

NHS Long Term Plan

Focusing on Mental Health in West Sussex

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would you do?
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Executive summary

Background

Improving the provision of support for the mental health of local people is a commitment within the NHS Long Term Plan, for **children, young people** and **adults**. This is supported by an increased investment by at least £2.3billion in real terms by 2023/24.

- It aims to create a more **comprehensive service system** (particularly for people experiencing a mental health crisis) through a single-point of access.
- This should also be achieved through **24/7 support** with appropriate responses from services, including NHS 111 and emergency services.
- It increases the **investment in services for young people** with initiatives such as mental health support teams in schools. It also builds upon the offer for children and young people aged up to 25 years, to reduce issues around service transitions.
- The plan sets out new **waiting time standards** for emergency mental health services to be implemented by 2020.
- There will be a significant redesign and personalisation of community mental health services, including re-establishing substance misuse support within the existing provision.

Understanding what is needed in West Sussex will help to develop a local long term plan to achieve this commitment.

Purpose

We were asked to undertake focus groups to gather feedback from people, as well as gathering peoples' view through a survey.

All the insight has been anonymised and this report will be used to inform the local plans for mental health services in Sussex. The local plans need to be submitted to NHS England in the Summer.

Objectives

We did not ask people to comment on the content of the plan but instead, asked them to think about how mental health improvement could be implemented in Bognor Regis and East Grinstead. We chose two contrasting parts of the county so we could understand what the local differences are and what might be similar.

What people said about mental health support?

Summary of Findings:

What matters most to people in West Sussex?

- Having **safe areas** in the community to help people to stay well and connected. These are safe because they provide non-judgmental relationships and an atmosphere of support and light-heartedness.
- Trusting that **access to services** (including General Practice), with trained/empathic professionals is available promptly when needed.
- Having **information** about support services at your finger-tips.
- Support to understand and **manage medication** is vital to peoples' long-term wellness.
- Getting a **diagnosis** for some was, they felt, something that could help them to move forward with their lives (but was missing).

What did people tell Healthwatch West Sussex?

What works well?

- Being able to self-refer to *Time to Talk* and having this provided free to people is particularly important in low-income areas such as Bognor.
- Having places like *Grandads Front Room* that provide safe spaces, where others can help and support you to stay positive or help you when you *can't do this*. Key is such spaces don't make you feel judged or stigmatised for your mental health.

However, it needs to be recognised that organisers of these groups/facilities need support. Being able to sustain their commitment means understanding the impact of having to deal with business matters/lack of funding and challenges of living their daily life with disabilities.



What could be better?

- Services and society need to make mental health a discussion topic and not a taboo.
- Workplaces need to acknowledge mental health and provide support. Royal Mail was given as an example where there is support, as they now have *Mental Health Peer Supporters*.
- The hours services are available do not match when people need them.

- Doctors need to deal with the causes and not just symptoms. More training is needed to enable general practice to support people in non-medicated ways.
- Have more preventative/earlier intervention support. The lack of psychiatrists within the community has meant people are only getting support if they are likely to be hospitalised or harm others. People in both areas have been told this, which has created mistrust and a loss of faith in mental health services.
- Labelling everyone as having the same traits, when they live with a specific mental health condition, is unhelpful. For example:

Having bipolar does not automatically mean you can't control your spending, it's the opposite, for some of us.

- Reducing the need for form filling, especially benefits forms and mental health questionnaires, is important - people find this stressful.
- Access to information about services. People at the focus groups were not aware of Pathfinder or West Sussex Connect to Support.

People felt this was not so much about creating a *single front door* but ensuring the right people within the community know the information.

Having a mental health information guide, such as the *Street Sheet* (compiled by Grandads Front Room for homeless people) available from GP surgeries and community spaces would be useful.

In focus

- Jenny (who runs a support group for Autistic people) feels there are many people, children and adults who need counselling, but there is no appropriate provision. There is a risk that counselling delivered by people who do not understand Autism could do more harm than good.
- Community Groups need to be supported so they can continue to exist (or find the energy to continue to support others), and this isn't just about money. Any support provided needs to be led by them.

Assessment, diagnosis and treatment

Not having a diagnosis, and/or medication reviews - some people felt this was stopping them from moving forward with their lives.

One working age person told us how he gets *subjected* to a job centre meeting every six weeks. These are to assess if he is still entitled to disability benefits. He is required to take his medication with him (which he does in a large bag) and has been told he has a flag on his file that he is aggressive. He has not been diagnosed but suffers from anxiety and other health issues that are exacerbated by the journey, cost of transport (which is over £15 each time), having to justify his mental state and being in a room full of people who are judging him. He feels that if he could get the right support for his mental health, he could start to move forward with his life. He has now been living with mental

illness for years and attempts to get a diagnosis and treatment (other than medication) have led nowhere.

Accessing GP support

Some of the Bognor group, who were registered patients at Bognor Regis Health Centre expressed concerns over accessing GP support.

You can't get an appointment unless you tell the receptionist what the problem is, and you can't speak to anyone if you call after 10am. They also ask if its an emergency and don't book routine appointments.

I won't tell the receptionist what's wrong because its none of her business!

In contrast, someone said that they had agreed, with their surgery, a password for anything that he feels unable to discuss with the receptionist. Others commented that Avisford Surgery and Flansham Park are very good - if you tell them its personal. Flansham Park also has specific clinicians for conditions such as: diabetes and dementia.

Accessing consultant support

Tracy's daughter needs to see a neurologist and was told there was a six month wait but that if they paid £200, they could get seen by the consultant the following week. They found the money so she could see the consultant the following week, and they were told that she needed an MRI scan and that this would cost £1,000. As this cost was outside what they could afford, they asked to go on the NHS waiting list for the scan but the consultant said no, if they wanted to go back to the NHS they would have to start the whole process again and go back onto the waiting list to be seen by him, in the same place, but on his *NHS day*.

Talking therapies

Paul's story:

Paul suffers from poor mental and physical health and has done, for over half a decade. Several years ago, he asked his GP to refer him to see a psychiatrist because he felt there was something wrong with him and he needed to be diagnosed to get the support he needed. His GP won't or didn't refer him. Feeling he could no longer control himself, he smashed up his flat and tried to commit suicide. He took illegal drugs but was luckily found by a neighbour.

Following this, he got an appointment with a GP, who put him on more medication, which Paul feels gave him other health complications. Although he was referred to *Time to Talk*, but he didn't use this support, as each session would cost £15, which he simply could not afford. The only accessible alternative was the Samaritans, but this would cost double the amount.

Luke's story:

In contrast, Luke told us how he is enjoying good mental health now because of the support his counsellor has recently given him. Luke shared how the loss of his mum had led to anxiety and agoraphobia. A military friend suggested he seek help and he called *Time to Talk* and was given a telephone consultation the next day. They asked him to use their online service *Silver Cloud*, which he did. Whilst he made some progress after accessing this, after a review it was decided that he needed a more targeted, one-to-one approach. He went to counselling and described his counsellor as an *absolute angel*.

Luke puts the success of this support down to the fact he trusted his counsellor because she let him talk and explore his feelings around other issues/things, whilst keeping things relevant to his bereavement. He does not feel he would have felt comfortable talking to someone on the phone, as he likes to read peoples' body language and he felt it could make him feel paranoid if he couldn't. He suggested that perhaps Skype/Video calls could work.

This service was provided free to Luke.

The provision of ongoing care and support

Medication Support

A lot of the people at the focus group are living their lives with medication.

One person in their thirties is on 12 difference medications, including the controlled drugs Zopiclone and Temazepam, and feels there is no follow-up once the drugs have been prescribed. They spoke of not having a medication review, and still waiting on referrals to other services two years on from when they saw their GP.

In their mind you're fine. They know I attempt to overdose but just give me more drugs, with no mental health assessment.

Community/peer support

In both areas people spoke about how important the community support was to them.

In Bognor, *Grandads Front Room* provides an open house, where no one judges you (apart from peoples' tea making ability), where you can have a laugh and take the mickey. Where there is no grief, and everyone keeps you up and they look after you. In turn, you can give back and we heard how many of those attending now volunteered regularly to support the community.

In East Grinstead, the Art Group (which meets every Thursday supported by volunteers and a local artist) also offers a safe; non-judgmental space and peer support. We saw this and how they support each other beyond the few hours they meet each week.

What was being offered, we believe, would not be affordable if it had to be commissioned as a service. That's not to say these community groups do not need funding.

Jenny and Frank's story:

We met a couple who have two children with Autism. Faced with a lack of people/services that could help, they set up a parent support group, over a decade ago. They continue to run the group out of various community facilities (where coffee is topped up freely, as they are not funded and need to keep costs down for parents). Their group also has a Facebook presence.

Their youngest, who is now an adult, has been suicidal since the age of 14. Despite funding being available for counselling, and various professional agreeing they need counselling, no one has been able to find a provider whose staff have the knowledge/skills to communicate with someone who is Autistic. A psychologist at The Bedale Centre was good but could not give the right level of help.

Jenny says her members tell her that the Children and Adolescent Mental Health Service (CAMHS) are not dealing with Autism and are sending people to *Aspens* (formally Autism Sussex) and then their case is closed. They are then 'out of the system'. Her personal experience, of this service is a negative one. As their oldest did not want to take Ritalin, knowing they would become a *zombie*, they were discharged without any further support.

There is nowhere to get support. They won't give a diagnosis and if they do, then transitioning from child to adult services is awful and families are ill-informed. During an application for benefits (at 18) we decided to put our son into education, as we knew he wouldn't cope in work. But when we notified the Department of Work and Pension (DWP) we were told that he should have had a Work Capability Assessment first. We've been told our case has been closed and he would not be entitled to any benefits. As a family we are now really financially up against it and I'm having to do more work, which in turn means I don't have the time and energy I used to have to give to the support group. So many other groups have folded over the last few years - so there is very little support out there.

It took us 2 years to get back into services properly after the transition at 18.

Positively, there are many groups on Facebook supporting people living with Autism and mental health. These are run by people who have found gaps in service provision and need to find support. People who are linked with such groups, and community groups, however, feel there is a huge pressure to fill the gaps and lots of pressure on the organisers of these groups.

In terms of physical groups, these can be hard to find unless you know what you are looking for, or you do lots of research.

When you are in crisis, researching what's out there may be the last thing you want, or can do. There needs to be a community network. No one tells you about these groups.

Community Mental Health Services

Tom's story:

Tom, who is in his late teens, had a breakdown. He was hospitalised. Once discharged, he was referred to the community mental health team, where he met a support worker. He got to know this worker and started to build a relationship with them but then she left. He met another worker and he went from weekly visits to two weekly visits, then three weekly and now he cannot contact anyone at all. He is on medication and feels like a zombie and his life is just stagnating. He did a questionnaire which came back as him being borderline on the Autistic Disorder Spectrum (ASD) but with a comment, that no further investigation was needed. He has requested a medication review to lower the dosage but was having no luck in getting this. However, on the day of the focus group meeting he had received an appointment. This was after a 3 month wait.

Sue's story:

Sue lives with Bipolar Disorder and her mental health care is registered at the Bedale Centre (Bognor Regis). She is on Lithium and has never had a medications review in all the time she has been under their care. She has spoken to a psychologist who has told her that they will not see her now because she is not suicidal or wanting to hurt other people. Sue said,

I'm not bothering to ask them for help. I manage my symptoms and visit Grandads Front Room for support. My friend, who is also under the Bedale Centre, has always had a dedicated mental health worker but they left, and she has to rely on an on-call psychologist, so doesn't bother now either.

Julian's story:

Having lived with mental health issues for many decades now, Julian has seen mental health support decline to the point where it is a fight to get any support.

I'm under the Bedale. Every time my appointment is due, I get a call a few days before, asking if the date can be changed due to the fact that my psychiatrist is now being asked to perform more duties, including the rounds in a safety unit.

I've worked hard on my self to be honest. I've also worked and fought hard to get what I want from the Bedale Centre.

It worries me that there are so many people out there who can't fight for what they want, as they are unable to speak up and therefore get left by the wayside.

Prevention and/or early intervention

The general view was that doctors were only dealing with the symptoms and not the causes and that GPs need more training in understanding mental health and how to support people.

Steve's story:

We met Steve after he had been trying to get support from Community Services in the north of the county but without success. When we met him in preparation for the focus group, he was acutely aware he was going through a crisis. His communication demonstrated he was a risk of self-harming but on checking, he was able to show he had ways of contacting services if he was going to action his thoughts. At this time, Steve was still able to make decisions but some of these were being led by a real fear of being hospitalised and deeply medicated.

Engaging people in health service delivery

What people expect during their treatment journey

People currently feel they have not been treated as an equal partner in their treatment.

They have found it challenging to get their voice heard, both at a GP level and when accessing mental health services and some continue to struggle or have now given up.

People expect to:

- have follow-up discussions to make sure any treatment and/or medication is right for them
- attend appointments and not have these cancelled a few days after being made, or before due

In one case we heard about the person finally getting an appointment with the community mental health team after waiting over a year. This was then cancelled the next day for a reason that would have been known to the service.

What people expect during service change and transformation

People are keen to understand how sharing their stories is going to change anything. Those who have lived with mental health issues for many years have previously shared their experiences and views but have not seen changes, as a result.

Recognising the energy and commitment people have within their community for supporting others is important (many are volunteering in a variety of ways). This also suggests there would be a willingness to contribute - provided people are listened to and not judged, and that what they say is taken seriously.

People expect to:

- understand what is being proposed and how this could improve the access to support and service - given in a way people can relate to.
- have their contribution taken seriously and not dismissed - meaning the responding language at the time needs to do this, as well as any reports and plans.

For example, avoiding making comments like '*that doesn't happen*' to something someone has said they experienced.

Next steps

The STP Executive have expressed their thanks and appreciation to Healthwatch for the work undertaken to gather the insight within this report. The feedback will be reported to the STP Executive and the STP Clinical and Professional Cabinet in July and will inform the development of the system-wide health and care strategy that is due to be published in the autumn. The report will sit alongside the findings of the engagement work that has been carried out by the NHS across the STP around the NHS Long-Term Plan and will act as one of the evidence sources for the actions, recommendations and plans that result from the local strategy.

To ensure there is a clear link between the insight in this report and the development of the strategy, Healthwatch will continue to be involved in the STP Strategy Steering Group and will be asked to provide comment in the final recommendations of the strategy before publication.

In addition to informing the strategy, the feedback in this report will feed into existing work across the STP to ensure 'business as usual' better reflects the needs of our local populations. To achieve this, the report will be shared with all system partners and considered within the development of local organisation strategies and the planning process for 2020-21.

In addition to the engagement work carried out across the STP as part of the local health and care strategy development, a significant amount of public engagement has taken place around mental health over the last two years. This work has fed into the 2019-20 STP-wide business plan, the STP Mental Health Programme and has informed plans for the proposed improvement of mental health provision in West Sussex.

Public engagement will continue across the STP following the publication of the local strategy to track progress and to ensure service users and populations remain informed and involved in the transformation of future services.

Methodology

Consent was obtained from participants and our methodology was established using guidance from Healthwatch England.

The informal nature of the setting meant that we spoke to people without using the PowerPoint or resources, but the presentation was sent to the people who had given us their email addresses.

Acknowledgements

We would like to thank Danny from *Grandads Front Room* in Bognor and the people who attended. Also to the East Grinstead Art Group.

Thank you to you all for trusting us to tell your stories honestly and with integrity.

A draft of this report was shared with the groups and emailed to those who gave their contact details for comment.