healthwatch

What people have told us about mental health

Mental health care project

This report forms part of our multi-year project to understand people's experiences of mental health care.

Over the course of the project we intend to:

▶ Look at the mental health support people want, from childhood to old age, focusing on the key moments in life when people need support.

▶ Examine how people from different sections of the community experience life with a mental health condition to highlight any inequalities in mental health support.

▶ Identify solutions, where we can, which do not treat mental health in isolation, and which seek to address the broader needs individuals may have.

Our ultimate aim is to make sure future mental health reforms focus on measuring the outcomes most important to people and to continually use people's feedback to improve support.

Our next findings will focus on:

Maternal mental health

Contents

We've heard from over **34,000** people about their experiences of using mental health services.

Key messages

▶ We know that when mental health professionals act on what people say, this can lead to improvements in both services and the support that specific groups receive.

▶ Since January 2016, over 34,000 people have shared their views and experiences of using mental health services with us.

▶ Local Healthwatch have also produced 229 reports highlighting what people like and what could be better about mental health services.

▶ This report sets out what we know about people's experiences of accessing mental health services and the wider support available.

▶ In contrast to other areas of health and social care, most of the feedback we receive about mental health care is negative.

▶ Common issues people report include:

- Struggling to find information about the support available

- Mental and physical health needs being treated in isolation

- Not always getting the same level of service

- Waiting too long to access mental health services and receive a diagnosis

- Non mental health professionals not always having the information and training they need

- Not feeling listened to or involved in decisions that affect them.

▶ When it comes to specific services, people most commonly talk to us about the support provided by GPs, community services, crisis care and children and young people's services.

▶ It is clear that not everyone has the support they need to manage their mental health conditions. For those that do, the quality and consistency of support is not always enough and does not always meet people's needs.

▶ Mental health policy is currently focused on addressing many of these issues. However, if changes to services are to be effective we believe more needs to be done to understand different people's experiences of mental health care, at different stages in their lives.

▶ Our work on mental health will now focus on developing an evidence base which policy makers and professionals can use to identify, and deliver, the improvements in support that matter most to people.

Overview

For the past three years mental health has been the number one health and social care issue for the Healthwatch network.[1]

This reflects polling carried out by Ipsos Mori, which shows that the public prioritise spending on mental health services above most services, with the exception of urgent and emergency care.[2] Since January 2016, we've heard from over 34,000 people about their experiences of using mental health services. They say it's vital to be able to access the support they need, when they need it, but this doesn't always happen. It's clear from the feedback that while many areas of health and care need extra attention, support for mental health is a significant concern.

Our new programme will focus on people's mental health experiences and concerns at key stages of life. From birth to death, we want to better understand the support people do and should expect to receive, and how those from different communities may experience life with a mental health condition.

We know from the work of Healthwatch to date that gathering views in this way – from teenagers in Bristol to army veterans in Norfolk – can lead to important changes in the way services are delivered and result in better mental health support. This builds on the growing evidence from across the sector of the benefits of applying a user-led approach to designing services and support.

Learning from a user-led approach

We want to highlight and promote the best ideas that come from the people using services. We know that services are better when they treat people as individuals, understand their needs, and actively involve them in shaping support.

To do this services need to learn from existing examples of support developed by people living with mental health conditions. These ideas can then be adapted, with professionals and service users making them fit around local need.

The concept of 'recovery' is one example. Created by people using mental health services, for many the concept means recovering – or discovering – a life that is fulfilling after a diagnosis of a mental health condition.

It involves individuals designing their own personal recovery and well-being plans. People define their own goals and the support they need to achieve them – for instance, building friendships, taking part in community activities, engaging in education or work, or managing their symptoms. Professionals can then arrange support to enable people to achieve those goals.

In the UK, there are now over 70 'recovery colleges' where both professionals and people with experience of living with a mental health condition design and deliver courses, as equal partners, on issues from managing medication effects to dealing with stigma and discrimination.

Another growing area is peer support, where those with experience of mental health challenges support one another during recovery or in a crisis.

Whilst people value the help they receive from professionals, they want more than just clinical support. People want to be able to talk to someone who has been through a similar experience; someone who can show them empathy and give them confidence that they will be able to overcome or manage their mental health challenges and conditions.

Peer support can be provided in a number of ways and research has found it can help result in improved symptoms, larger social support networks and enhanced self-esteem.[3]

During our programme, we aim to identify and promote models of support that are valued by people with different experiences, from different communities.

Changing attitudes

People can experience mental health concerns at any point during their life. For some, these are temporary and triggered by life events, whereas others need life-long or long-term support. Two-thirds of the public say they know somebody affected by a mental illness.[4]

Current research suggests that each year, approximately one in four adults in England will experience some form of mental health challenge.[5] We know that not everyone with mental health challenges will receive help, and for those who do get support, the quality of support doesn't always meet their specific needs or general good practice.

More people are talking about mental health than ever before. Attitudes to, and awareness of mental health conditions are improving, in part due to national campaigns such as Time to Change and Heads Together, which encourage everyone to speak up about their experiences, and thanks to these initiatives, we've seen more celebrities and members of the public raise awareness of mental health concerns by sharing their own stories. Politicians have also increasingly prioritised mental health, introducing a range of initiatives to improve the support available to people.

Across the health and social care sector there is growing focus on mental health. Positive steps are being taken to ensure that mental health concerns are treated with equal importance to physical ill health, and that the quality of support available continues to improve.

The policy picture

When the Five Year Forward View for Mental Health was published in 2016, it prompted a sector-wide shared focus on achieving change. It highlighted not just the current state of mental health services in England, but specific areas where things could be better.

Some of its recommendations include:

▶ more 24/7 services for people in crisis
▶ expansion of community services
▶ 10% reduction in suicide rates
▶ supporting 30,000 more women within perinatal mental health services
▶ support more people with mental health conditions to find or stay in work by doubling the provision of Individual Placement Support.[6]

The Government has directed NHS England to carry out these recommendations by 2020, and the majority of health and social care organisations have also signed up to support the programme.

In November the NHS is due to publish a long-term plan, setting out the key areas for the next ten years. We have already heard from the Chief Executive of NHS England that mental health will feature as one of the top issues but the detail is still to be decided. As with the other strands of the long term plan, we will be feeding in the insight people have shared with us about what support they want and need.

We want to ensure that the NHS plan sets a long-term ambition for mental health, focused not just on increased activity but on improved outcomes and experiences. By evaluating services in this way, the health and social care sector can make sure it is meeting all the support needs of everyone with mental health challenges or conditions.

It is very difficult to get an appointment... it can take many days and by the time I get to the appointment I am very anxious and unable to focus on the reason why I needed the appointment in the first place.

Common issues people share

Every day, Healthwatch are out in our communities, visiting services and speaking to people to understand whether health and social care services are working for them.

In the last two years over 34,000 people have shared their experiences with us and local Healthwatch have produced 229 reports highlighting what people like and what could be better about mental health services.

In contrast to other areas of health and social care, most of the feedback we receive around mental health care is negative, so we want to investigate why this is and look at how people manage mental health and wellbeing in all aspects of their lives.

We also know from the work of local Healthwatch that when mental health professionals act on what people say, this can lead to improvements in both services and the support that specific groups receive.

People told us about six common issues. This report provides an overview of these and the connecting problems commonly found across different services.

1. **They struggle to find information about the support available**
   People tell us they have difficulties understanding and navigating health and social care, so accessing the right mental health support can be challenging. Many are largely unaware of the help available. Although people can turn to their GP for guidance, many have told us that they would prefer to talk to someone who has been through a similar experience and can understand their needs. Clearer information and advice during difficult times would also make things easier.

2. **Their mental and physical health needs are treated in isolation.**
   A lack of coordination between hospital services and social care or mental health services means that some people have been discharged without the care they need. People diagnosed with multiple conditions, including mental health, often find services do not work well together to provide consistent support. This is a particular issue for people with drug and alcohol problems, and those with learning disabilities. For example, some people may have both physical and mental health symptoms, so services need to be mindful and take account of an individual's full needs whether they are medically connected or not.

Four main areas of support people tell us about *

6/10 commented on children and adolescents' services

4/10 commented on support from GP's

3/10 people commented on community treatment

1/10 commented on crisis care

* From a total of 34,184 comments

3. They don't always get the same level of service

The support people receive varies between areas and between services. People tell us that moving or changing areas has led to unnecessary reassessments and not receiving the same level of care, which can prolong recovery. Not getting to see the same health professional and being asked to repeat their story can also distress people with mental health conditions. Not only does it mean less time spent discussing diagnosis or treatment, it's also difficult to build a trusting and empathetic relationship.

4. They are waiting too long to access mental health services and receive a diagnosis

From GPs through to crisis care, there are long waits for mental health support. This can lead to delays in receiving a diagnosis and treatment, meaning people are not supported early on. This can result in conditions getting worse or in more severe cases, putting people at risk.

Our evidence highlights a significant concern for those using children's mental health services, community mental health teams and pre-natal services. Alongside this, the long wait for support can result in double waiting times, whereby people reach the front of the queue only to be told that a specific support service is unsuitable for their needs.

5. Professionals don't always have the training they need

Some people felt that health and social care professionals outside of mental health services don't understand the challenges they face, and don't always know what support services are available. We have also heard some staff say they lack the right skills to best support those with mental health conditions, and would like more training.

6. They don't feel listened to or involved in decisions that affect them

Many people are concerned there is a lack of empathy and respect from professional staff. This feeling can be made worse by short appointment slots. They want to be involve in decisions about their care, and to be taken seriously..

How we plan to tackle these concerns

Healthwatch has a wealth of insight into people's experiences, and we use people's views to help identify areas for improvement and shape the future of health and social care services. However, we cannot look at mental health in isolation. Factors such as employment, housing and relationships, influence people's recovery. This is why, when looking for examples of best practice, we will look for areas where people are supported with a whole range factors in people's lives that may affect their mental wellbeing.[7] These include:

▶ social networks

▶ relationships

▶ housing

▶ employment

▶ finance.

Our mental health programme will take a birth-to-death approach to mental health support, which includes taking a wider look at how people manage their condition and how they are supported. We also want to identify how people from different communities and backgrounds experience life with a mental health condition to highlight inequalities in support.

Why have we chosen to look at mental health?

As we've learned, mental health is a top concern for many communities across England, so we've reviewed over 34,000 comments to gain a better understanding of the areas that are most important to people. We've also combined this with research from a number of external sources, including user-led research, professional research, NHS Digital and a wide range of think-tank and voluntary sector research, to form a broader view of people's experiences.

We have four main areas of mental health which people most frequently talk to us about:

▶ primary care

▶ crisis care

▶ community treatment

▶ children and young people's services.

We have decided to look at these areas in more detail, including at a wider range of support services to gain a broader range of people's experiences and views. To start this process, we'll look at the mental health support available to people planning to have a child, who are pregnant or who are new parents.

What people said

This section is an overview of the four areas of mental health support that people have shared their views and experiences about.

Primary care: GPs support for mental health

Over the last two years, 12,940 people shared their experiences of seeking mental health support from their GP with us. This represents 37% of the total feedback about all mental health services.

What role do GPs play in managing mental health conditions?

GPs are usually the first point of call for people who need mental health support. Ninety per cent of adults with mental health conditions are supported by primary care.[8] They can offer several support routes depending on what people tell them about their mental health concerns.[9]

In 2017, GPs reported an 85% increase in the number of people who discussed a mental health concern with them, highlighting how managing mental health conditions has become a significant part of GP workloads.[10] A recent survey of GPs (undertaken by the charity Mind) found that mental health challenges are discussed at 40% of all GP consultations.[11] GPs can provide diagnoses, prescribe medication, refer people to another service such as talking therapies, or tell them about services they can access themselves. Alternatively, GPs may recommend some lifestyle changes or choose to monitor the situation.[12]

What do people think about getting mental health support from their GP?

While many people contacting Healthwatch have felt negatively about the way GPs handle their mental health concerns, there has been a positive shift in some areas. Around half of the feedback we received in 2017/18 about GPs dealing with anxiety and depression was positive. This could be a sign that the initiatives outlined in both the Mental Health Forward View and the GP Forward View are improving things. However, we now need to see this across the board, to ensure everyone has good access to care and support.

The following points are the main issues raised by people experiencing challenges in getting the right support for their mental health condition:

▶ **Lack of mental health awareness and early intervention**
There are indications that some GPs lack awareness of specific mental health conditions, find it difficult to spot the signs consistently, and don't always know where to refer people for support, particularly as there is local variation in the way services are set-up and the type of support they provide. This means people don't get the help they need early on. Without early intervention, people might not get the right diagnosis, treatment and access to specialist services that can help prevent long-term effects.

▶ Long waits for GP appointments

In some areas of the country, it can be a challenge just booking an appointment with a GP. People feel they are waiting too long for support, which could prevent them seeking mental health support quickly. This results in higher demand on crisis care. Many are also unaware of alternative support routes, so more should be done to inform people of what help is available beyond GPs, and how to access these services.

"It is very difficult to get an appointment... it can take many days and by the time I get to the appointment I am very anxious and unable to focus on the reason why I needed the appointment in the first place. I have many issues I want to raise with the doctor and then feel rushed because I can't talk about all the issues. It builds in my head and instead of feeling better I feel worse."

Member of the public speaking to Healthwatch Rochdale

▶ Needing a visit at home

Some people can struggle to leave their home because of their mental or physical health challenges, so a home visit from a GP could help to solve this problem. However, these appointments are not routinely available across the country.

▶ Changing GPs can mean delays in getting care

Moving area can be a difficult time for those with mental health conditions. We've heard from people who were deregistered from their GP, but could not find a practice in their new area that would accept them. This meant some faced delays to care or others slipped through the gaps, causing further stress (especially for those needing ongoing medication).

▶ Not being treated with dignity and respect

When people are not listened to or taken seriously by their GP there's a risk that they won't get the support they need. Short appointments can make it harder for people to speak in detail about their concerns, so GPs don't always hear the full story. Others say they want more understanding and compassion from all staff, not just doctors, as there can often be a lack of empathy during treatment. Without this, people can be afraid to ask for help and be left feeling unsupported and at risk of future crisis.

"I went to my GP, accompanied by a work colleague as I have an eating disorder and mental health issues. The GP was very cold and uncompassionate. The whole appointment was based around getting the information onto the computer... it seemed that the computer was the most important thing and not the experiences and issues that I have."

Mental health service user speaking with Healthwatch Rochdale

"I initially went to my GP hoping to get a referral for some sort of counselling or therapy. I waited about four months before I made the appointment. Beforehand, I was worried that the GP would not take my concerns seriously or would not be able to provide any useful advice. However, the first time I visited my GP I felt comfortable talking to her. She listened and was sympathetic to how I was feeling."

Mental health service user speaking with Healthwatch Lambeth

Understanding more about people's views

To understand more about people's views and assist the development of our mental health programme, we've been speaking to people at a series of focus groups around the country. Using these sessions, we've worked with different communities to gain a deeper understanding of people's experiences, and build a vision of what care they want for the future.

For example, in Birmingham we discussed prevention and early intervention. To summarise, people said:

▶ they see GPs as the first port of call for advice and support on mental health.

▶ some have concerns with the role GPs play as 'gatekeepers' for a number of reasons, including

  • pre-existing relationships with the GP could be a barrier to speaking up about mental health challenges

  • the pressure on GPs makes people more wary about raising their concerns early on, and

  • doctors don't always have enough time to deal with complex mental health conditions.

While most people spoke about GPs as their main point of support, it's clear they were using this description to discuss the broader role local GP surgeries play. They wanted:

▶ mental health care through GP surgeries to be more 'personal not professional'

▶ to focus on alternative treatment routes, such as talking therapies, mindfulness, and exercise

▶ more peer support, which was seen as vital and could be tailored to people's needs by involving others with similar conditions

▶ someone to support them through diagnosis, referral and care. This wouldn't need to be a GP, but someone who could provide a 'human' side to the service, and has similar personal experiences.

"Empathy and someone who's been there, we know our doctors are there and can write a prescription and pass you on but they'll never really be walking in your shoes."
Participant at a Healthwatch England deliberative research event in Birmingham

Lessons for the future – Important messages for professionals

We're pleased to see GPs taking positive steps to better support people with mental health conditions. However, those who design services need to find long-term solutions to long waits for appointments and limited home visits.

▶ GP practices should be suitably resourced with knowledgeable staff who can provide information on specific mental health conditions and treatment options.

▶ We agree with the Royal College of General Practitioners' suggestion that GPs should have longer appointments for people with mental health conditions.[13]

▶ The impact of the 3,000 new practice-based mental health therapists, as outlined in the GP Forward View, needs to be evaluated properly to ensure they are meeting people's needs.[14] Alternative treatment routes, such as self-care and peer support, should be clear and easily accessible for people with mental health conditions.

- Where GPs undertake mental health appointments, there should be a consistent level of empathy and understanding for everyone.
- We support the Five Year Forward View for Mental Health's suggestion that all NHS staff need to have training that equips them to understand mental health challenges and to treat people with dignity and respect - treating 'the person, not the diagnosis'.
- By capturing people's experiences of care, GPs can learn what is working well for people and where they may need to change the support they offer.

Community mental health services

Since January 2016, 8,590 people have shared with us their experiences of seeking mental health support from a Community Mental Health Team. This represents 25% of the total feedback received about all mental health services.

What is a Community Mental Health Team?

For serious or complex mental health conditions, a Community Mental Health Team can provide support to maintain wellbeing.

Most people with long-term mental health conditions are supported and treated by their GP, or by talking therapies such as those provided through the Improving Access to Psychological Therapies (IAPT) programme. However, if someone has a complex or serious mental health condition, GPs will usually refer them to a Community Mental Health Team for further support. Other services can also make these referrals if they are not the right place for an individual. Community Mental Health Teams include professionals from different specialisms, such as social workers, psychologists, nurses and psychiatrists.

What do people think about using Community Mental Health Teams?

We've heard those accessing Community Mental Health Teams don't always receive the care they need. Most of the feedback we hear is largely negative, with lack of information and signposting as recurring themes. These findings align with other research, such as the CQC's survey of people using Community Mental Health services[15], which highlighted the gaps between what people want – advice on employment and finances, as well as better response in a crisis – and what is actually offered.

Below are some of the main concerns and challenges people have told us about.

- **Lack of clear, consistent guidance**
  As with other mental health services, information about what treatment and support is available isn't always clear. This means people struggle to find support and often end up waiting longer than expected to see Community Mental Health Teams. People don't always get the guidance needed or know what to expect from their assessment or care, especially after a more serious diagnosis. This can cause unnecessary stress from not knowing how and when they will be supported.

- **Long waits for Community Mental Health Teams**
  In certain areas of the country people have told us they face delays of up to six months before getting access to Community Mental Health Teams. This can leave them feeling unsupported and potentially make their symptoms worse. Some people also say they experience long waits between appointments, so they may have a diagnosis but little guidance on how to cope.

People have told us that they can't access primary mental health services while waiting to hear if their referral has been accepted to a Community Mental Health Team.

This can mean they are forced to wait twice as long if their referral is unsuccessful, leading some to say they feel like "just a number".

"Going to the GP to tell him. You go in ready, all fired up. You haven't slept. You throw up and feel ill. You then hear yourself say it and it's double the pain. You will get a letter through the door and it may take up to four weeks. You wouldn't wait that long with a broken leg."

Mental health service user speaking with Healthwatch Redcar and Cleveland

▶ **Lack of consistency and continuity of care**

Being unable to see the same health professional can be particular distressing. Not only are people asked to repeat their story multiple times, there isn't the opportunity to build a trusting relationship with staff. People can become seriously affected, especially if changes are made to their medication or treatment. High turnover of staff (due to stress, terms and conditions, and pay), can exacerbate this issue, while a high number of vacancies can also affect the consistency of support.[16]

"I can't do with seeing different people. I don't want to start this again. I've started with you and now you're passing the buck. I can't drag the past 15 years of my life up again and again."

Mental health service user speaking with Healthwatch Redcar and Cleveland

▶ **Not everyone meets the eligibility criteria**

People whose needs are too complex to be treated by their GP or primary mental health services, but not severe enough to be assessed by a Community Mental Health Team, can easily fall through the gaps. Therefore, getting the right support isn't always straightforward.

"'The Eligibility criteria to gain access to mental health services seems to be going up all the time, making it impossible for someone with a moderate mental health need (i.e. not yet at the point of crisis) to get any help."

Mental health service user speaking with Healthwatch North Tyneside

▶ **Lack of coordination between services**

We also heard that services are not always well coordinated, with poor communication and a lack of clear referral routes between GPs and mental health services. Community Mental Health Teams are meant to work with GPs to manage people's care, but when communication fails, it leaves the individual responsible for relaying previous decisions about their care. Many people have also told us they rarely receive updates between appointments.

"There needs to be more joined up services from GPs to mental health services, from the beginning. All the services are separate from each other, they all need to be singing from the same hymn sheet."

Mental health service user speaking with Healthwatch Redcar and Cleveland

▶ **Support after leaving Community Mental Health Teams**

Treatment and support from Community Mental Health Teams can really benefit people with mental health conditions. However, even after building a good relationship with a staff member, support can stop abruptly. Where people are not confident or ready to leave, it can cause them to relapse and start the whole process again. Many would prefer a tapered end to ease this anxiety. Peer support groups have been highlighted by many people as a positive way to increase chances of recovery.

Making a difference to community mental health

After hearing one in five people with a serious mental illness don't have a care plan, Healthwatch Birmingham raised the issue with the local Trust. Care plans are important because they provide practical information for people, such as what to do in a crisis and what support will be provided during recovery. The National Institute for Health and Care Excellence quality standards say a care plan should be in place for each person and that it should be jointly agreed.

As a result of Healthwatch Birmingham's work, the Trust developed a strategy to ensure that all inpatients, including those in rehab, receive a care plan. Since then, 85% of people using a services across the Trust say they now have a care plan in place.

"I have been using the service for ten years and I was referred by my GP. I feel dependent on the service and I am being discharged in June. This is scary. There has been no explanation about what will happen after discharge - there's no discharge plan or information for ongoing support."

Mental health service user speaking with Healthwatch Hampshire

Lessons for the future – Important messages for professionals

One of the main concerns raised about Community Mental Health Teams is the gap between primary care services and secondary mental health services. Often this is bridged by the patient, who is likely to be living with deteriorating mental health and may be approaching a crisis point. This lack of coordination between services must be fixed so that people can access the care they need, when they need it.

▶ People who use Community Mental Health Teams could benefit from a single point of contact within the team so they don't have to be reassessed or repeat their story.

▶ GPs should – as is good practice – work closely with secondary mental health services, such as Community Mental Health Teams, to ensure that people are receiving coordinated and consistent care.

▶ Care pathways and referral routes need to be clearer. This is so GPs and other primary care professionals can provide accurate advice in good time to those who would benefit from a Community Mental Health Team.

▶ GPs should be provided with clear guidance on the threshold for referral for a Community Mental Health Team assessment. This would stop people falling through the gaps between GP and secondary mental health services, and reduce the number of unnecessary assessments.

▶ Community Mental Health Teams should also carry out routine discharge planning to ensure that people who use the service feel more confident about leaving services.

Mental health crisis care

Over the last two years, 2,619 people shared with us their experiences of seeking mental health support in a crisis. This represents seven per cent of the total feedback we received about all mental health services.

What is mental health crisis care?

A mental health crisis refers to when a person no longer feels able to cope or keep control of their current state. This could include feeling emotionally distressed or anxious, struggling to cope with day-to-day life or even thinking about self-harm or suicide. The Five Year Forward View

What help should people expect?

The Mental Health Crisis Care Concordat is a national agreement between services and agencies involved in the care and support of people in crisis. It sets out how organisations will work better together to ensure that people get the help they need at a point of crisis. The agreement focuses on four main areas.

▶ Access to support before crisis point – people with mental health challenges should receive 24-hour support and should be taken seriously when asking for help.

▶ Urgent and emergency access to crisis care – mental health crisis is treated with the same urgency as a physical health emergency.

▶ Quality of treatment and care in crisis – people are treated with dignity and respect in a positive, helpful environment.

▶ Recovery and staying well – preventing future crises by making sure that people are referred to the right services.

for Mental Health emphasises the importance of having effective and responsive emergency care to support those in crisis, at point of need.

A wide range of services can offer support to people in a mental health crisis, these range from Crisis Resolution and Home Therapy Treatment teams to listening services like the Samaritans.[17]

People with mental health conditions have also set up support for others, including helplines, drop-ins, and crisis houses. Others have worked together with professionals to develop joint crisis plans, to enable people to identify triggers and seek support to avoid or manage a crisis.

At crisis point, it's critical people get the level of urgent care they need. However, while looking at the quality, safety and effectiveness of crisis care services in England, the CQC found clear differences in the support available to people.[18] Factors such as where people live and which part of the system they approach first affected the type of care people experienced. Only 14% of adults surveyed felt they received the appropriate response in crisis[19], and around half of community teams were able to offer an adequate 24/7 crisis service.

What do people think about mental health crisis care?

The feedback we receive about crisis care is predominantly negative. The main concerns are around people not being able to find the right support, access the right services and experiencing incorrect mental health crisis services referrals. The following issues have been brought to our attention.

▶ **It's challenging to find support in a crisis**
People tell us that accessing suitable mental health services during a crisis can be confusing and unclear. Many people turn to their GP for support, as they don't always know who to turn to in a point of crisis. This can lead to inconsistent levels of care.

"I do not feel like I was taken seriously by my GP...they see me as a liability. They do not have the skill or time to help me."
Mental health service user speaking with Healthwatch Norfolk

▶ **People feel professionals aren't listening to them**
Despite proactively trying to find mental health support during a crisis, people feel

they are not being listened to. Many tell us they are passed from one service to another without any resolution. This is when conditions can worsen, putting people at risk. Accessing crisis support through helplines can also be challenging, particularly for those with a hearing impairment.

▶ **A lack of communication, empathy and respect**

When professionals don't communicate with them about their care, people feel their needs are being ignored. Not receiving correct advice on how to reach appropriate services is also a concern, which can affect people's confidence and trust in mental health professionals.

"I would like the GP practices to be more supportive and give more help on other places to go, rather than just being given a leaflet. In my experience it took me 67 episodes of panic attacks over 13 days, and for me to say to the GP that I didn't want to be here no more for them to help me. After this I was given an IAPT booklet, wasn't told who to contact so I was left in limbo."

Mental health service user speaking with Healthwatch Sheffield

Where some people have experienced a lack of empathy and respect, they say mental health crisis staff can be 'hostile', 'resentful' and at times 'intimidating'. This can create a barrier to accessing support in the future.

"At a time of vulnerability and distress, the one thing that you need is compassion."

Mental health service user speaking with Healthwatch Wokingham

▶ **Accessing emergency care**

When people are not sure of where to go during a mental health crisis they visit A&E as a last resort. However, not every A&E department has trained mental health professionals, so there can still be a lack of support and treatment. The Rapid Assessment Interface and Discharge team (RAID), which can help to identify people's mental health needs, are only available in some A&E departments.

"[Friend] rang me and said how they would end their life. I rang the GP and got an appointment and the GP rang the crisis team but we were told that would have to wait. We went home and waited and heard nothing and as I was so worried and I did not know what to do so we went to A&E. We waited for six hours and all we saw was the triage team. I could not wait any longer and so I rang someone from Rethink and they kindly came and sat with my friend as I was worried that they would walk out of the hospital if left alone and go and kill themselves."

A member of the public speaking with Healthwatch Derbyshire

Making a difference to crisis care

Safe Havens is an evening and weekend drop-in service for people and carers in Surrey experiencing a mental health crisis. Healthwatch Surrey visited seven Safe Havens to find out more about the vital support people can access. Healthwatch highlighted people's views in a report about the service, and following this, two Safe Havens received extra funding. The good work has also been shared in Norfolk, where commissioners are also looking to roll out similar services.

Lessons for the future – Important messages for professionals

Across the country we've heard that accessing care in a crisis can be a challenge, and even when people are supported, the level of care they receive can be inconsistent. Not getting the right help at crisis points can lead to serious consequences, so the following vital steps should be taken to improve these services.

▶ The significant variation in the quality of care people experience in a crisis is a concern. This is an ongoing issue and more needs to be done to better understand the reasons behind the variations in access and quality of mental health services.

▶ It is important that telephone support lines are user-friendly, particularly for people with sensory impairments. Providers and commissioners of these services need to ensure that disabled people, including those with sensory impairments, can access these vital services in line with the Accessible Information Standard.

▶ GPs need better guidance and information about local crisis care services and how to refer people for this support. This way, people in a mental health crisis get access to the most appropriate service in the first instance.

▶ Not all A&E departments have trained mental health professionals or RAID teams to support those during a crisis. As this is a recognised issue across the sector, more needs to be done to ensure A&E patients are given the care they need. Links with other community mental health teams can also ensure referrals and care are well coordinated between different services.

Children and young people's services

Maintaining the mental health and wellbeing of children and young people is vital to preventing mental health conditions developing in later life. Since January 2016, 22,387 people have shared with us their experiences of seeking mental health support from Children and Adolescent Mental Health Services (CAMHS). This represents 64% of the total feedback received about all mental health services.

What is a Children and Adolescent Mental Health Service?

CAMHS is used as a term for services that work with children and young people who have difficulties with their emotional or behavioural wellbeing. Local areas have a number of different services available, who are also able to support parents and carers.

NHS CAMHS services are multidisciplinary teams that are often made up of psychologists, social workers, therapists, nurses and other workers. The process of getting help from an NHS CAHMS team can vary depending on where you live.

What do people think about using CAMHS?

The problems people currently experience in accessing support during their formative years have been well documented, in the Five Year Forward View for Mental Health, and most recently in the CQC's national review. CQC highlighted local Healthwatch as a key source of insight about what people think of CAHMS and an important partner in helping local services understand people's suggestions for improvement.

The area of mental health provision for children and young people is where we have gathered the most insight to date. In the last two years, local Healthwatch have published 80 reports on children and young people's experiences. Some of these have focused on general issues around mental wellbeing, such as managing stress in school or relationships. However, 43 of these reports include more detailed commentary on people's experiences of using CAMHS services.

Importantly, the reports include feedback from young people themselves, as well as their parents. The following issues have been brought to our attention.

▶ **The importance of providing adequate information**

Providing quick and easy access to information is a really important part of helping people understand what local services are on offer, and what they can expect in terms of support. But for many of those speaking to Healthwatch, finding this information is a real challenge. This comes through strongly in our findings, but also as a theme in the advice and information requests we receive on a regular basis. The feedback suggests that even when people do find information it isn't always comprehensive, and it's sometimes out of date. Both parents and young people question whether the materials are appropriate for them.

▶ **Talking about mental health in schools**

Children and parents would also like mental health to be talked about more in schools. Many feel there is a disparity in the way schools and their staff support and signpost children and parents to access information about local mental health services.

"At school, they have tried but they just don't understand the situation and their advice wasn't useful and their help is useless, but they did try and they don't really understand or even know what I am, and what I do, and how it really affects me."

Mental health service user speaking with Healthwatch Gloucestershire

The Government's Green Paper on children and young people's mental health[20] emphasises the role of secondary schools in providing support to pupils. We welcome this, however people have told us that they want advice and information about mental health to be available in both primary and secondary schools.

▶ **Referral processes, access to support and moving between services could be better**

Local Healthwatch reports include a lot of feedback from people about long waiting times for mental health services. People also said that it seemed referrals were only given to people in crisis.

Parents shared concerns that long waits for a diagnosis resulted in their child's condition worsening, which caused additional stress, anxiety and depression and affected their school work. They also found the lack of communication from CAMHs services particularly frustrating.

"Waiting list is 18 months as the course can only take six parents at a time. Young people are often not meeting the criteria to be referred for autism assessment (if not self-harming or psychotic), even if they are violent or at risk when at home. Professionals often make the decision based on what is presented at appointments which is a very different picture to how they present at home - not seeing the full picture."

Local resident speaking with Healthwatch Leeds

▶ **Support for children and young people as they grow up**

Moving from services for young people to adult psychiatric services can also be difficult. Family members tell us the transition can be confusing and challenging, due to a lack of planning and preparation, and it can be slow and unstructured. This transition can affect young people's start in adult life, for example, those with mental health conditions may need additional support in employment, education and relationships. Parents also said that they didn't feel involved in the decision-making process when their child was discharged.

The Government's Green Paper also recommends the introduction of waiting time standards for mental health services, and we view this as positive. However, the referral process must be simple, transparent and timely to be effective. The report recommends that children and young people on waiting lists should be given more information about interim support services. It also highlights that those who are leaving services should be given adequate support to help maintain their mental wellbeing.

Over the course of our mental health programme, we want to better understand the experiences of children and young people transitioning to adulthood. We also want to find out if experiences differ significantly across the country so we can identify areas of good practice and make sure they are shared more widely.

▶ **Specific focus on learning disabilities**
We received a lot of feedback about children and young people with learning disabilities and autism. Often, these individuals also have a mental health condition, such as anxiety or depression. The feedback we received suggests that some services are not tailored to individual needs and they often fail to recognise the existence of multiple conditions. Because of this, parents believe their children receive ineffective support and treatment

Parents also said that services refuse to talk to one another about specific cases, which leaves families feeling like they are being passed around the system.

"GP would not refer me to CAMHS, said it must go through the school, school would not then get involved, it was complicated and I felt out of control. I was and still am angry, frustrated and disappointed. Even though he continues to be a threat to himself, self-harming and threatening

suicide, six sessions he was deemed 'fit'! Which is ridiculous. He needs long-term CAMHS support, which is just not offered. There is nowhere to turn to, no one to pick up the pieces, no one to help. I'm sorry if it sounds depressing but it is. I'm left with a confused, suicidal, depressed, anxious teen with no way forward."
Mental health service user speaking with Healthwatch Wiltshire

Thirty-six per cent of children and young people with a learning disability also have a diagnosed psychiatric disorder, compared to eight per cent of those who do not have a learning disability.[21] We will investigate the experiences of individuals with both a learning disability and a mental health condition in more detail as part of our work on mental health.

Lessons for the future – Important messages for professionals

Mental health support for children and young people is already a top priority for the Government and the NHS and they have brought in a variety of new initiatives and invested additional funding in recent years.

It is important the policy makers, mental health services and professionals monitor the impact of these initiatives to ensure they are having the desired impact.

▶ Ensure feedback from young people and their parents is captured and analysed to see whether issues around information and referrals are improving.

▶ Structure evaluation against targets around outcomes for people rather than activity, for example measure whether the 70,000 additional children and young people supported under the Five Year Forward View have had a positive experience of care.

Making a difference to children and young people's services

Healthwatch Suffolk spoke to more than 6,800 children and young people from local schools to get a better understanding of the current state of children and young people's mental health.

More than 82% of the young people they spoke to said that participating had improved their understanding of mental health. The schools that took part also used the findings of the survey to help improve their approach to supporting the emotional health and wellbeing of their pupils.

Conducted as part of a local plan that will determine the support available to young people and their families in the future, the results of this work have also helped influence a number of improvements, including how funding is used to enhance local efforts on mental health prevention.

▶ Monitor regional variation in waiting times and identify where lessons learned from best practice can be used to improve areas with poorer performance. Which parts of the country have the longest waiting times for children and young people and what are the main barriers? (For example, lack of local service provision, lack of capacity, lack of clear referral routes, complicated referral guidelines to access.)

▶ Conduct analysis of what happens to children on waiting lists, and how many end up in crisis, to identify ways of providing interim support to those in need.

▶ Focus on the support available for young people transitioning to adulthood to create the best possible environment and support for people to manage their condition and successfully negotiate relationships, education and employment as they reach adulthood.

Our aim is to make sure future mental health reforms focus on measuring the outcomes most important to people

Next steps

It's clear from what we've heard that not everyone has the support they need to manage their mental health conditions. For those that do, the quality and consistency of the support they receive isn't always enough and does not always meet people's needs.

We have outlined what we know about people's experiences of accessing mental health services and the wider support available, based on the feedback we have received. However, there is much more to address. We plan to work together with stakeholders to identify issues, highlight best practice and see whether the Five Year Forward View is succeeding.

Over the course of our mental health programme we will:

▶ Look at the mental health support people want, from childhood to old age, focusing on the key moments in life when people need support.

▶ Examine how people from different sections of the community experience life with a mental health condition to highlight inequalities in mental health support.

▶ Identify solutions which do not treat mental in isolation and which seek to address the broader needs individuals may have, including how social networks, relationships, housing, employment and finance can significantly affect recovery.

We will start by seeking people's views about maternal mental health; we will then look at the support available to young people.

Our ultimate aim is to make sure future mental health reforms focus on measuring the outcomes most important to people and to continually use people's feedback to improve.

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About us

Healthwatch is the independent champion for people who use health and social care services. We're here to find out what matters to people, and help make sure their views shape the support they need.

There is a local Healthwatch in every area of England. We listen to what people like about services, and what could be improved, and we share their views with those with the power to make change happen. We also help people find the information they need about services in their area.

We have the power to ensure that the government and those running the services hear people's voices. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them.
Our sole purpose is to help make care better for people.