during which workshop participants raised the following concerns:

- People with autism are not treated well on the whole.
- Young people are less likely to report if their rights have been breached. They are afraid to speak up as this may affect their care and no one will take it seriously.
- Carers/legal guardians tend to be overprotective and often don't let young people act for themselves

- Participants said that there is no dedicated youth mental health service – CAMHS is not specific to 16-25 or 16-30 year-olds which would be preferred (their knowledge on Teen to Adult Personal Advisors (TAPAS) which is helping 14-25 year-olds with their mental health needs seemed to be limited).
- There isn't enough work done on prevention - addressing teenagers' issues before they become too unwell.
- Mental health services under pressure tend to hide and use the extra pressure as an excuse to hide.
- Mental health services are hard to access - difficult to get beyond the first point of access/reception.
- The message is not getting out there – differences between services remains unknown and promotion of the mental health services available is not good.
- Problems with transition between services could be improved – TAPAS are dedicated to this but cannot cover everything.

Participants also highlighted some positives. They mentioned good links with the community services and the fact that Brighton has a lot more community services and support than outside the area. However, because these organisations often work in isolation, their impact is limited. Some concerns were raised regarding council cuts and how this will affect young people.

Activity 2

The true and false activity was followed by putting together the jigsaw pieces. The group was asked to talk about what they think each area of the jigsaw means for young people. Then they were given cards that represent the rights in the NHS Constitution and were asked to discuss which cards relate to the jigsaw themes, and how the right might make things better for young people using mental health services. Finally, all the jigsaw pieces were put together to create one large image/jigsaw map of how the rights fit together. Participants had a discussion on how many people knew these rights existed, if they felt their rights were being met by their mental health services or if there was anything missing from this picture?

During the second workshop we used only the cards in order to have more time to talk about rights in more details.

Main highlights from the discussions

- Mental health isn't treated equally alongside physical health.
- Attempts to reduce stigma are starting to slowly have an impact on people, however more work still needs to be done.
- Terrence Higgins Trust counselling was very good; they gave good tips about ways to help yourself (art etc.).

- Changing counsellor seems to be a very long and complicated process - sometimes it's better to stay with the old one.
- Cognitive Behavioural Therapy is very basic and not for everyone. It is hard to get access to other forms of therapy.
- Sexual health tests at Claude Nicol clinic were done well – lots of advice and support – it felt comfortable making decisions based on the advice they gave.
- Content to make own decisions but did not seek advice from the NHS – some young people are able to learn a lot about themselves – they don't trust the NHS to help.
- Young people are afraid to complain as they don't believe it will be taken seriously and are also afraid that this will affect the care they receive.
- Some of them also don't necessarily want to make a complaint; they just want providers to know what could have been done better. They don't believe someone will listen to them and take it seriously. Also, they don't know how to do this.
- Some young people look for help within the private sector – the NHS for them seems to be in a mess and not trustworthy
- Young people can hardly ever choose if they want a female or male professional to work with them.
- Young people don't feel respected while they are accompanied by adult/carer/guardian, as often health professionals talk about them like they are not present.
- Young people in general don't know much about rules behind waiting times, the Friends and Family test or other forms of having a say.
- Young people can hardly ever choose a GP practice, because of the boundaries system, which is very unclear to them.
- Young people struggle with "grey areas" around confidentiality and consent.

During the workshops, besides general comments, we also collected some personal stories. For instance, one of the individuals shared own family experiences at Burwash Surgery. The shared story was about their sibling who also has complex health needs (mobility issue, living on strong painkillers) and who the individual is caring for. Overall, their experience of Burwash Surgery has been very negative. The individual felt not listened to and often ignored by the GP at this practice because of their young age. In addition, the individual raised the following issues:

- ✓ difficulty in getting appointments as practice is open only half days
- ✓ being seen by different doctors
- ✓ GP didn't take the individual's chronic pain seriously

- ✓ lack of appropriate referral following blood tests.

Another individual reported having treatment discontinued without any warning or explanation.

Activity 3

Each person was asked to choose a scenario printed out on paper, which was the closest to own experiences. Then they we asked to read out chosen scenario/tell own story, the others in the group were encouraged to 'vote' on which of the rights that they've on cards apply, by holding up the rights statements. The activity was followed up by the discussion on what could be done differently and where to look for help.

Main highlights from the discussion (not mentioned above)

- None of the participants experienced any difficulties when they disclosed their own mental health condition.
- One of the participants didn't know that equality monitoring information on job applications is not shared with the appointing manager. It was explained that mental health disclosure would not guarantee anyone an interview, but it should not stop you getting one either.

Discussion what/who can help?

The first workshop ended with a presentation on support offered by community CAMHS services, an explanation of the CAMHS Tiers system and support offered by various organisations in the city. During both workshops, each of the participants was given a pack with a copy of the NHS constitution, information on complaints procedures, a website of support services for young people aged 13-25 in Brighton and Hove (www.wheretogofor.co.uk) and other support offered by various community organisations in the city.

Main highlights from the discussion

- There was a long discussion on how to take away the stigma from CAMHS services. It was suggested that the name of the service should be changed, but participants could not pick one and came to the conclusion that any name chosen would be stigmatised.
- Participants also said that stigma is different when you are taking about depression or anxiety or schizophrenia (the latter more difficult).

Post workshop participants' feedback

In total the workshops were attended by 7 young people. Overall, the majority (6) of participants agreed that the workshop was fun and interesting and that they felt listened to. 5 people were highly complementary about the session. On the other hand 1 person wasn't convinced they were listened to.

I had a lot of fun sharing my experiences and hearing others people's from different backgrounds. I loved the puzzle activity.

We all were able to contribute to the session and it was very informative.

The Practitioner had a good variety of resources

All participants felt that they had learnt something new and now knew more about the NHS Constitution, rights and complaints system. Asked how confident they would feel to visit a mental health service tomorrow and ask a question about their own mental health or treatment, 3 participants said that they would feel confident about this and 4 felt very confident. 6 felt very comfortable to ask the services to explain things again and more clearly, while 1 wasn't sure about this. Finally, 5 felt very comfortable to admit that they were not sure about something and request additional information, 1 felt just confident and 1 wasn't sure. 5 highly enjoyed the session and learn a lot which they wanted to share now with their friends and families. 2 felt that the session was repetitive at some points, however were pleased to learn more about the work of Healthwatch, Mind in Brighton and Hove and TAPAS.

Post workshop facilitators' feedback

In general, after the first session they felt that the workshop scenario had too many activities therefore there wasn't sufficient time for proper discussions/gathering young people's stories. Fewer activities should be used and any repetition should be avoided. They also felt that:

- The session leader should explain the questions focus only on the rights in the UK and responses provided to myths/true statements should include a brief explanation. The jigsaw puzzle exercise should be done in one group.
- The resources were not really suitable for this age group - some of the participants were highly knowledgeable and articulate, therefore they could find resources a bit infantile.
- There is a need for more resources that explain grey areas in the NHS constitution and rights better.
- The theme is quite broad and difficult to be delivered within a 2-hour session; most scenarios provided were relevant to this age group and it was difficult to choose only a few.

- The session should include some information on how the system works, barriers that people may come across trying to access their rights and how to overcome them.

The second workshop facilitators felt that having fewer activities worked much better and there was enough time to discuss each of the rights. They also liked having a small group as it let participants fully express their thoughts and views. None of them felt rushed and they had a decent amount of time to speak up.

What is coming next?

Following the workshop, it is hoped that the views gathered through the discussion can help to influence the local health system. This will involve a range of different approaches in each area, engaging with health professionals, creating new materials that fit with the issues raised though the workshop delivery, or using the tools created in other areas.