

Wiltshire Council

Health and Wellbeing Board

2 December 2021

Subject: Healthwatch Wiltshire Update report

Executive Summary

- I. Healthwatch Wiltshire is the local independent consumer champion for health and social care. We listen to people's experiences of using health and care services and share these with decision makers and commissioners to influence change.
- II. This update report gives an overview of our recent work including:
 - What people with autism spectrum conditions think of health and care services
 - The achievements from the first year of the Mental Health Open Forum
 - The views of people with lived experience of mental health on what good community support looks like
 - Experiences and views of using the Advice and Contact service
- III. All of these reports have been shared with the relevant commissioners and providers. We have received positive responses highlighting how the findings from these reports will be used to help inform, shape and develop future work.

Proposal(s)

It is recommended that the Board:

- i. Notes the key messages from the report.
- ii. Confirms its commitment to listening to the voice of local people to influence commissioning and service provision.

Reason for Proposal

Healthwatch Wiltshire has a statutory duty to listen to the voice of local people with regard to health and social care services and then feed this back to commissioners and providers to influence change. Healthwatch Wiltshire therefore ask the board to receive our latest report, make comment and reaffirm its commitment to listening to the voice of local people.

Stacey Sims
Manager
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Wiltshire Council

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Purpose of Report

1. The purpose of this report is to present to the Health and Wellbeing Board an update of our recent work, to invite comments, and confirm a commitment to listen to and take in to account the views of local people about health and social care services in Wiltshire.

Relevance to the Health and Wellbeing Strategy

2. The projects outlined in this update fall into several themes within the Health and Wellbeing Strategy.
 - 2.2 Their findings provide insight into people's experiences of how services work together, their ability to access support and care and at a time and place that is suitable to them.
 - 2.3 The views of local people shared in this report can be used to influence developments in health and care services. Active participation in health and care services by local people and communities can lead to people having more responsibility for their own health, maintaining their own health and improving their health outcomes in the future.

Background

3. Local Healthwatch and Healthwatch England were established in 2012 as part of the Health and Social Care Act 2012. Healthwatch England is the national body which provides leadership and support to the Local Healthwatch network. There is a Local Healthwatch organisation in each upper tier authority area of England. Local Healthwatch has an important role to listen to and share the voice of local people in the design of health and social care services, and in monitoring the quality of those services. Commissioners and providers of these services have a duty to listen to that patient and public voice.
 - 3.2 Healthwatch Wiltshire was set up in 2013 to deliver the statutory activities of a local Healthwatch service. Wiltshire Council provides core funding to Help and Care, a charity based in Bournemouth, to provide the Healthwatch Wiltshire service through a contractual agreement. It is important to recognise that the Council does not direct the work plan of Healthwatch Wiltshire but contracts the organisation to deliver the statutory activities.

Main Considerations

The report summarises four of our recent projects, what we heard from local people and the recommendations made to services.

5. What people with autism spectrum conditions think of services

- 5.1 This project was carried out in late 2020/early 2021 by Healthwatch Wiltshire, working in partnership with Wiltshire Service Users' Network (WSUN).
- 5.2 We designed and ran two surveys, one for those with an autism spectrum condition and one for carers. The surveys ran for about 10 weeks. Due to Covid-19, we were not able to meet people face to face but we provided options for the survey to be completed online, over the phone or on paper.
- 5.3 We received a total of 102 completed surveys:
- 43 from adults with an autism spectrum condition.
 - 29 from carers of adults with an autism spectrum condition.
 - 20 from carers of children with an autism spectrum condition.

What did we find out?

- 5.4 We were told that an appointment with a doctor or nurse can cause considerable anxiety and stress for someone with an autism spectrum condition. We heard of difficulties in terms of booking appointments, waiting at the surgery and explaining the reason for the visit. We were told that staff having an awareness of their autism diagnosis and longer appointment times would be helpful.

“Long waiting time on the phone makes me anxious, the music or/beeping is overwhelming. Receptionists aren't always friendly. They don't have awareness that I am autistic. They can't offer me a more accessible booking process or appointments.”

“I find the waiting room can be a very very challenging place for my son with his sensory issues being triggered just because of the number of people in the room. It would be helpful to have a quiet area for us to wait and reduce his anxiety.”

- 5.5 Difficulties were reported in explaining things to health professionals and in understanding what they were told about their treatment and follow-up. The provision of written information, including easy read was identified as something that could help them understand information that they were given.

“Because I forget as soon as I walk out of the room. I nod and say yes but 99 out of a 100 I have not stored the information I was given.”

- 5.6 Hospital environments were particularly difficult for those with an autism spectrum condition. A range of options were identified that would help prepare for an appointment, including a leaflet with a map, written

information about what to expect at the appointment and their notes identifying that they had autism.

“Information about timings, both potential waiting times and duration of appointment. Prewarning of potential for medical students and explanation for why it can be good for them to sit in on an appointment.”

Issues of confusing environments, busy waiting rooms, noise, formality of staff, and the need to see several different people, were identified as being very stressful. Improved training to increase awareness about autism was frequently mentioned as something that would be beneficial.

“I have sat in a corridor rocking back and forth and not one member of staff asked if I was OK. I have asked for quiet area to wait in, only to be told on arrival they didn’t know anything about it.”

5.7 Experience of phone call and video appointments were mixed and depended on the individual concerned. It was clear that there were some individuals for whom phone and video appointments were not suitable.

“All three make me feel very insecure and anxious, I do not like talking on Zoom or the phone, I have never even done this with my daughter in Australia as I feel so out of my depth, so that should explain how hard it is for me to do that with doctors or hospital appointments.”

However, there were also several carers and those with an autism spectrum condition who reported a positive experience of phone or online appointments.

“Having to wake up and get ready to leave the house is very difficult for me so being able to do the appointment in bed was very helpful. It also alleviated the stress of eye contact and constantly observing body language.”

5.8 A large proportion of those with an autism spectrum condition and their carers said they felt they did not have enough information about support or services that were available. One thing mentioned frequently by those with an autism spectrum condition and their carers that would be helpful was a directory or list of support services and groups.

“An easy to read directory of what is on and what there is.”

5.9 Most of those with autism spectrum conditions and their carers did not feel that they got enough support related to their condition.

5.10 We were told that most people were supported by unpaid carers. This included parents, partners, other family members and neighbours.

5.11 Other support services were valued but we were told there was not enough information about them or their availability.

5.12 There was mixed feedback about respondents’ experiences of diagnosis. One thing that was frequently mentioned was that the information pack provided was overwhelming.

“Both times the diagnosis was well explained, but knowing you have something doesn’t tell you how to live with it day to day.”

Recommendations

- 5.13 The report made the following recommendations to services:
- Introduce initiatives and training to improve awareness of autism among staff working in GP practices and hospitals.
 - Consider offering people with autism a written summary of their appointment, treatment and follow-up.
 - Establish a system of recording preferences and/or needs for face to face, phone or video appointments and consider how these preferences can be met as far as possible.
 - Establish a system that flags a person's autism spectrum condition in their medical notes.
 - Include the findings of this report in pathway reviews for support services in Wiltshire, with the aim of providing improved access to services for people with an autism spectrum condition.
 - Consider how information about, and experience of, transition from child to adult services can be improved.
 - Investigate a reduction in the volume of general information given at diagnosis and the provision of a more individually tailored pack.
 - Work with people with autism spectrum conditions and their carers in taking forward the above recommendations.

The full report can be read here:

https://www.healthwatchwiltshire.co.uk/sites/healthwatchwiltshire.co.uk/files/What_people_with_autism_spectrum_conditions_think_of_services.pdf

6. Wiltshire Mental Health Open Forum - the first year

- 6.1 The Wiltshire Mental Health Open Forum was established in August 2020, and is run jointly between Healthwatch Wiltshire, mental health service users, and mental health service provider Avon and Wiltshire Mental Health Partnership NHS Trust (AWP).
- 6.2 The forum provides a safe space for service users, and those who support them, to speak directly to those who run mental health services, to get involved in helping to shape the design of these services and highlight gaps in mental health support. There are now over 80 forum members and on average 25 attend each meeting.
- 6.3 It also provides a platform for sharing information about local support available and for organisations and community groups to showcase the services, and activities, they provide.
- 6.4 At every forum meeting, there is a you said, we did session. Issues shared at the forum are taken to a monthly Quality and Standards meeting held by AWP. Feedback and any actions are reported back at the next meeting. For example: Issues regarding access to mental health services if you do not have a registered GP were raised (this was a particular concern from the Rough Sleepers Team). The Clinical Lead reported back that not having a GP should never be a barrier to receiving support. The AWP Access Service Manager for Wiltshire attended the Homeless Link

Community of Practice meeting and discussed the referral process with those working with the homeless community.

- 6.5 Forum members are also able to get involved in the shaping and development of mental health services in Wiltshire and they have helped shape 4 services in their first year including the redesign of the Recovery and Inclusion service and a new initiative by Wiltshire Citizens Advice to run a pilot Advice/Support Scheme for those with poor mental health who need support with life's practicalities.
- 6.6 In response to the recurring theme that service users were unaware of, or not able to access, up to date information on services and activities in the community, the forum produced their own comprehensive guide to mental health and wellbeing services on offer in Wiltshire. This guide has been downloaded over 400 times.
- 6.7 The forum has been welcomed by commissioners and providers as a valuable opportunity to hear directly from people with lived experience and continue to meet on the first Wednesday of every month.

The full report can be viewed here:

https://www.healthwatchwiltshire.co.uk/sites/healthwatchwiltshire.co.uk/files/Wilts_MH_Open%20Forum_Year1_report.pdf

7. The future of mental health support

- 7.1 We worked with Wiltshire Centre for Independent Living and Wiltshire Parent Carer Council to host a series of online focus groups looking at the future of community mental health services in Bath and North East Somerset, Swindon and Wiltshire (BSW).
- 7.2 The joint work follows the publication of the national Community Mental Health Services Framework, which looks at how support for people in the future can be delivered more locally, to help them live well.
- 7.3 We held 3 online sessions, one in Banes, Swindon and Wiltshire which listened to the views of 32 people with lived experience of mental health and asked:
 - What does a good life look like for you?
 - What do you need to live a healthy life in your community?
 - What does good community mental health support look like for you?

Key findings

- 7.4 For most people having purpose, a reason to get up out of bed is crucial to them having a good life. People want to have active roles in society, they do not want to be passive recipients and be done on to.
- 7.5 Having aspirations, something to look forward to and things to do and occupy time are important when people consider what makes their good

life. This included being active, being creative and having the opportunity to participate. It helped if things were planned in advance and if events were local.

- 7.6 People enjoyed and benefited from having someone to spend time with and socialising and social networks. The necessities in life that we all expect and hope for were also mentioned such as feeling safe, hope, being able to clothe myself, being physically healthy.

What do you need to live a healthy life in your community?

- 7.7 We talked about what people need to live a healthy life in their community, several themes emerged.

- 7.8 People wanted to have a vocation, to work, have opportunities to volunteer and take part in purposeful activities.

- 7.9 Connections with people were crucial to building and leading healthy lives in the community. People found that peer support helped to form social networks in the community.

“I met someone else going through exactly the same situation as me on the day that they were releasing me. It was a chance to talk to someone in my situation. I don’t even know his name, but he was a lot older than me. It was nice eventually to manage to meet someone in the same situation”

- 7.10 People really reflected on the importance of relationships and connections, describing how some GP’s only offer medication when meeting other people may be far more beneficial.

“I do not want a prescription, I want a connection”

- 7.11 Many people talked about how having access to support enabled them to live a healthy life in their community. The area where most people felt like they needed support was with transport.

- 7.12 People listening properly meant that you only had to tell your story once and reduced the feeling that you have to jump through hoops to prove you have tried things.

- 7.13 Being equipped with knowledge empowered people to live healthy lives in their community. Knowledge and information about what is out there and what is going on in peoples’ communities was of particular pertinence.

“Need for information about what is available is important as you don’t know what you don’t know so don’t ask for it”

What Does Good Community Mental Health Support Look Like?

- 7.14 There is a very clear message that good mental health support should at its core be preventative. It was highlighted repeatedly that what people

needed and felt was the most effective way of supporting them was to provide low level support before things escalate and develop into a crisis. But, that crisis support (when needed) should provide/offer real help.

“Good mental health support is about prevention...prevention is better than a cure, it’s about understanding a table (professional plan) isn’t the answer, let’s work on the causes.”

7.15 Having low level support for people who don’t meet thresholds for higher levels of intervention was also crucial. People described how difficult it is to access support, they were either not ill enough, too ill, or just the right amount of ill.

“Services that are accessible whatever level of mental health issue you have, preventing escalation. Not only focusing on people who are unwell, offer support before then to avoid a crisis.”

7.16 Good mental health support should be person centred and holistic. A range of different types of mental health support should be available for people, with acknowledgement that one size does not fit all. Nonmedical options need to be available, suggestions included listening cafes, support cafes/walks, being able to watch football or knitting groups, art and music therapy.

7.17 Much of the support that people feel will benefit them does not require ‘professional’ involvement. It should be self-organising and people need to be given the autonomy to be able to get on and do it.

7.18 Young people and parent/carers highlighted how there is relatively little support for young people after the age of 25 in comparison with what is available and on offer for young people up until this age.

7.19 Central to all good mental health support is listening. People want to be heard and listened to, having to tell your ‘story’ time and time again is exhausting for people.

7.20 The rural geographical nature of the area ran through all of the discussions about where mental health should be provided. The conclusion being that good mental health support services should be provided in local communities. It was frequently suggested that when designing and delivering good mental health support that the physical assets that are available in local areas should be utilised. These assets are also in a familiar environment for people.

7.21 How mental health support is delivered determines how good and effective people feel it is. It is clear that there needs to be a variety of platforms for people to choose from so that they can access support in a way that suits them. People want to be able to access support through a variety of mediums including physically meeting people, through drop ins and virtually via social media, Facebook groups, WhatsApp, virtual groups, Zoom and on the telephone and through websites.

“Mixture of face to face and virtual services can be offered, tailor made packages depending on the needs of the individual, changing as needs change e.g.,

assessments face to face in early support giving followed by virtual sessions to maintain, prevent deterioration.”

7.22 All support should be provided in a timely manner, people are frustrated with long waiting lists, not being acknowledged, phones not being answered. Support needs to be responsive, flexible and recognise fluctuations in (peoples) needs. Only being able to access support between the hours of 9-5 causes difficulties especially for people who work, there is nothing at the weekends or in the evenings. People require access to support 24/7 when they need it most.

“Good mental health support for me would be having a way to access help when I need it, not with a year’s wait, to have someone at the end of the phone who has my file, knows my info, and can offer realistic options, that can support my husband and then make a house call if needed. It needs to be fast not dragged out going over the same stuff and jumping the same hoops just wears me down...”

7.23 When considering who should provide mental health support there was a call for much of it to be developed and delivered by people with lived experience of mental health not by professionals. The ideas of buddy’s and champions were suggested frequently. It was discussed how people with their own mental health needs can and want to offer support to their community.

“In addition to obtaining support, a mixture of giving and receiving support is beneficial – getting something for yourself and giving to others.”

Young people talked about wanting to be given the responsibility to organise their own activities/groups (with guidance but be led by the young people themselves).

7.24 Based on what we have heard we make the following recommendations:

- More emphasis should be given to early support and prevention
- There should be more support available locally and in the community. This should be flexible and accessible
- People should be supported and empowered to set up their own support groups, activities and events
- Support should be co-designed and co-produced with people with lived experience of mental health.

7.26 This report has been shared with BSW Clinical Commissioning Group (CCG), which plans and commissions mental health services for the region and the feedback is being used to help shape and develop local mental health services.

The full report can be read here:

<https://www.healthwatchwiltshire.co.uk/sites/healthwatchwiltshire.co.uk/files/The%20Future%20of%20Mental%20Health%20Support%20Report%20Sep%202021.pdf#>

7.27 Whilst publicising this work, several organisations contacted us wishing to share their experiences. We highlighted this with the CCG and as a result 3 further workshops were held, one in Banes, one in Swindon and one in Wiltshire allowing organisations that support people with mental health to

share their experiences. These took place in late October and we are currently writing up what we heard.

8. Experiences and views of using the Advice and Contact service

8.1 The Advice and Contact service run by Wiltshire Council provides guidance and information aiming to help its users find the support they need. They provide information about social care and other community support and aim to help people live as independently as possible.

8.2 We worked with the Advice and Contact team and carried out our engagement during early 2020, before the Covid-19 pandemic. The work was paused while responding to the pandemic took priority. During March and April 2021, we wrote up the report and met with team members to discuss how to use the findings.

What did we do?

8.3 We gathered information in several ways:

- The Advice and Contact team sent or emailed our survey to some callers who agreed to this.
- We carried out telephone interviews to complete our survey with callers who had given consent.
- We carried out a mystery shopping exercise. Our volunteers made calls to the Advice and Contact team and asked questions based on five different scenarios.

44 people shared their experiences of using the service.

What were the key findings?

8.4 Most of those who contacted the team were calling about care assessments or care support for someone else. Most callers thought they were given enough time during their call and wait times did not appear to affect the quality of information given.

“They got a mass of info out of me. I wasn’t hurried. Took the time to get everything needed.”

8.5 Overall, 63% of those we spoke to were very satisfied or satisfied with the service. Respondents identified several aspects that they thought positive. Key things that were valued were helpful and pleasant manner, listening, answering questions, providing information, and arranging onward referral. However, a notable proportion were not able to identify anything good about the call, suggesting inconsistency of experiences.

“Really pleased with the whole process. Nothing complicated. Couldn’t have been more helpful. Knock-on effect makes Mum feel more secure. Positive results for her — reassured her as she doesn’t want to go into a home, so quick response has really helped to reassure her”

“Nothing. I was left feeling frustrated and having to cope with an enormous situation on my own with no professional support.”

- 8.6 Wait times were the top thing identified that people thought could be improved, followed by advice and information, onward support available and staff approach.
- 8.7 Some of our respondents were satisfied with the call but were dissatisfied with the follow up and/or support that was available.
“At the time I was fairly satisfied but now not so due to lack of response. I think I should have had a response, even a message to acknowledge it has been received and action taken. Really frustrated.”
- 8.8 Some carers and relatives of those who would be funding their own care did not feel they were given enough advice and information to arrange care and support.
“I was just amazed that, even after being in hospital no professional advice was available. I accept paying but needed help to evaluate what my father needed...I thought everyone (and their carer) was entitled to a needs assessment as a baseline, not just dismissed as soon as you have answered the question do they have more than £23K. I know the council has no money but surely they should be legally obliged to do better than this.”
- 8.9 Evaluation of our mystery shopping calls found considerable variation in the quality of responses and felt that some were more helpful than others. Our volunteers identified several things that helpful responses would include such as listening and providing tailored advice, and explanations and information on the range of services available. They also identified aspects that weren't so useful including the use of jargon, and abrupt questioning.
- 8.10 Working in collaboration with the service, the findings of this report have been used to create a checklist for Advice and Contact team. This identifies aspects that were seen being most useful, with the aim that this can be used by team members to support them to improve the consistency of information given.
- 8.11 Based on what we found, our recommendations are that the service:
- Considers what action can be taken to reduce long wait times.
 - Reviews the information given while callers are waiting to see if this can be clearer and provide other ways that people can get in touch.
 - Looks to improve the consistency of the quality of information and advice given. This could include the development of some resource lists.
 - Provides the checklist that has been developed to team members and regularly review it; this may support opportunities for sharing good practice within the team.
 - Develops the advice and information that is available to carers and for those who will be paying for their own care.
 - Considers using the checklist and/or this report as part of the induction of new team members. Healthwatch Wiltshire would be happy to support with this.

- 8.12 As this engagement took place a while ago, we are pleased that some improvements have already been implemented and that this report has been used to identify priority areas for the service going forwards. We are in conversation about how we can continue to work with and support the Advice and Contact team.

Full report can be viewed here:

https://www.healthwatchwiltshire.co.uk/sites/healthwatchwiltshire.co.uk/files/Evaluation_of_adviceandcontact_report.pdf

Next Steps

- 9.1 All of these reports have been shared with the relevant commissioners and providers. We have received positive responses highlighting how the findings from these reports will be used to help inform, shape and develop future work and we will be continuing our work with them to follow this up.
- 9.2 We look forward to continuing to work closely with system leaders to ensure our contribution to health and care services in Wiltshire delivers a positive impact for local people.

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