



Mental health: What matters most?

Your feedback and experiences of
mental health services in Wiltshire



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Introduction & background

During 2018, Healthwatch Wiltshire asked local people what they thought our priorities should be for the year ahead. Mental health was chosen by many as a key area we should be focusing on.

Previous work by our Healthwatch Young Listeners also highlighted that mental health was a concern for young people¹, while nationally, concerns were raised about the experience of people using mental health services.

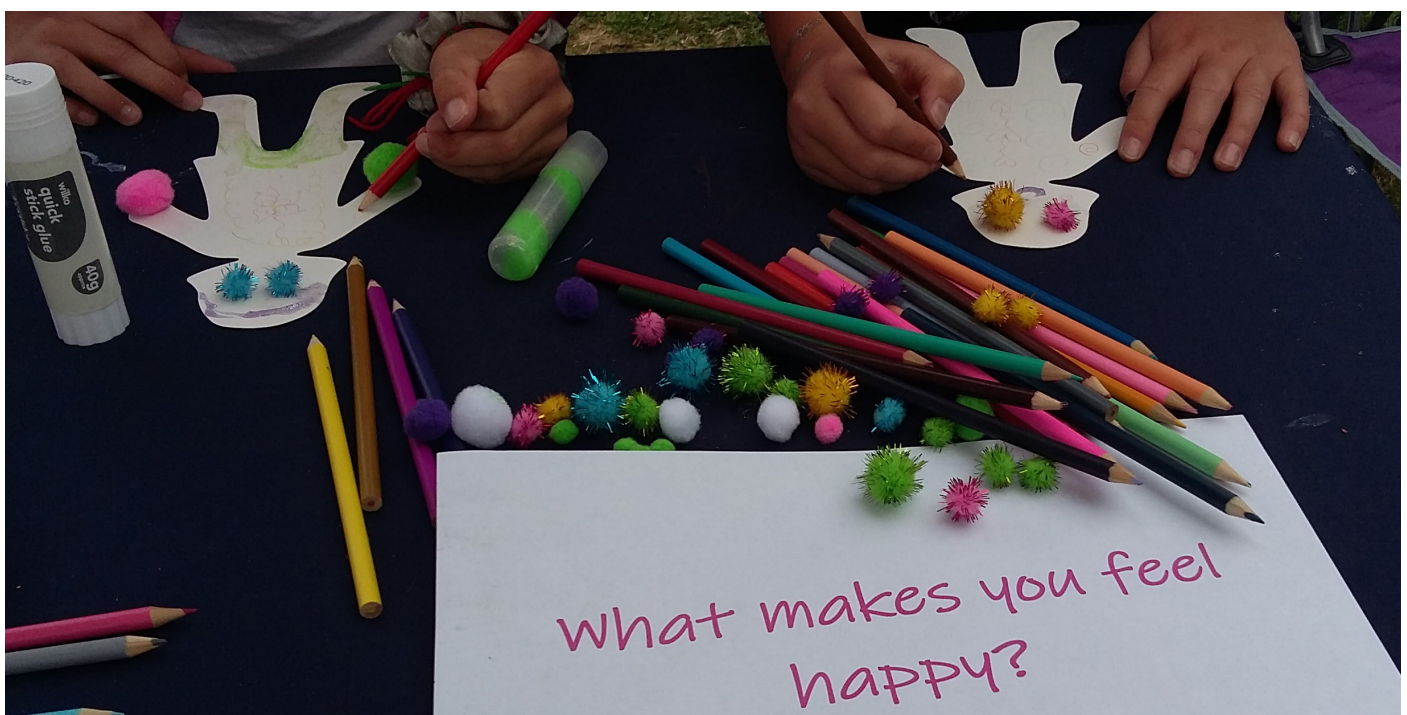
Results of a recent national survey published by the Care Quality Commission (CQC) indicated that people's experiences of mental health care have deteriorated in recent times. This report highlighted that access to care was a concern, and a quarter of their respondents reported they had not seen mental health workers enough to meet their needs over the past year.²

Healthwatch Wiltshire wanted to find out more about which areas of mental health services local people felt we should focus on and to gather some initial feedback about experiences of using mental health services.

For references, see page 20

Our volunteers

Healthwatch Wiltshire has a team of committed, trained volunteers. Our volunteers supported this engagement by sharing our survey, attending events, carrying out interviews, carrying out an enter and view visit, and entering data. Twelve volunteers contributed a total of 50 hours of their time.






Our approach

We designed a short survey which asked people to choose one area they thought we should focus on from these survey options, and to tell us the reasons for their choice.

In determining the survey options, we took into account previous experiences of using mental health services that had been shared with us, people's views at a mental health peer support group and we consulted with Avon and Wiltshire Mental Health Partnership NHS Trust (AWP).



Survey options

- Access to mental health services
 - Crisis support and care
 - Experience of discharge
 - Mental Health Services for Children and Young People (CAMHS)
 - Community support
 - Mental Health in-patient care
 - Transition from Mental Health Services for Children and Young People to Adult Mental Health Services
 - Other
- 

We also asked people if they had experience of using mental health services in Wiltshire or knew someone who did and, if so, asked them how this had gone. We kept these questions quite open to gain an overview and some initial insight into people's experiences.

Between August and November 2018, we arranged to visit several events across Wiltshire. These were planned to reach a variety of people living in Wiltshire and to cover as much of the county as possible. During these events we asked people if they were happy to complete our survey and gave out information about Healthwatch Wiltshire. We spoke to a range of people including younger people, families and older people, and people who had used mental health services and their families.

We found that most of those we spoke to were very willing to complete our survey as a 1-1 interview, and there was a lot of interest and support for mental health being one of our priority areas.

Some of the events we attended were aimed at families. During these events we took paper outlines of people and colouring materials. Children were invited to decorate a person and to tell us what made them happy. This proved to be a popular activity and also gave us an opportunity to talk to their parents whilst they were doing this.

Our survey, which was also available to be completed online, was shared with voluntary and statutory agencies and promoted through mail outs and on social media.

We carried out some targeted engagement at mental health outpatient settings, a specialist care home and a mental health support group. During these events, we had more detailed conversations with people there about their views and experiences of using mental health services.

Both the surveys we used are shown in the appendices at the end of this report.



Above, Five Rivers Health and Wellbeing Centre, Salisbury, and below, Fountain Way, Salisbury





How were people involved?

Our survey was completed at the following events or locations:

Event and location	Surveys completed
Warminster Library	16
Five Rivers Health and Wellbeing centre, Salisbury	10
Lackham College Freshers Fair	30
NSPCC Ashdown Family Centre, Tidworth	13
Chippenham College Freshers Fair	19
County Hall, Trowbridge	23
Melksham Dementia Roadshow	6
Rowde Family Fun Day	34
Salisbury Hospital	6
Emergency Services Show, Kemble	30
Heathwood Reception area, Fountain Way, Salisbury	6
Tidworth Garrison Theatre Allied Services Meeting	19
Children and Families Voluntary Sector Forum, Potterne	9
Total completed face to face at events	221
Surveys returned by post	29
Surveys completed online	72
TOTAL	322

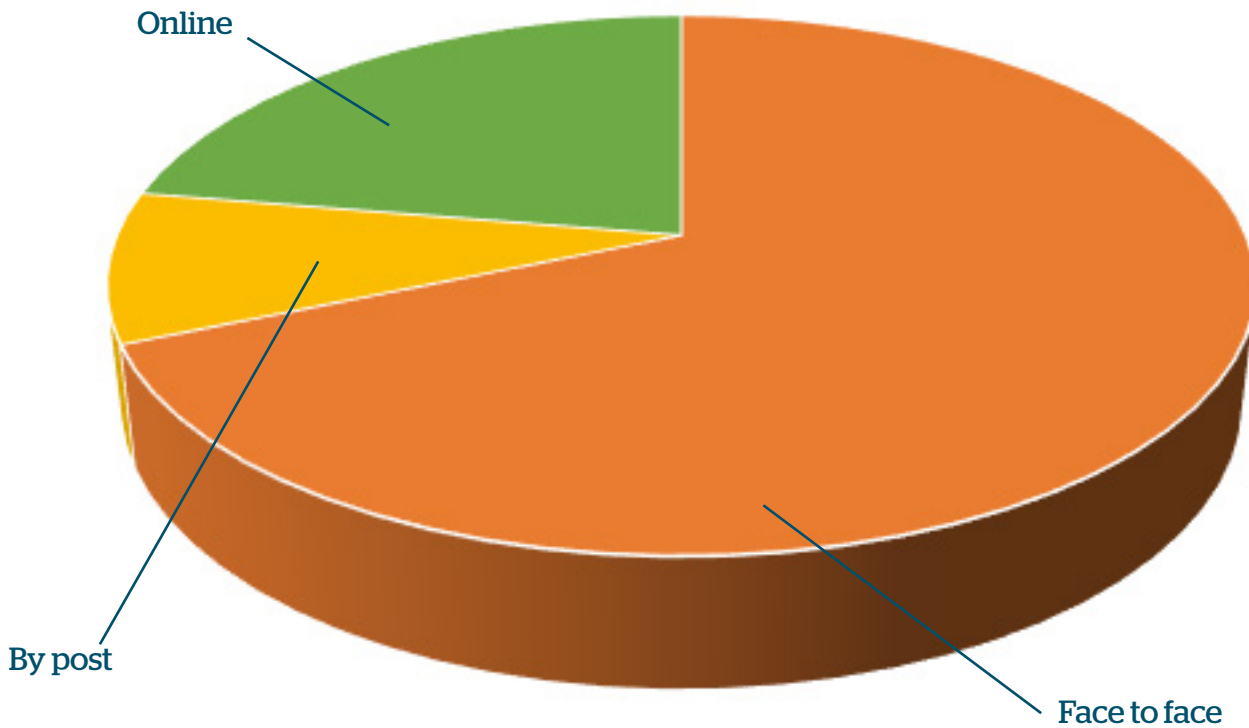
We had in depth conversations with people at the following locations:

Service	People spoken to
Trowbridge 'Service Users' group	8
Green Lane Hospital Reception area, Devizes	4
Heathwood Reception area, Fountain Way, Salisbury	8
Ashgables Care Home, Chippenham	4

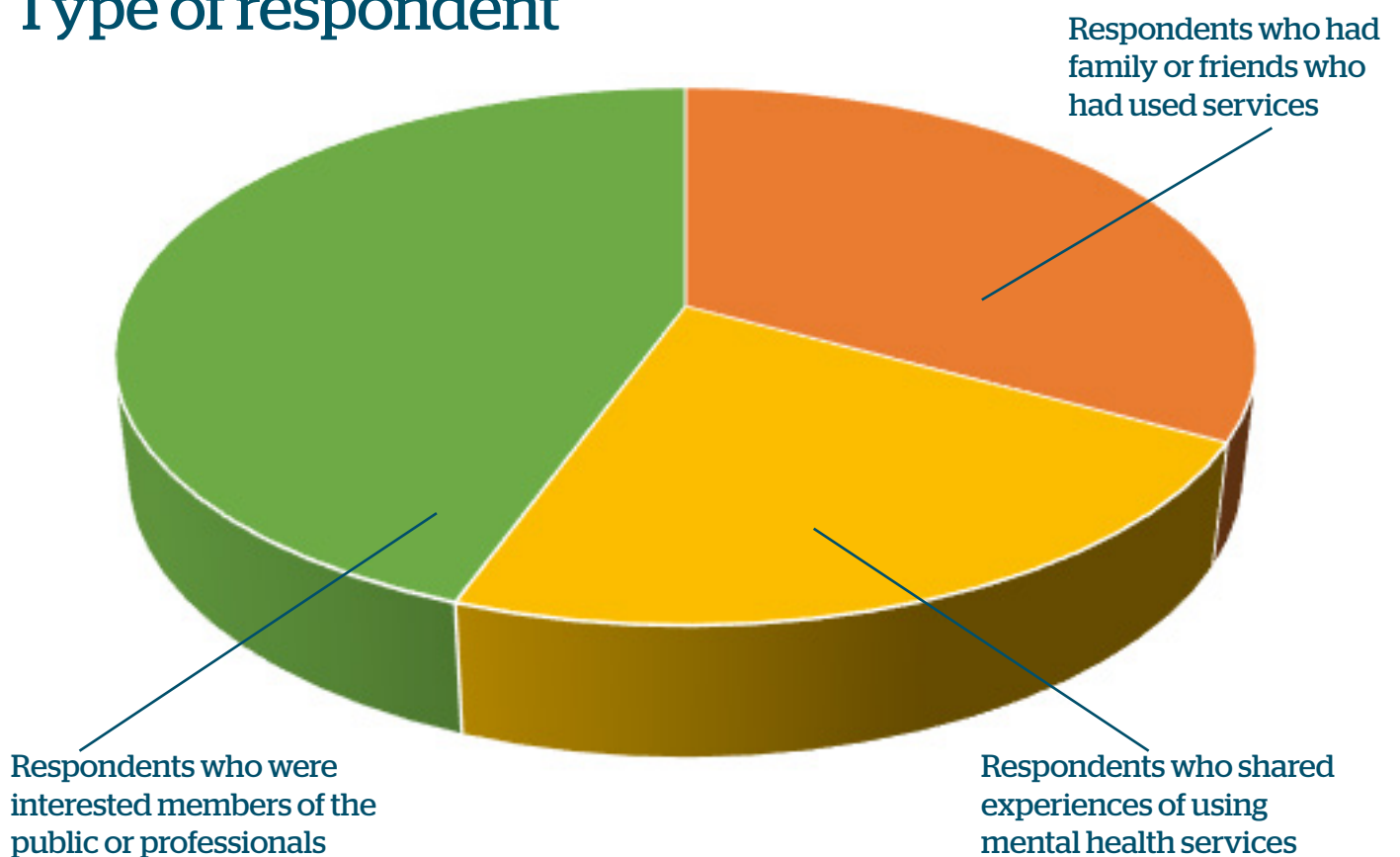
And here are the numbers:

Total number of responses	346
Respondents who shared experiences of using mental health services	114
Respondents who had family or friends who had used services	78
Respondents who were interested members of the public or professionals	154

Surveys completed



Type of respondent



Additionally, about **100** children were involved in decorating a person and telling us what made them happy.

Key messages

- Access to services was chosen by most respondents as a priority and there was concern about long waiting lists.
- Difficulties with access due to stringent criteria and complicated access pathways was reported.
- There was concern about quality of mental health services.
- Crisis support was thought to be crucial to provide support in difficult times.
- It was thought to be important to maintain people's mental health so that they are supported to remain active in their local community.

People who suffer from mental health problems are not given enough help from NHS services. The NHS needs severe rationalisation and equal funding of care.

Overall there was widespread support that mental health was a priority area for Healthwatch Wiltshire. Several people mentioned that they did not feel that mental health issues were treated in the same way as physical health issues and that this was a concern.

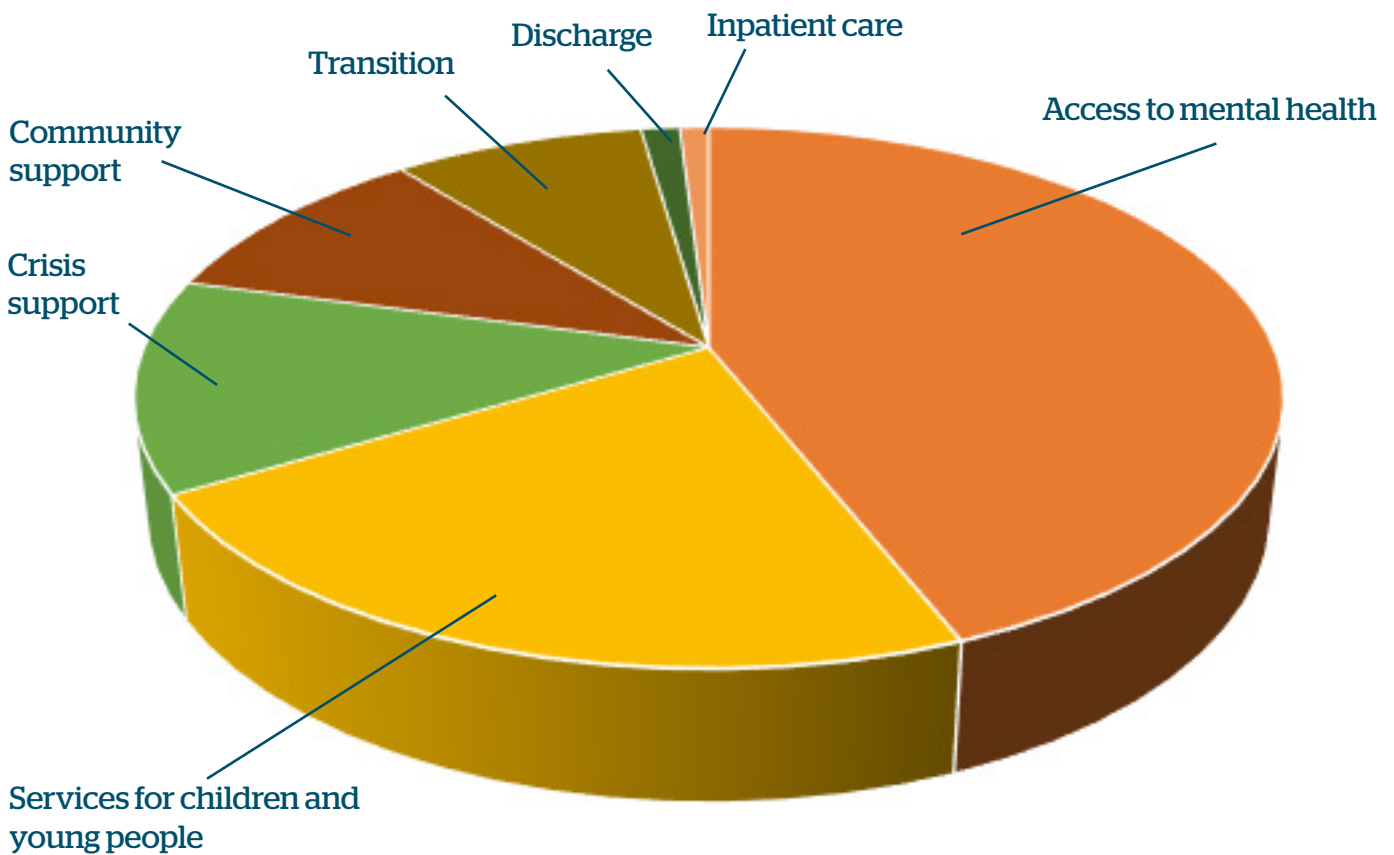
Some people told us that they found it difficult to pick just one area as a priority and thought that all or several of the areas were important. Many of these gave feedback about several different areas. Although this does not form part of the rating of each area, the feedback is included in the analysis of each area.

The graph on page 9 shows the breakdown of what were thought to be the main areas of mental health that should be focused on.

Mental health is nowhere near physical health in priority. Access is the start, same as access to physical health services.

Separation from physical health creates a massive stigma, labelling people.

Priorities



Survey option	Number of responses
Access to mental health services	44% (135)
Mental Health Services for Children and Young People	22% (69)
Crisis support and care	12.7% (39)
Community support	10.1% (31)
Transition from Mental Health Services for Children and Young People to Adult Mental Health Services	8.5% (26)
Experience of discharge	1.3% (4)
Mental Health in-patient care	1% (3)
Not answered	(15)

Comments about people's experiences

We collected 314 comments about people's mental health experiences from our open-ended survey questions (see Appendices, page 23). Many people we spoke to gave their feedback on more than one area of mental health.

Of the 314 comments, 26% were positive, 65% were negative and 9% were neutral.

Access to mental health services was the main area highlighted for us to focus on with 135 people choosing this option, representing 44% of the total responses.

We looked at the reasons that this area was chosen. The most common reason stated was that people either had experienced or knew someone who had had difficulties in accessing mental health services in Wiltshire.

Of those who talked about their experience of difficulties accessing services, the most common issues reported were long waiting lists and not meeting criteria for services. Several people told us that they had paid privately for counselling services because they had been unable to access them through the NHS.

Other concerns mentioned were:

- Difficulties accessing services out of hours.
- Lack of awareness about available support.
- Unclear referral processes.
- Problems transitioning between services.
- Lack of access to a range of services including psychiatrists, and services related to bereavement, post traumatic stress disorder and military redeployment.

The second main reason for people choosing access was that they felt it represented the ‘way in’ to all other mental health services and therefore would be important to everybody who needed mental health support. The importance of ensuring timely support to prevent issues getting worse was emphasised.

It was also commented that a positive initial response to asking for help could influence people’s views of services and lead to more positive interactions, with treatment, as well as a willingness, to seek help if it was needed again.

All are important, but access to mental health is most important as otherwise no other services.

All people need full access to support. Also a full range not just reliance on CBT which is often a sticking plaster not a solution.

Putting barriers between anyone seeking help and their care tends to generate problems. Early intervention is important and should be better supported.

Many of those we spoke to talked about their experience of accessing mental health services for themselves or for family members. Several people said that they had reached crisis or near crisis point before they had been able to access services and commented on the effect that this had on their physical health and wellbeing, and that of their families and carers.

Where people had been able to access services they told us that this had benefited both their mental and physical health.

Waiting for over a year for appointment. Referral as GP didn't want to prescribe antidepressants until seen by psychiatrist. Didn't tell me how long the wait was, not getting any support at all.

People in crisis need to feel supported because it may be their first experience and could shape how they view their care and advice from that point of access.

I have been denied access to mental health services although at times I find it very difficult to cope.

When my child became very mentally ill it was very difficult to get the help he needed quickly, furthermore if various problems that had been raised with CAMHS earlier had been addressed then maybe he wouldn't have reached the crisis point he did.

Case study

An experience of accessing mental health support was shared with us.

The person described how they were experiencing depression, anxiety, an eating disorder and a lack of motivation. They felt that they were "spiralling down, out of control and unable to help myself."

They received 12 sessions of Cognitive Behavioural Therapy (CBT). They told us that this had enabled them to lose weight, start exercising and resume previous hobbies. Their blood pressure reduced as did their joint pains.

They told us that they believed this had prevented the need for costly NHS treatment for physical problems and said: "the mental health support and CBT was the start of it all."



Services for children & young people

The second most important area that people said we should focus on was mental health services for children and young people. Of those we spoke to, 22% (69 people) thought that this should be a priority area. In addition to this a further 8.5% thought that transitions of services between young people's and adult mental health services should be an area of focus.

One of the main reasons given for choosing this area was concern about accessibility of mental health services for children and young people (NHS Child and Adolescent Mental Health Services, or CAMHS). Our survey respondents thought that there should be prompt access to services so that mental health issues could be tackled early.

Another reason mentioned for the importance of this area was that it was felt that there are more young people now in need of support. It was thought that support in schools was a good opportunity for early intervention and that the availability of this could be improved.

A high number of people we spoke to had either used or tried to access mental health services for children and young people. They told us of their concerns about long waiting times to be seen and said that they felt the criteria for accessing services was too stringent. They said that both these factors meant that mental health issues that might have started off as relatively minor were getting much worse before support was put in place.

There was concern about the effect of this, both on the young person and their family and about the impact this might have on services, if young people then needed more complex and long term support.

Many of those we spoke to said they felt that mental health services for children and young people were very overstretched and could not cope with the demand for their services.

There were a total of 50 comments about access to services for children and young people. Of these three were positive, 46 negative and one neutral.

The world has changed, younger people seem to grow up faster, it should be taken just as seriously.

By concentrating on the younger 'end', we might reduce/alleviate the problems for the future.

Incredible difficulty accessing CAMHS for children in great need.

I was referred to CAMHS - later discharged although I felt I still needed the service. I was discharged because the suicidal thoughts went but I was still hearing voices and felt I needed support.

CAMHS - This went very well, approachable, understanding.

The threshold for going to CAMHS is so high. The child often doesn't meet the threshold. The waiting list is long – by the time they are seen, the mental health condition can be quite entrenched.

Transition from children and young peoples to adult's mental health services was also highlighted as an area that we should focus on with 8.5% of those we spoke to choosing this as their priority. We were told that this is often not a smooth process. There were several comments from people saying that differences in the criteria between services had meant young people who had been using mental health services were no longer able to access them when they became adults.

I have heard from people how once they reached 16-18 they were almost 'dropped' as if to say you can now get on with it. Also a lot of mental health in adults stems from childhood.

We work with adult services and find that children going through transition don't always get continuity because of how differently the two services work.

Case study

An experience of transition was shared by a parent whose child had been supported by children and young people's mental health services.

When the child reached 18 this stopped and was followed by several different assessments for different services.

They were told that their child was not ill enough to receive support from the community mental health team. Following advice, they also requested assessments from Mind and IAPT (Improving Access to Psychological Therapies) and were told that their child was considered too ill for their services.

The parents said they felt that they had to support their child and constantly chase various services for support during which time their child's mental health considerably deteriorated.

We heard of several similar concerns.



Services for children & young people (continued)

Views about the quality of services for children and young people were more mixed and there were many more positive comments. Of the 61 comments received about this 27 were positive, 23 were negative and 11 were neutral.

The positive comments highlighted that receiving services had benefited young people including increasing self confidence and supporting them to cope with traumatic events. Negative comments mentioned that some people didn't feel therapies worked for them, and others felt that support was withdrawn too quickly.

My child is under the services and is doing well with the support. There when you need it.

My daughter has been really well supported and actually did get a quick referral.

Counselling goes along but sessions end abruptly and didn't get the chance to have proper access.

I've had experience of CAMHS and they were good. Helpful and made me more confident.



Crisis support & care

The third priority area from our survey was crisis support and care. 12.7% of survey respondents (39 people) said that this was something we should focus on. There were several reasons given for choosing this area:

- Crisis support was thought to be crucial in making a difference at a difficult time.
- It was felt that immediate support could prevent things getting worse.
- The need for crisis support for domestic abuse and homelessness were mentioned.
- There was concern about the quality of crisis support.

People shared their experience of accessing or trying to access mental health crisis support and care. There were concerns that support in this area was inadequate and not able to respond quickly enough.

We were told that out of hours support was difficult to access. There was concern that unpaid carers, family members and friends often had to step in, and about the impact that this had on them.

However some people who had received crisis support told us that they received quality support and it had been beneficial.

Crisis events really test people and to have clear, unambiguous support services/channels is a lifesaver.

It was good with the support. Was reassuring.

A friend in crisis was lucky enough to get support from friends. Professional support got lost in the system.

Slow response and unsupportive in times of great crisis. You feel at a loss. Some life and death situations.

Personal experience of lack of support during times of crisis. Not reactive enough, poor ongoing/preventative support.



Community support

Community support was chosen by 10.1% of our survey respondents (31 people), making it the fourth area of focus. The main reason given for choosing this area was that it was felt that it was very important for people's mental health that they could remain active in their local community and not become isolated.

It was said that, as most people with mental health issues were living in their local community, it was important that mental health support was available there. Our survey responses mentioned that both psychiatric and social support should be available in the community.

People talked to us about their experiences of community support. A general theme was that it was felt that there was too little of this available and that it was sometimes needed for a longer period. People also said that the pathways for accessing community mental health services could be complex.

Several people told us that they found counselling services helpful. Some of these had received this through the NHS and others told us that they had paid for this privately. People felt that more NHS funded counselling should be available.

We were also told that community support groups were valued. This included peer support groups and activity groups. Online support and phone lines were also mentioned, but it was stated that people often didn't know about them.

Some mental health service users told us that they had received good quality community support and were very appreciative of this.

I think a lot of mental health problems are the result of social isolation and lack of support in the community. When people are discharged from hospital they need continuing support in the community.

You have to be in crisis before you get any support. I have a plan which tries to stop me from going to A&E but the only way I can get help is by going to A&E.

Support and activity groups provide ongoing peer support and social inclusion e.g. wellbeing through nature or therapeutic gardening groups.

Very grateful for looking after me. We are really beautifully looked after, people do check up on us.



Other priorities

Inpatient care

A small number of people thought that inpatient care should be the first priority. Here, a shortage of beds was mentioned. Some issues around care and dignity at inpatient hospitals were mentioned. These related to the attitude of some agency workers and showers which we were told only allow water for three minutes. However, overall, the feedback about inpatient care was more positive than negative.

Experience of discharge


This was chosen by a small number of people as a priority. These responses largely related to the experience of people being discharged from acute hospitals where they were receiving treatment for physical issues, but also had mental health issues.

Mental health services for older people

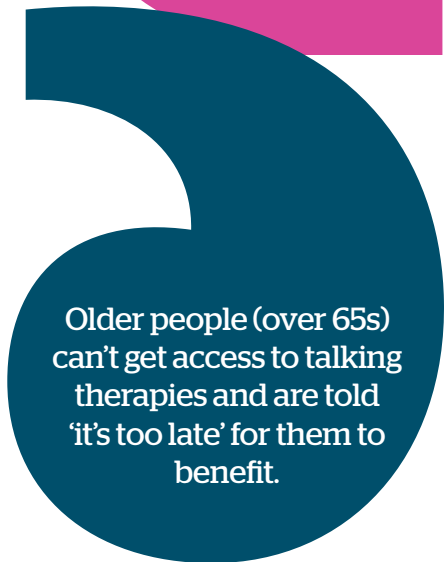
This was mentioned as a concern. It was felt that older people were not treated in the same way as younger people and that there should be more mental health training for care home staff.

Mental health support for people with autism

Some people said that they had encountered difficulties accessing mental health support for this group.



My sister got good support. It helped her and she was a lot happier.



Older people (over 65s) can't get access to talking therapies and are told 'it's too late' for them to benefit.

What children said made them happy



Being with mummy


At the family events we visited, we invited children there to decorate a person and asked them what made them happy. They mentioned a great variety of things. Many of these related to spending time with family and friends as well as a range of activities.



Colouring and dressing up



Rounders



Having two dogs and a cat



Dinosaurs



My family



Football



Above, Emergency Services Show, and below, County Hall, Trowbridge





Recommendations & next steps

We recommend:

- Avon and Wiltshire Mental Health Partnership NHS Trust (AWP) and the Oxford Health Child and Adolescent Mental Health Services (CAMHS) consider ways that they can make accessing services more straightforward.
- Oxford Health works with Healthwatch Wiltshire to ensure that the views of young people are heard to help improve their services.
- AWP and Oxford Health consider ways that they can improve crisis support when people are near to or in crisis.
- Services work together to support people in the community in order to reduce the likelihood of reaching crisis.

Healthwatch Wiltshire plans to:

- Prioritise focusing on access to mental health services for adults and children and young people.
- Listen to children and young people about their experiences of using mental health services.
- Work with AWP to ensure that people's views are gathered and used to shape service development.
- Work in collaboration with the Clinical Commissioning Group, council, providers and other services to contribute to the Sustainability and Transformation Partnership (STP) mental health work stream to ensure that people's views are included. This aims to show how health and care services will evolve and become sustainable over the next five years.
- We will let people know what has happened as a result of what they have told us.



Rowde Family Fun Day



Responses

Oxford Health Foundation Trust

Oxford Health Foundation Trust very much welcome this report and support its recommendations.

We are delighted that mental health services for children and young people are highlighted as a key priority in Wiltshire and shall continue to work closely in partnership across the whole system with education, health and social care (including the voluntary and community sector) to do the best we can to provide children and young people with easier and timely access to the right help they need. Children and young people are always at the heart of everything we do, and we shall be using the feedback and findings from the report to inform service development and improvements.

Based on the needs and views of children, young people, parents/carers and multi-agency professionals we are in the process of developing a new service delivery model for the Child and Adolescent Mental Health Service (CAMHS) in Wiltshire. This is based on the nationally recognised 'Thrive Model' for CAMHS which provides a whole system and integrated approach to the provision of both early mental health support and specialist provision. It's a model that recognises the need for all stakeholders involved in supporting children and young people's emotional wellbeing and mental health to work better together to provide the right help, in the right place, at the right time according to needs.

New service features being developed within Wiltshire are outlined below:

- Online referral (including self-referral).
- Single Point of Contact.
- Closer links between CAMHS and education.
- Access coordination – extra help for families to get the right support.
- CAMHS staff embedded in other agencies that work with children and young people
- Supporting other professionals that work with children and young people to feel confident in dealing with mental health issues.
- Interactive websites and better use of technology.
- Improving specialist pathways e.g. TEDS (Eating Disorder Service).
- CAMHS staff based in Hospital Emergency Departments.
- Easier access for children, young people and their families to CAMHS.

In line with Future in Mind and the Long-Term NHS Plan local strategic priorities for Oxford Health CAMHS include:

- Promoting resilience, prevention and early intervention.
- Improving access to effective support through a system without tiers and maximising time spent with children, young people and families.
- Improving care for the most vulnerable children and young people.
- Improving accountability and transparency.
- Developing an effective, confident workforce.

Wiltshire Clinical Commissioning Group

Wiltshire Clinical Commissioning Group (CCG) is committed to working with individuals with lived experience of mental health, their families, carers and friends, and key services in the development of a local Mental Health Strategy.

This Mental Health report, and the fact that Healthwatch is making Mental Health a priority, is therefore very welcome.

The CCG's Mental Health strategy will be co-produced over the course of 2019/2020, and will set the direction for the commissioning of services in future. We are also committed to ensuring the improvement and expansion of mental health services in line with national targets and to meet the needs of the local population.

As part of the co-production process and to ensure we continue to keep people at the centre of our work, we will be engaging with people regularly through events, workshops and focused sessions.

Wiltshire CCG has increased our annual investment in mental health services, and will seek additional funding to allow us to improve and expand services. For example, we are very proud of the Specialist Community Base Perinatal Mental Health Service available across Bath and North East Somerset, Swindon and Wiltshire, which is the result of a successful bid made in 2018/19.

We look forward to working with Healthwatch, service users and the public to improve and deliver the best mental health care service across our county.

Avon and Wiltshire Mental Health Partnership NHS Trust

Avon and Wiltshire Mental Health Partnership (AWP) NHS Trust welcomes this report and that mental health has been identified as a priority by Healthwatch Wiltshire.

We will continue to work with our partners across the system, including Healthwatch Wiltshire and Wiltshire Clinical Commissioning Group (CCG), to ensure mental health provision and services are delivered to improve people's lives, to meet their individual needs and to achieve true parity of esteem.

We are passionate about promoting good mental health and wellbeing and we strive to use the expertise and resources within our organisation, and through our partnerships, to deliver high quality services that are safe and focused on people's recovery.

We always welcome feedback from people who have experienced our services. Engagement with service users and co-production is a Trust priority for us and we will continue to keep the voice of our service users and carers at the centre of our work.

We note the recommendations in the report and will continue to work with Healthwatch Wiltshire to ensure we can provide assurance on their delivery.

Thank you

Thank you to all the individuals that stopped to share their honest thoughts with us and to the community groups and organisations that supported this project.

Thanks also to our volunteers who gave their time to take part.

References

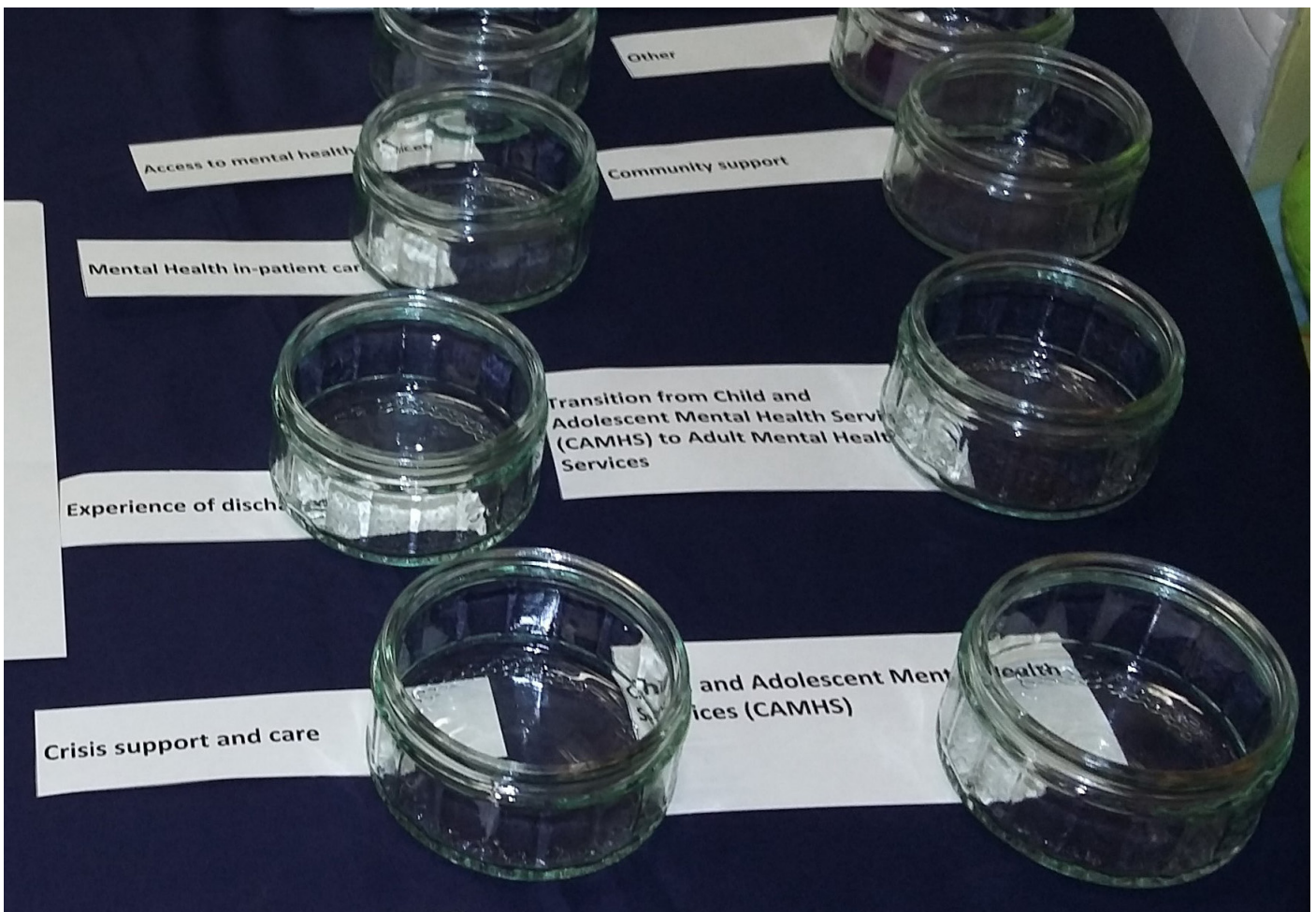
1. Listening to Children and Young People - Healthwatch Wiltshire Report
<https://www.healthwatchwiltshire.co.uk/reports.html>
2. <https://www.cqc.org.uk/news/releases/national-survey-highlights-decline-peoples-experiences-community-mental-health>



Allied Services Meeting, Tidworth Garrison Theatre



Above, Warminster Library and below, the survey priorities we asked people to choose from





Appendix 1

Mental Health Priority Survey

Earlier this year we asked local people what they thought our priorities should be for the year ahead. Mental health was chosen by many people as a key area we should be focussing on. We would now like to know what you think are the key issues within mental health so that we can focus our work.

1. What area of mental health do you think that we should focus on?

(Please pick one area you think is the most important)

- Access to mental health services
- Crisis support and care
- Experience of discharge
- Mental Health Services for Children and Young People
- Community support
- Mental Health in-patient care
- Transition from Mental Health Services for Children and Young People to Adult Mental Health Services
- Other, please say what:

2. Why did you choose this area?

3. Have you or a family member or friend used any mental health services in Wiltshire? If so, can you tell us how this went?

Please return the completed survey to:
Healthwatch Wiltshire, The Independent Living centre, St Georges road,
Semington, BA14 6JQ



Appendix 2

healthwatch
Wiltshire

Earlier this year we asked local people what they thought our priorities should be for the year ahead. Mental health was chosen by many people as a key area we should be focussing on. We would like to hear about your views and experiences of using mental health services?

1. Can you tell us about how you have accessed mental health services?

2. Which service/s have you used and what did you think of them?

3. What do you think was good about the services you used?

4. What do you think could be improved?

5. Is there anything else you'd like to tell us?

Please return the completed survey to:
Healthwatch Wiltshire, The Independent Living centre, St Georges road,
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