



Healthwatch Insight Report on Mental Health

A summary of people's experience of mental health support in West Yorkshire

August 2023

West Yorkshire
Health and Care Partnership



healthwatch
working together in West Yorkshire

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Introduction

Challenges around accessing support for mental health is something that Healthwatch and other partners have consistently heard about over the last few years. A lot of engagement work has already been carried out and insight produced on this topic. Reports produced in local areas highlight the ongoing issues that people with poor mental health face when trying to get support. The pandemic has further added to the existing challenges of providing quality mental health support that is person-centred, timely and delivered in a kind and compassionate way.

Mental health has also been highlighted as one of the priority areas for improving health outcomes in the [joint forward plan](#) published by West Yorkshire Health and Care Partnership (WYHCP) in April 2023.

Based on what people have been telling us about mental health support there has been little improvement or change over the last few years and in many instances things have got worse. The issues outlined in this report come from different geographical areas, populations, and services, however, there are consistent themes throughout. These issues are further exacerbated for people experiencing the greatest health inequalities, with many facing additional challenges.

People have also told us that they are tired of being asked about their experiences of mental health support and not seeing real change. They want to see outcomes based on the many experiences and personal stories that have already been shared.

What are we hearing?

This report is a summary of the key messages around people's experience of mental health support across West Yorkshire. The data comes from a range of sources including previous engagement work and research carried out in local areas by Healthwatch and third sector and statutory partners, enquiries received by Healthwatch, feedback shared with West Yorkshire Voice and reports produced in local places and at a West Yorkshire level.

Based on what we have been hearing about people's experience of mental health support across West Yorkshire over the last few years the following have been highlighted as key themes:

- **Person-Centred Care** – Care should be centred around the needs of each individual.
- **Communication** – Communication needs to be simple, clear, and provided in a format that meets the person's needs.
- **Information** – There should be clear accessible information about what support is available and how to access that support.
- **Access** – People should have timely access to mental health support when they need it and in a way that works for them. People's care should not be restricted by referral criteria or them 'falling through the gaps' because they do not fit the criteria.
- **Coordinated Support** – Services should talk to each other and work together to offer quality support that meets each person's needs.
- **Kindness and compassion** – People should be treated with kindness and compassion and in a respectful way.

- **Health Inequalities** – The additional challenges faced by those with the greatest health inequalities and their needs and preferences should be recognised and supported by all services.

Person Centred Care

It is important that mental health services are flexible enough to meet the needs of different people and communities and are available to anyone who needs them.

“Being person-centred, recognising that the service needs to be designed around the users and not the other way round”.

People want mental health care and support to be tailored to their individual needs and to take account of all the different factors and complexities of their lives. They do not want to feel like another number in the system and want to be seen and heard.

“I want to be seen as a person, not a number”.

“It is like they go through the motions of offering support, but it is not person-centred or individual to me, more a tick box exercise”.

Services need to be flexible and adapt to people's different needs, working in a trauma-informed way and not taking a 'one size fits all' approach. People also asked for a choice in how they are seen, and length of appointments and the type of support they would like.

“I want face-to-face meetings, I am often told to look online, I don’t do online”.

“I would like them to give me more time to sit and talk to someone who will listen to me so I can look after my own wellbeing..... I would also like to have more help with practical things such as information on how to manage mood swings”.

Many people felt that the support offered was inflexible and did not meet their needs. People talked about feeling like they had to take what was offered and a lack of flexibility around the length and type of support they could receive. This resulted in people declining the support or leading to their mental health deteriorating.

“I would like some home-based treatment or support, but they want me to go out and access support, I can’t do this so not getting any help at the moment”.

Communication and Information

Poor communication and a lack of information are consistent themes around mental health support. Many people talk about the lack of information about what is available and simply not knowing where to go for help and support. Others talk about being given a lot of information that they are not always able to process while they are unwell and then having no further information once the support stops.

“I got a lot of information and people calling at the beginning and then it stops”.

“I don’t know what is available. I have not been told who is organising my care”.

A lack of information and not knowing where to go for help has especially been highlighted when people are in crisis. Many people do not know where to go for support and when people do reach out for support this is not always a positive experience.

“I don’t know who to contact in a crisis”.

“I haven’t been helped when I am in crisis”.

People told us that when they did try to get help, the communication was not always clear and consistent, and they were not always kept informed about what was happening.

“I have had a diagnosis and was told a psychologist would be in contact with me to let me know more about this and offer support, but I have not had a letter or any contact from anyone”.

Others highlight the need to get initial communication right when being contacted by a service.

“When they first rang I thought it was like a telesales person. They didn’t say what service they were with and just said, “Is that ...?” And then said, we’d like to ask you some questions. I nearly put the phone down going like, ‘Sorry, I don’t want to do this’ ...so that was really confusing”.

The importance of having good information prior to receiving support is vital. This enables people to understand what will be happening and gives them the best possible opportunity to prepare and participate in their care.

“We didn’t really know why we were being called in other than to review. But in the meeting discharge came up, lots of things came up but I wasn’t told this. So that was confusing for me and hard to understand”.

People also talk about how follow-up information and communication can be confusing, and many are left feeling unsupported or not knowing where to go when they need help and support.

“After my counselling, I was given a number to contact in an emergency, when I rang them, they said they could not help me now”.

“When I was being discharged, I was literally told on the day, with no real warning that that was going to happen, and that was quite stressful because obviously you go from having all the support around you to nothing”.

Access

Access to mental health support when it is needed is a challenge that many people have consistently highlighted. People talk about long waiting times; support not being tailored to their needs, staff being very stretched, and services being reduced or condensed which overall compromises on quality of care when they do access it.

“Personally, I think there is a gap between diagnosis and the help that is available. We had to wait a long time before we were informed about help of any kind”.

“Mental health diagnosis and access to support needs to be significantly easier and faster. People need support at the time they reach out, not months or years later”.

Quicker access to support when in a mental health crisis is repeatedly mentioned as a way to improve support and for waiting lists to be reduced so people are not left waiting for long periods of time and as a result, their mental health deteriorating.

“If someone was in a mental health crisis, you would expect the service to respond in a timely manner. Well, over 7 days is just not good enough for not receiving the proper support that they required at the time”.

“If they had been given the right support with their mental health they would not have ended up in hospital. They would have been able to cope better but were not listened to”.

People also told us about the challenges of different referral criteria making some services difficult to access and resulting in people not being eligible for any service and ‘falling through the gaps’. Others talked about being passed around different services and not getting the support that they needed.

“Having to refer myself to IAPT to be then told I’m not eligible for support there, basically left suffering”.

“I feel like I am being consistently brushed away and failed by this system, and the only way I will get support is if, or when I end up in a serious crisis”.

Coordination of Care

We have heard a lot about the importance of support being well coordinated and different services communicating and talking to one another. This is especially important when people use a lot of different mental health services. When there is good coordination of services this can make things so much easier for the person being supported and means they do not have to keep repeating themselves. When services work together and are all up to date with how things are progressing, they can tailor their approach better and provide better care. Good coordination transforms people's experience and the impact on their wellbeing is tangible.

“They all kind of seem to communicate, so I haven't really got to say the same thing twice too much, which I think is a good thing because saying the same thing three times a week is just really, really irritating. And especially if the thing you need to say is difficult you don't want to have, to have that difficult conversation three times... I think it just makes the care feel a bit more joined up”.

“This is probably the best ever that it's been joined up, especially between different places and between different services and I think a lot of this is to do with my care coordinator, she's very very good. I think it's contributed to how more positive I feel at the moment as well”.

When services do not work well together people often feel like they are passed around and not getting the support they need. Services working on different systems and not talking to each other can have a detrimental impact on people's care and support. People also talk about the frustrations of having to repeat the same information to different staff.

“I feel like I am struggling and get passed from service to service, not able to speak to the person who is supporting me”.

“Every day, someone was ringing. I got mixed up by who they all were. It would be better if all the services spoke to each other and just one person then came to see me and explain things to me”.

Some people told us that better data sharing between services would be helpful to fill in the gaps that exist at the moment and would reduce stress on the individuals and services, especially for those accessing a range of different support.

“It's just not joined up. Everybody is working on a different system, and it does more harm than good”.

Kindness and Compassion

Kindness and compassion and being treated with respect are highlighted as crucial factors throughout mental health engagement work and research. The importance and impact of being treated with kindness and listened to cannot be overstated. People have consistently talked about how their experience of support has been positive when staff have treated them with compassion. Staff can often make the biggest difference to someone's outcome, particularly in times of mental health crisis.

“I felt like they listened to me, and they also got what they wanted out of the situation without it, escalating into a big kerfuffle”.

“Although these nurses and staff weren't specialist mental health nurses, the response I had from them was so supportive and kind and really, really helped me avoid what could have been another really bad situation. And they were completely non-judgemental”.

Equally, a lack of kindness and compassion has resulted in people having poor experiences. This has especially been highlighted when people are accessing crisis services.

“Staff need reminding how it feels to contact mental health services for the first time or be vulnerable and reaching out for help, they lack empathy and compassion, and this is from professionals who should know better”.

“Staff are not really helpful when you call them, they can be dismissive, they need to show more kindness and a caring attitude”.

People talk about the variation with some staff being supportive and positive, but this is not consistent. When people have poor experiences and are not treated with respect and listened to, this leaves them feeling like they have not been heard and reluctant to seek help again.

We have also heard about people falling in between services when they are ‘too ill’ for one service but do not fulfil the criteria for another service.

“I had tried the core team and crisis team, and all said they were not the right people and couldn’t help so I ended up in A&E”.

Health Inequalities

Based on all the insight and engagement already available we know that certain groups and communities who face the greatest disadvantages in life also have poorer mental health. In addition to facing mental health inequalities, these groups and individuals face additional barriers when accessing support for their mental health resulting in much poorer experiences and outcomes. People’s experience can be impacted by many factors including trauma, financial hardship, social disadvantage, and discrimination and dealing with multiple long-term health conditions. For many people, there is a mistrust in services and a reluctance to seek help based on previous negative experiences.

This section documents the additional challenges faced by some groups and communities. It is important to recognise the impact of discrimination and disadvantage on people's mental health, however each person's experience is unique to them, and they will be impacted differently by different factors.

Carers

People who are caring for someone with mental health issues talk about the many challenges that they face when trying to support the person they care for. This includes a lack of support when needed, not being involved in conversations about the care and support for their loved ones or being listened to, having to deal with their own health issues along with the additional stress of being a carer and a lack of support for them as carers.

“Often we need support on a night or weekend and crisis support services just tell us to call the police, that makes the situation so much worse”.

“Often, they will be discharged back to live with the carer, but the carer won't be consulted or told what will happen next due to 'confidentiality' which sets everyone up to fail”.

“I am a carer, I don't feel listened to and included in any decisions or given any information. Mental health affects all the family, they don't think about this, and I'm told they can't tell you anything as they are over 18”.

We have also heard from people caring for someone with dementia and the challenges faced when trying to get support for their loved ones. People talk about a lack of understanding of the impact of caring for someone with dementia or their mental health and wellbeing and the lack of support available.

“No one seems to recognise mental health of someone suffering from dementia and the impact it has on the loved ones who care”.

Some carers also talked about the challenges of being an older person and a carer. There is sometimes a lack of flexibility in how support is provided, and the help offered to them.

“But wouldn't it be easier for the medical professional to come and see them at home, for ease wise for the person, but also the taboo of speaking about mental health? We are of the generation that mental health is not spoken about otherwise you are locked up”.

When carers can get help for themselves and when the support offered to their loved ones meets their needs, they can have positive experiences and outcomes. Many times, this support comes from third sector and other support organisations and not mainstream services.

“Community mental health services could learn a lot from [...] and the third sector organisations”.

“I am a carer for a family member with mental health, I am getting good support to help me with this”.

Culturally Diverse Communities

People from culturally diverse groups face many additional challenges when accessing support for their mental health. It is important to remember there are huge variations between different groups, communities, and their personal experiences. Intersectionality also plays a huge part in shaping people’s experiences and outcomes.

We have heard about some key themes that impact the experiences of people from culturally diverse groups and communities. These include language barriers, the impact of culture and faith, discrimination and racism, stigma around mental health, mistrust and a lack of accessible information, services, and support to meet their needs.

“It is difficult to access any service with the word “mental” in the title because that is synonymous with “crazy” and carries a lot of stigma”.

“My English is OK, not great, but I cannot always understand the support offer”.

People want to be supported by services that understand their needs and by people who look like them and in places that they feel comfortable in and are familiar with. People talked about the importance of taking services and support to people and where they already meet, rather than expecting people to come to where the services are provided.

“To make me feel welcome I would need to see people that look like me or I can feel comfortable with”.

People valued opportunities to have discussions and receive support for mental health in an environment or setting where they felt safe and comfortable. People also commented on the need for open conversations to remove some of the stigma and to promote a more preventative approach to mental health rather than waiting until people have reached crisis point.

“I’d like more opportunities to discuss men’s mental health and wellbeing. In our group, people support and listen to each other’s stories and conversations”.

Children and Young People

We have heard a lot about the experiences of young people and their families trying to access mental health support. People talk about the frustration of long waiting lists and limited access to services and support when needed. The wait can be debilitating for those in need of treatment, leaving people in limbo.

“It is difficult to get help with mental health for children, getting the right services and getting assessment done. Families wanting help and support for their mental health are just put on long waiting lists”.

“Waiting lists are lengthy and appointments short. I’m on a list for support BUT with no idea how long I’ll be waiting”.

“I am forever calling to speak to my child’s CAMHS doctor and they never call back. It gets to crisis point”.

“My son waited 4 years for an assessment. He now has a diagnosis, and I was advised 12 weeks before he could see a psychiatrist for medication. I have now been informed it’s not 12 weeks it is over 10 months. This is not acceptable. I have a child who is struggling with everyday life and to be told 12 weeks and then over 10 months is disgusting”.

However, when people receive the support that they need in a timely manner this results in a positive experience and outcome for the young person and family.

“My son was seen very quickly by the crisis team. They came to our house every week to speak with him, which was very helpful. They offered a lot of support to him and reassurance to me and made a big difference to his mental health. He has now been discharged and is in a much better place thanks to the team”.

Some concerns have been highlighted about young people with mental health problems who fall between CAMHS and adult mental health services and get lost or disengaged during their transition. The lack of provision and support during transition can have tragic consequences for young people and their families. There needs to be better communication to support the transition between services and both the children and young people and parents need to be supported.

“Found difference from child to adult services[...]Once they reach 18, parent becomes ignored”.

“Unable to access support for mental health and problems transitioning from children's services to adult services”.

Young people have also talked about the need for services to be person-centred, offering different types of support and not be time limited. Others talked about the need for the environment in which support is offered to be less clinical and more young-person friendly and the positive effect that this can have on people.

“It feels a bit more like staying at like a hotel, it’s not clinical. It looks more cosy, you’ve got proper duvets, and they don’t refer to you as patients or service users, they refer to you as guests, which I think is quite nice. They prioritise the actual supporting people, talking with people, even just sitting with people”.

“The waiting area is bland, nothing to interact with, it’s off-putting, not welcoming”.

Schools and colleges were highlighted as a crucial resource in the prevention and early intervention of mental health problems, by both young people and adults. People told us that it was important to support young people and to have skilled, knowledgeable staff available in educational establishments with adequate mental health training.

Autism and Mental Health

Many people have talked about the challenges of getting support as an autistic person and the issues around being passed between services and not being able to get support for their mental health. People told us that having a diagnosis of autism impacted their ability to access mental health support and excluded them from particular services. Staff appear unwilling or unable to support people with a dual diagnosis of mental illness and neurodiverse conditions.

“I don’t feel respected as an autistic person and wish to have treatment tailored to my particular situation, concerns and priorities”.

“As soon as I got an autism diagnosis, they want to shove me off to the autism services, but I have both conditions and should be supported holistically for both mental health and autism and not separate them”.

“I am currently getting support from mental health services but if I go for autism specialist support (out of area) it would mean I would not be eligible for support from mental health services locally which is not fair”.

Feedback from West Yorkshire Voice Check-In

We have also reached out to members of the West Yorkshire Voice network to check in about people's current experiences around mental health care and support.

We put out a short survey and received 188 responses. The responses came from across West Yorkshire: Bradford District and Craven (53), Calderdale (31), Kirklees (19), Leeds (39) and Wakefield District (46).

Key Messages

People who are in crisis report being left alone with no support. There is a lack of options and sources of information about what crisis help there is. Some people described being re-traumatised by the interventions and poor practice when they were in crisis.

Waiting a long time for help with no information about when they may be offered support was a consistent theme. Some people were not offered any support after waiting for many months and were told they were either not in severe enough need or their distress was too complex for the services available.

“I genuinely feel that the NHS has at many times simply thrown me away to die”.

Getting a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD) was identified as particularly slow and many people reported that this has made their mental health distress much worse.

Communication has been difficult for many people, some describe facing judgemental and disrespectful attitudes from staff, lack of listening skills, poor practice around confidentiality, not returning calls/emails, being put on a waiting list, and getting no communication about how long the waiting time will be.

“Dreadful communication. They send letters/emails frequently but it's always the same stock email with crisis numbers on it”.

Cognitive Behaviour Therapy (CBT) has helped some people with coping strategies, but many people said that it doesn't address the causes of their distress.

“Didn't actually get any counselling to help understand the causes of the issues”.

Lack of knowledge and cultural competence, discriminatory behaviours and inaccessible unsuitable ways of working were reported by older people, LGBTQ+ people, people who have a learning disability and neurodivergent people.

“LD mental health dreadful”.

Staff welfare was also mentioned by many people who recognised the impacts of staff shortages and burnout.

What people told us was good about the support

Some people received support from staff who were compassionate and had a good understanding of people's needs:

“Staff very caring. Listened. Offered advice on an online support programme and wellbeing workshops to attend while waiting for a face-to-face appointment”.

“Brilliant care coordinator, who always listens is compassionate and great at signposting”.

“The therapy was good, and the staff were very patient when dealing with communication needs and have time to explain”.

We received a lot of positive feedback about community-based peer support programmes.

“Meet other people with lived experience of mental distress. I have made acquaintances and friends. I met my best friend via a peer support group. Accepting environment. Can just turn up and get social contact. Don't have to organise it myself”.

What carers and staff told us about their experience

Difficulties accessing services and information, long waiting times and lack of options for suitable support for their friends and family members were also reported by carers.

“Horrendous being the parent of a youngster and trying to access support for them while watching them collapse in front of your eyes. Much more needs to be done for under 16's”.

People described the negative practical, financial and health impacts.

“I'm having no support at all, she has been referred 5 times to Meridian House, but they've not done anything, this is taking a toll not only on my health but my family's too”.

“I have had to adjust work so financially it has had a big impact, being a single Mum dealing with this on my own”.

Many staff also described the difficulties of finding good support:

“It’s extremely hard when people are bounced between services and no one takes ownership, when a patient is seeking help. When my client called Crisis they said they were too busy and to go to A&E. When she did they referred her back to her GP. Appalling”.

“I have supported several people who have slipped through the net of support. It’s not my job but I think because I listen and empathise, people come to me. I have found it exceedingly difficult to get the right help at the right time for the person’s needs”.

What people told us could have made their experience better:

- Better and immediate crisis support, and clear information about how to access crisis services.
- More therapeutic options for support especially additional to or instead of medications and Cognitive Behavioural Therapy (CBT). They want more self-referral routes to support (some that are not reliant on the GP) and more community-based options.
- Better cultural competence, awareness and understanding of neuro-divergence, gender variance and the barriers faced by people from marginalised communities.
- Better communication by staff including returning calls and updating on waiting times, respectful and non-judgemental attitudes, better listening, better accessibility standards, better practice in confidentiality but also information sharing to reduce the need for people to keep repeating their experiences.

Key Messages/Recommendations

- **Person-Centred Care** – Care should be centred around the needs of each individual and should take account of every aspect of people's lives. People should be fully involved in their care.
- **Communication** – Communication should be simple, clear, and provided in a format that meets the person's needs. Good communication greatly improves people's outcomes and minimises some of the harm caused by lengthy waits for treatment.
- **Information** – There should be clear accessible information about what support is available and how to access that support. The information should be provided in a format that meets the needs of the individual.
- **Access** – People should have timely access to mental health support when they need it and in a way that works for them. People's care should not be restricted by referral criteria or them 'falling through the gaps' because they do not fit the criteria.
- **Coordinated Support** – Services should talk to each other and work together to offer high-quality support that meets each person's needs, especially for those that have multiple and interacting health conditions. Good coordination can lead to a positive impact on people's wellbeing and make people feel safe and in control.
- **Kindness and compassion** – People should be treated with kindness and compassion and in a respectful way. There is a key link between compassionate care and people's confidence and trust in services and better outcomes.
- **Health Inequalities** – The additional challenges faced by those with the greatest health inequalities and their needs and preferences should be recognised and supported by all services.

References

List of reports and documents reviewed

West Yorkshire Health and Care Partnership (May 2022) Involvement and Consultation Mapping.

West Yorkshire Health and Care Partnership and NHS West Yorkshire Integrated Care Board (Autumn 2022) Mapping Report to support the development of the five-year strategy refresh and joint forward plan.

Healthwatch and West Yorkshire Integrated Care Partnership (August 2022) Healthwatch insight Report – What people across West Yorkshire are telling us about their experience of health and care services.

Healthwatch Calderdale and Healthwatch Kirklees (April -June 2023) Feedback on mental health services in Kirklees and Calderdale.

Healthwatch Calderdale and Healthwatch Kirklees (Jan – March 2023) Accessing Mental Health Services.

Healthwatch North Yorkshire (May 2022) Mental health and well-being: young people's experience.

Healthwatch North Yorkshire (July 2023) The public's experience of mental health services in North Yorkshire.

Leeds Health & Care Partnership (January 2023) Insight Report: Mental health.

Healthwatch Leeds and The Big Life group (August 2023) Report on the existing knowledge of culturally diverse communities' experience of mental health services.

Healthwatch Leeds (December 2021) Community Mental Health Transformation – What people told us was important to them when getting mental health support).

Co-produced workshop in Leeds (March 2020) Young Women's Mental Health Outcome Based Accountability Report.

Centre for Mental Health (June 2023) Mental health needs and assets for racialised communities in Bradford.

Centre for Mental Health (July 2020) Bradford and Craven: Independent system-wide review of children and young people's mental health services.

Bradford District & Craven Health and Care Partnership, QA Research, Listen In – Hearing from local communities about what matters most (October 2022) Listen in Report: Craven.

Bradford District and Craven Health and Care Partnership (June 2023) Update from the Healthy Minds Partnership Board.

Community Mental Health Transformation Leeds (June to July 2023) Engagement summary.

Community Mental Health Transformation Leeds (March to June 2023) Engagement Summary.

The Big Leeds Chat (2021) What did we learn at the Big Leeds Chat 2021 - A collection of conversations about what matters to people in Leeds in terms of staying healthy and happy two years on from the start of the COVID-19 pandemic?



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