



Mental health and autism: Falling between the gaps

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Report summary

What is this report about?

This report highlights the findings from two surveys, one for autistic people and one for their carers, which gathered their experiences of accessing mental health services in Wiltshire over the last three years.

What did we do?

The surveys ran in May and June 2023. We shared the surveys through the Wiltshire Service Users' Network (WSUN) As We Are group for autistic people, through partner organisations including Wiltshire Parent Carer Council, and promoted the surveys through our social media channels and our website. This work follows on from a previous project with WSUN in 2021 that aimed to gather the views of people with autism spectrum conditions and their carers about health, care, and support services in Wiltshire.

What were the key findings?

- There is a lack of appropriate mental health support that takes into account the particular needs of autistic people.
- Autistic people, their carers and families told us of their desperation and frustration at not being able to get the help they need. Some say they have been unable to find any support. Autistic people said they felt isolated and misunderstood, and trying to get help was distressing.
- Most people went to their GPs as their first point of contact to get help but faced long waiting times for onward referrals to other services. People were also frustrated at being referred and re-referred.
- Autistic people did not find services helpful. They didn't think the talking therapies offered were suitable for them and sometimes even made symptoms worse.
- Mental health staff lack training, awareness and understanding of autism. Sometimes this has resulted in misdiagnosis and inappropriate treatment, or no support.
- Thresholds for getting mental health help are very high or inappropriate for autistic people.
- Some people said they had used expensive private consultants or therapists in an attempt to get help.
- Carers said the Child and Adolescent Mental Health Service (CAMHS) was overwhelmed and the waiting times very long.
- Waiting times for an autism diagnosis were seen as unacceptable, with little support or guidance post diagnosis.
- Communication difficulties faced by autistic people, coupled with a lack of flexibility from services – such as only offering phone calls rather than face to face appointments – creates a barrier for autistic people to be able to access help.
- The lack of suitable support has a long term impact on autistic people and their families/carers, with some becoming suicidal or a potential danger to others.

Conclusions and recommendations

It is clear that autistic people and their carers have struggled to access support for their mental health, and this has had a serious impact on them and their families. We have made a number of recommendations based on the feedback we have heard.

Introduction

Healthwatch is your local health and social care champion. We're here to listen to the issues that really matter to people and to hear about your experiences of using local health and social care services.

Healthwatch uses your feedback to better understand the challenges facing the NHS and other care providers and we make sure your experiences improve health and care for everyone – locally and nationally. We can also help you to get the information and advice you need to make the right decisions for you and to get the support you deserve.

For this project, we worked in partnership with Wiltshire Service Users' Network (WSUN), which runs the Wiltshire Autism Hub, which is funded by the National Lottery and Bath and North East Somerset, Swindon and Wiltshire Integrated Care Board. WSUN was formed in 1991 by people who use health and social services, to promote user involvement and support people to have a voice.

Background

It is widely understood that most people on the autism spectrum experience mental health issues. While this creates a high demand for mental health services from autistic people, they often have difficulties accessing these services. Barriers they face include a lack of knowledge and expertise surrounding autism from healthcare professionals, and even an unwillingness to treat them. [Source: see below*]

There are also substantial health inequalities for autistic people. They are at a greater risk of dying younger and developing health conditions such as diabetes and epilepsy, as well as mental health problems. They are less likely to get the screening, checks and treatment they need. These issues have also been exacerbated by the Covid pandemic. [Source: [University of Cambridge](#)].

We have heard from a variety of sources, including our [Wiltshire Mental Health Open Forum](#) and our Healthwatch Hub, that some autistic people in Wiltshire are struggling to get the help they need to manage their mental health.

In a previous project with WSUN in late 2020/early 2021, we heard of the difficulties autistic people faced when attending health and care appointments, who felt they didn't have enough support related to their condition. This included their mental health. This report, [What people with autism spectrum conditions think of services](#), is on our website.

Since then, Wiltshire Council has published their all-age [Autism Strategy 2022-2027](#) which took into account the recommendations made by WSUN and Healthwatch Wiltshire in our previous report and also the findings of Wiltshire Centre for Independent Living's work with autistic adults.

The strategy sets out a vision for autistic people in Wiltshire to be able to live fulfilling and rewarding lives within a society that accepts and understands them, and includes the following actions:

* US National Library of Medicine: [A blind spot in mental healthcare? Psychotherapists lack education and expertise for the support of adults on the autism spectrum](#)



- Following the national consultation process and development of code of practice, roll out Oliver McGowan Mandatory Training to all health and social care staff (including commissioned providers).
- Review accessibility of mental health provision for autistic adults and children and young people with autism, eg by adapting [Improving Access to Psychological Therapies] services.
- Develop training for staff to enable them to better meet the needs of people with learning disabilities and autistic people who are experiencing a mental health crisis.



The evidence we had heard merited further research into the availability and suitability of mental health services for autistic people in Wiltshire.

What we did

For this project, we wanted to find out what autistic people, and their families and carers, thought of mental health services in Wiltshire.

Working in partnership with WSUN, we wanted to learn more about the experiences of autistic people, aged 14 and over, who have accessed mental health support in Wiltshire in the last three years, and what they thought could be better. We also wanted to find out the experiences of carers and relatives in helping the autistic person they care for to get this support.

We developed two surveys, one for autistic people and one for carers, with WSUN. We tested one of the surveys with a group of autistic people and refined the questions following their recommendations.

We launched the two surveys, which could be completed online, by phone, or on paper, in May 2023. We offered support to anyone who needed help completing a survey.

The surveys ran for about 8 weeks. They were shared with the WSUN AS We Are group for autistic people and through partner organisations including Wiltshire Parent Carer Council. We also promoted the surveys through our social media channels and on our website.

Glossary

An explanation of some of the services and terms mentioned in this report.

Applied Behaviour Analysis (ABA) – an intensive therapy program for young autistic children.

Autism Spectrum Disorder (ASD) – the medical name for autism, a lifelong disability which affects how people communicate and interact with the world. Now referred to as Autistic Spectrum Condition (ASC).[Source: National Autistic Society]

Attention Deficit Hyperactivity Disorder (ADHD) – a condition that affects people’s behaviour. They may be impulsive, restless, and have trouble concentrating.

Asperger’s (or Asperger Syndrome) – Sometimes known as “high functioning” autism, as people with Asperger’s don’t tend to have the same learning disabilities that others with autism do. People aren’t diagnosed with Asperger’s anymore because it’s now thought of as part of ASC. [Source: NHS]

Avon and Wiltshire Mental Health Partnership NHS Trust (AWP) – provides inpatient and community mental health support to adults across Wiltshire.

Cognitive Behavioural Therapy (CBT) – a type of talking therapy. It teaches coping skills for dealing with different problems and focuses on how thoughts, beliefs and attitudes affect feelings and actions. **Dialectical Behaviour Therapy (DBT)** is a specially adapted form of CBT for people who feel emotions very intensely.

Child and Adolescent Mental Health Services (CAMHS) – NHS services that assess and treat young people with emotional, behavioural or mental health difficulties. The **Single Point of Access team** (CAMHS SPA) triages and assesses the mental health needs of a young person. In Wiltshire, CAMHS is provided by Oxford Health NHS Foundation Trust.

Early Intervention in Psychosis Team (EIT) – a multidisciplinary team supporting young people experiencing a first episode of psychosis.

Oliver McGowan Mandatory Training on Learning Disability and Autism – the government’s preferred and recommended training for health and social care staff. Named after Oliver McGowan whose death shone a light on the need for health and social care staff to have better training.

Improving Access to Psychological Therapies (IAPT) – now known as NHS Talking Therapies, this service offers short-term psychological therapies to people suffering from anxiety, depression and stress. Although the name has changed, it’s often still referred to as IAPT.

Neurodivergent – a non-medical umbrella term that means having a brain that works differently.

Primary care – the first point of contact for people in need of healthcare, such as a GP.

Primary Care Liaison Service (PCLS) – a first point of contact to access mental health services. They offer mental health phone triage, face-to-face assessment, brief interventions, support, advice and signposting.

Secondary mental health services – services which generally need a referral from a GP. These include hospitals, some psychological wellbeing services, community mental health teams (CMHTs), crisis resolution and home treatment teams (CRHTs). Outreach teams and early intervention teams are also secondary services.

Who did we hear from?

We heard from 54 people in total:

- 28 people who described themselves as autistic
- 26 carers of people with autism.

People who responded on their own behalf

96% of autistic people who responded described their ethnicity as White British and 4% as White Other.

16 respondents described themselves as female, 10 as male, 1 as non-binary and 1 as pansexual.

Respondents were from all over Wiltshire, providing a wide range of experiences throughout the county. (It should be noted that 2 respondents are no longer based in Wiltshire.)

Ages ranged from under 25 to over 84.

People who responded regarding a person they care for/loved one

Respondents were asked to describe the gender of the person they cared for. Our results showed 15 male, 9 female, 2 trans male and one choosing not to answer. Most of these people were under 30.

16 carers said that the person they cared for was white, 8 described them as British, 1 as mixed race, 1 as black/black British.

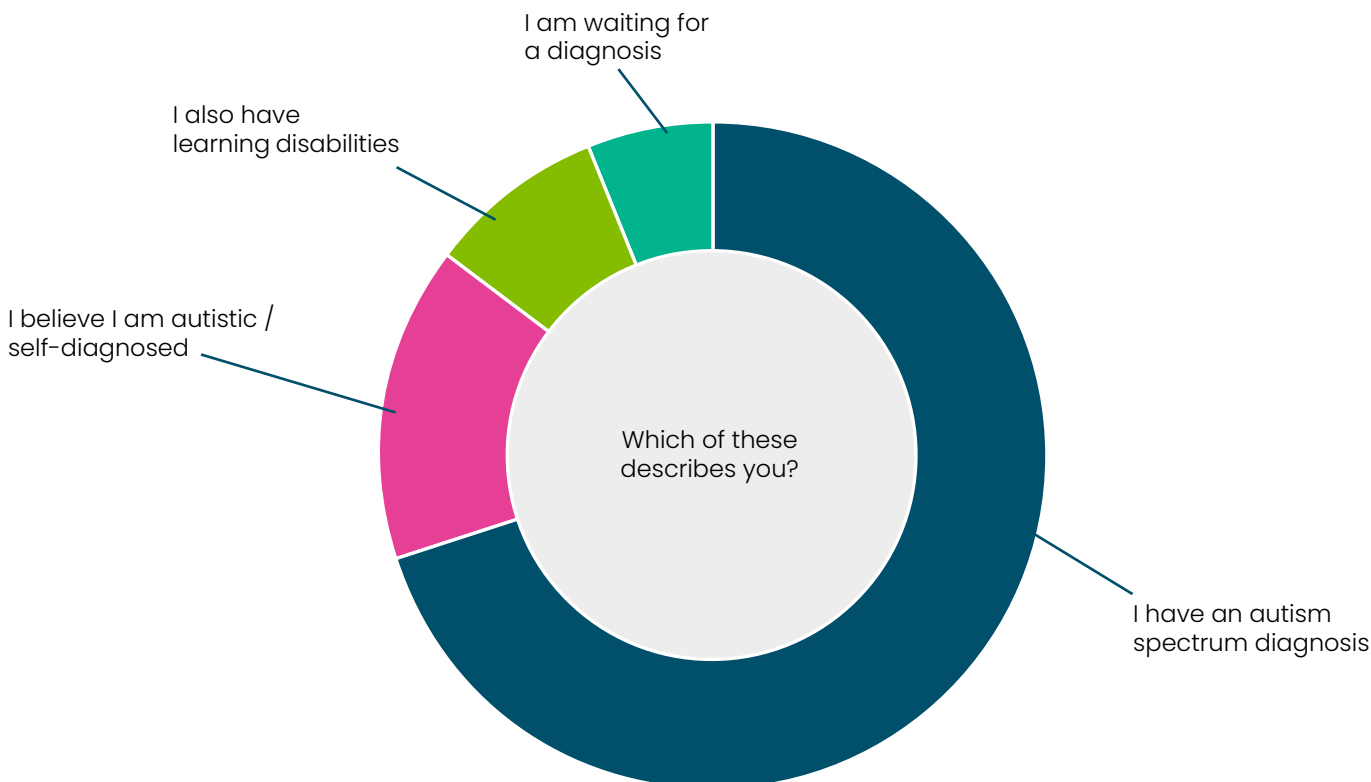
About the carers

When we asked the carers about themselves, 24 of them told us they are female, 1 said they were male and 1 person declined to say. Their ages ranged from 31 to 75.

A breakdown of the demographics can be found in **Appendix 1**.

What you told us

The focus of our survey was to hear autistic people's experiences of getting the support they needed for their mental health. The first question we asked was to understand whether respondents had a diagnosis of autism, or were awaiting diagnosis, and if they also had learning disabilities. The majority who responded on their own behalf (82%) told us that they have an autism spectrum diagnosis.



26 carers responded to this question. The majority, 52% (14), said the person they cared for was already diagnosed as being autistic but 4 respondents qualified this diagnosis as follows:

- 1 person has autism and mental health illness
- 1 has been diagnosed with Asperger's
- 1 has autism and learning disabilities
- 1 has Asperger's with ADHD (Attention Deficit Hyperactivity Disorder).

26% (7) said the person they cared for believes they are autistic, while 15% (4) are awaiting diagnosis. 37% of the people they cared for were described as having learning disabilities.

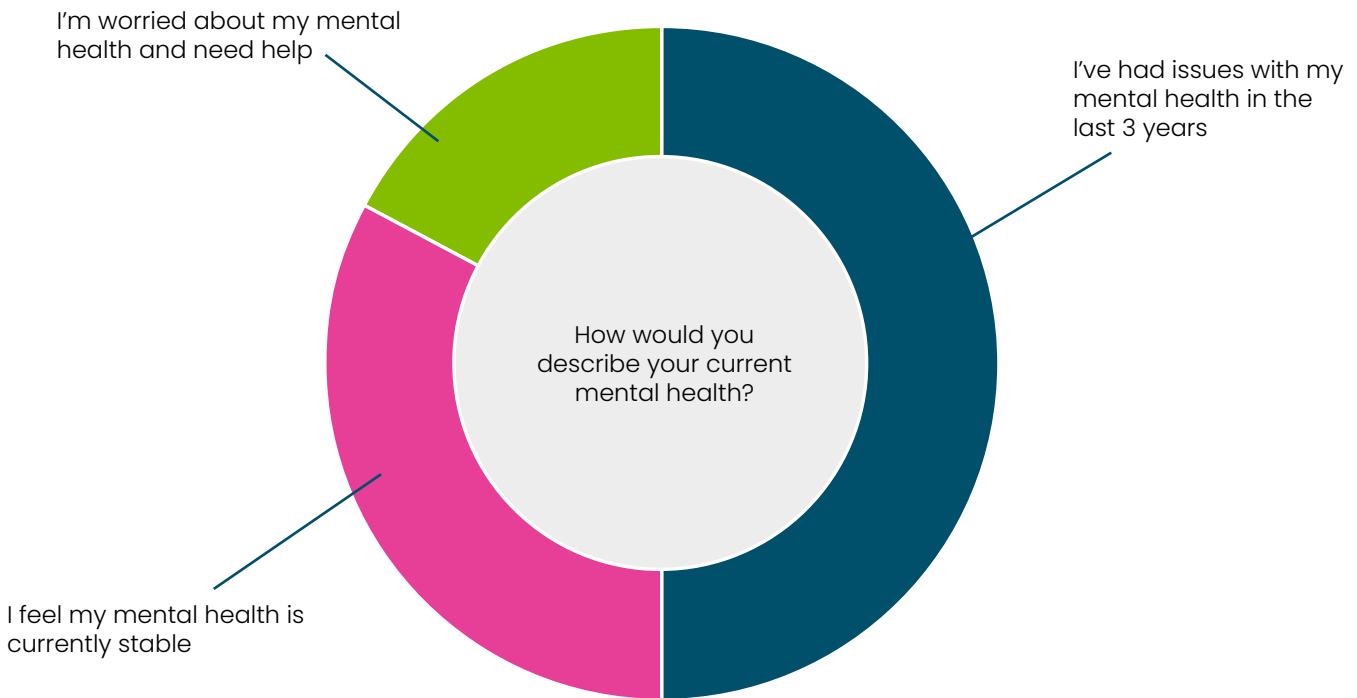
12 people commented on how long they were waiting for diagnosis or support and the impact their autism has had on everyone's lives.

We also asked the carers whether they themselves were autistic, as we had found from our previous survey and from anecdotal evidence from WSUN, that this could be the case. Of the 24 carers who responded to this question, 18 said they were not autistic, while of the 6 who said yes, 1 answered that they are probably autistic, 1 is awaiting referral, and 1 said they do not yet have an official diagnosis.

Mental wellbeing

Our next question asked how autistic people viewed their own mental wellbeing.

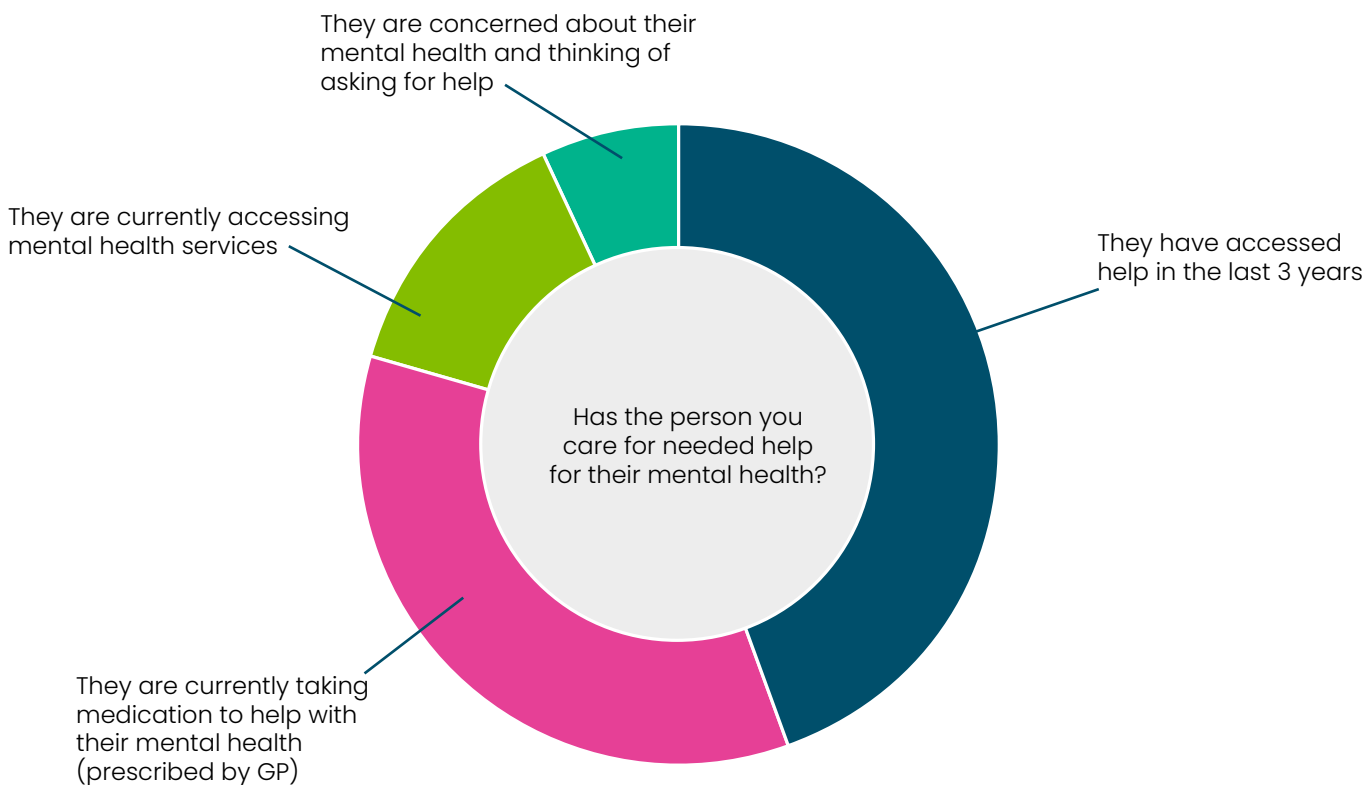
32% of autistic people said they felt their mental health was stable, 18% were worried about their mental health and felt they needed help, but 50% (14) said they had had mental health problems over the last 3 years.



When we asked if they have accessed, or are currently getting help from, mental health services, 26 people answered:

- 6 said they are currently accessing mental health services,
- 13 said they had received help in the last three years
- 13 were also taking medication
- 3 are thinking of asking for help.

The carers' responses showed a similar picture with 4 people currently using mental health services, 13 having used mental health services in the last three years and 10 currently taking medication. Two are concerned about their mental health and thinking of asking for help. Five carers did not respond to this question.



18 carers, (69% of those who completed the survey), made comments about this question. The comments are all negative but a key theme that emerges here, which is repeated on other responses, is that the GPs have tried to help.

- Support for my daughter's mental [health] has been non-existent, she is an outpatient under the care of a neuro psychiatric unit in Bristol for Tourette's, and is prescribed Sertraline [an anti-depressant] by the consultant there, but support for mental health continues to be a constant battle.
- Multiple attempts made by GP to refer back to secondary mental health care, where he was originally treated under EIT [Early Intervention in Psychosis team], failed every time due to repeated inadequate assessments by PCLS [Primary Care Liaison Service]. Patient left feeling hopeless and having no support as GP confirms the issues are beyond his ability to adequately treat. PCLS say patient doesn't reach their (newly elevated) threshold for acceptance and so patient's health continues to decline...
- They have tried to access mental health support but GP says there are no suitable secondary mental health services.
- My son has struggled with his mental health all through his teenage years and to the present. He suffers from anxiety, and low mood, sometimes manic behaviour. He had been on a waiting list for years before we could access proper help.

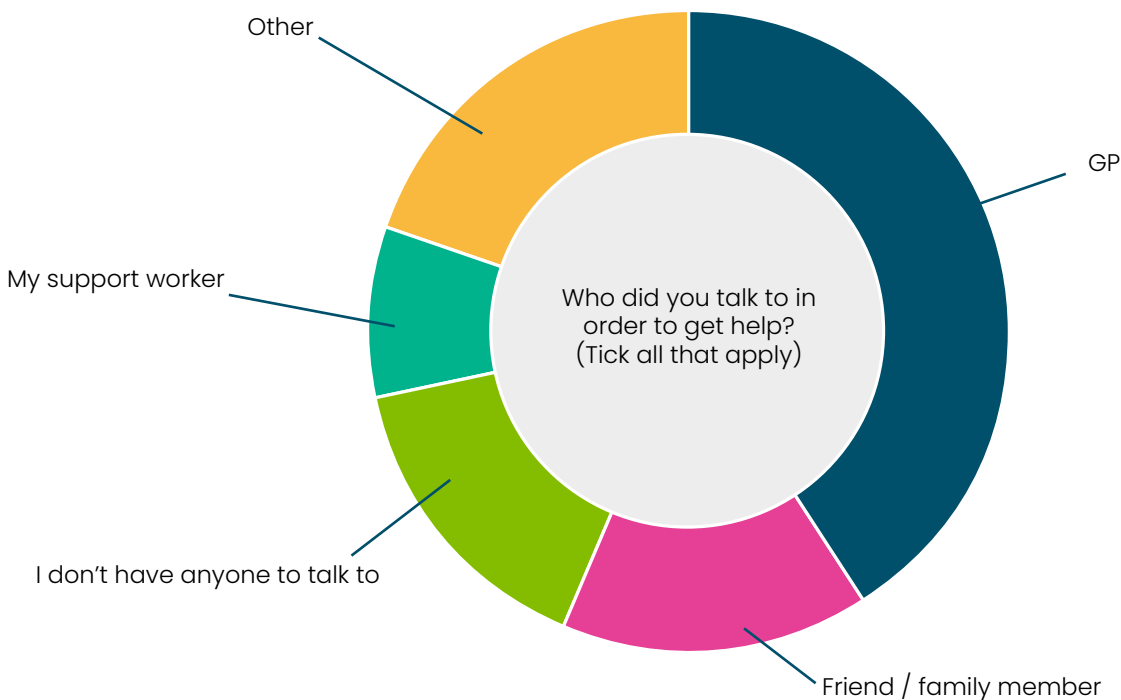
6 We were refused from CAMHS [Child and Adolescent Mental Health Service] when he was severely depressed and had to get a private assessment to actually get a CAMHS appointment which was UTTERLY USELESS and they discharged him with no reason except that he had started a new school. It was absolutely appallingly bad and I feel for anyone with mental health issues. The woman we saw at CAMHS was a social worker and completely UNTRAINED and with nothing at her disposal to help with his mental health. It was just ABSOLUTELY AWFUL.

6 They have tried to access help but CBT is not always helpful for autistic people (a fact not widely accepted by those pushing it). Six sessions of any therapy is rarely sufficient and the waiting list is worryingly long.

Getting help

We asked who people had first contacted when they tried to get help.

67% of autistic people said their first point of contact was their GP, followed by a family member or friend. 25% said they did not have anyone they could talk to. Nine people gave details of other people they contacted to get help.



Similar results were shown when we asked people who they would talk to if they were considering trying to get some help.

Key themes that stood out from the comments left with this question were:

- The number of older people who are diagnosed or seeking diagnosis around autism.
- The lack of help people have received, not from their initial contact, but following their referral to another service.
- Online diagnosis is being used rather than an NHS diagnostic service because people are unable to access services without a long wait.

[NHS mental health facility] not even worth phoning, even in crisis. No support anywhere. Get told to ring the Samaritans.

I told my GP I was feeling pointless, hopeless and disconnected, I was referred to Primary Care Liaison Service who arranged a Zoom triage with a non professional who would send a written report to a professional. I was informed by letter that there was no need for further treatment. I was dropped and no further treatment was offered and no GP follow-up.

Waiting lists too long, or I don't hear anything back.

Having been diagnosed later in life does not make things any better as I have been masking all my life trying to fit in and be normal. It has been a curse to me throughout my life, I am now 57.

At 74, in 2021, I realised I was Autistic, ADHD [Attention Deficit Hyperactivity Disorder] and asked for help, I was told I would be put on the list for certification and it will take 5 years. Since then I have researched my condition and more has come to light, but the surgery is not interested probably because of my age. I am on anti-depressants from long term mental issues, I was wrongly diagnosed after a breakdown in 1998.

Leah's story

Leah*, 62, has an autism spectrum diagnosis and has had mental health issues. She talked to her GP who she felt was helpful, although the appointment was short. But once referred on, she found the mental health services either unhelpful or unsuitable.

"PCLS [Primary Care Liaison Service] are just rude, sometimes they work in pairs so it's their word over yours. Don't understand the frustration and a meltdown, so I was classed as awkward.

"IAPT [Improved Access to Psychological Therapies] ... 1 year wait for a course which I didn't think was helpful and phoned 3 times to complain. It is a 12 week course of which 6 weeks was digging into your history and causing pain. Now you are lucky to get a 3 week video course.

"My medication caused anger and other problems. I was classed as a bad person.

It was the medication.

"Psychiatrist... stage 1 care good. The stage 2 one so bad made an official complaint. No support at all. They are only interested in people with bipolar or schizophrenia.

"Crisis team at [mental health facility] ... terrible, condescending, no empathy, told to ring Samaritans."

Leah does not have a support worker and did not know how to find one. She contacted WSUN but they were unable to help, and said it was outside of their remit.

Leah said her experience of getting mental health support could have been improved if staff were trained in autism to help, were not condescending and had some empathy.

"It's been appalling experience. I would rather commit suicide than deal with them again."

* Name has been changed.

Carers gave similar responses with 19 respondents (74%) saying they would contact their GP, followed by friend or family member as the next most preferred. Twelve of those who identified their GP also said they would talk to friends/family and others. Seven carers said they would only talk to the GP, 1 only to their support worker, and 1 only to a friend of family member. No one would approach hospital staff only, though they would speak to them as well as a GP. Two people said that they don't have anyone to talk to.

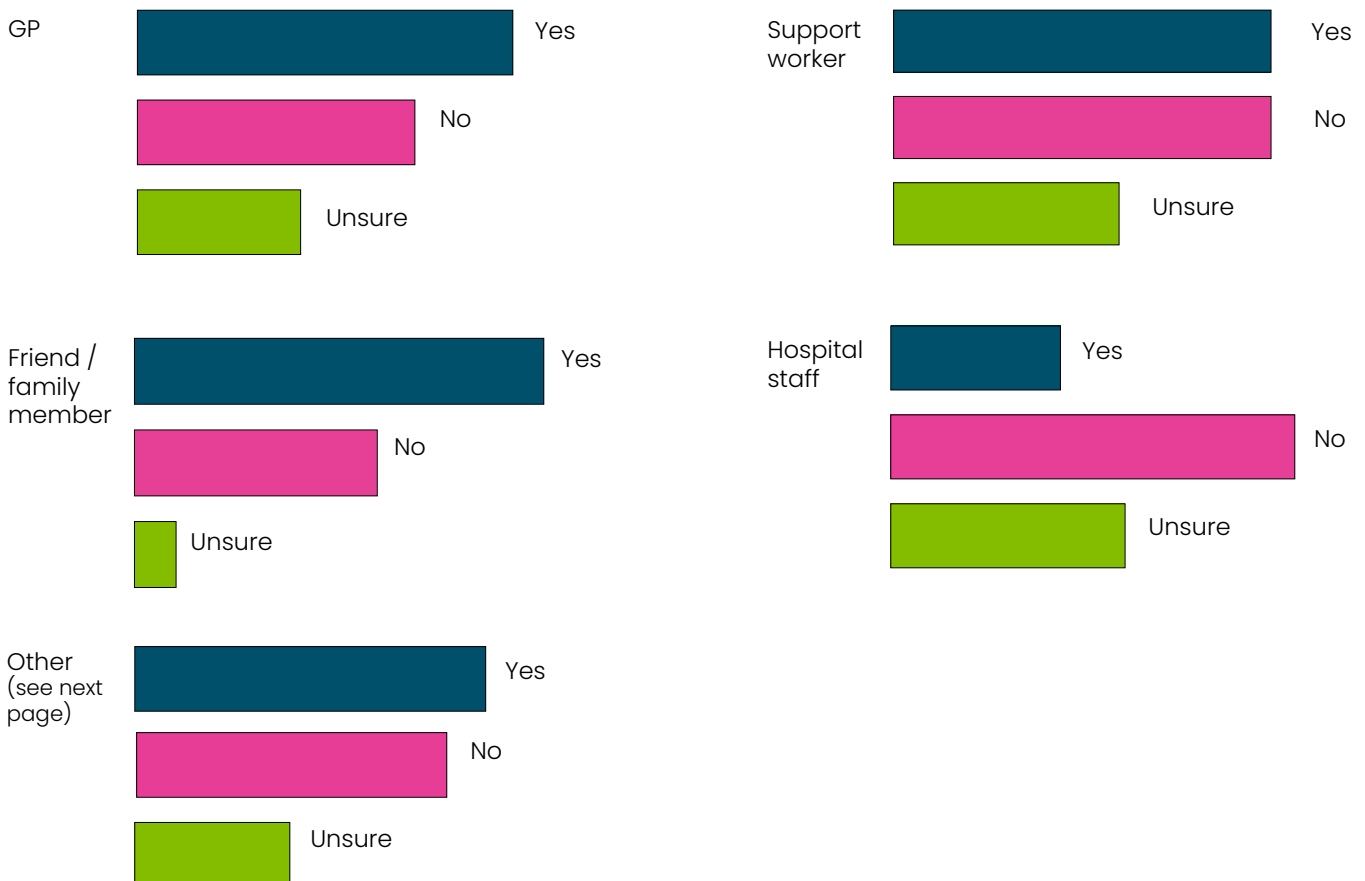
15 carers provided comments in addition to answering the question. These included one positive statement about CAMHS:

First GP we saw said the school would deal with it. By the time we saw a second, very sympathetic GP, my daughter's weight was dangerously low and she was referred urgently to CAMHS. CAMHS were wonderfully supportive and diagnosed autism, an eating disorder and severe anxiety which we have learnt often co-exist.

Other comments were not so positive. Topics included:

- No help received
- Still waiting for help from CAMHS
- School were helpful and staff understanding of mental health issues
- The only help was a carer support group at the GP surgery
- Had to get help privately
- Got support from trans services at [NHS gender identity clinic]

We then asked whether the people they talked to were helpful. The charts below illustrate the responses of autistic people.



The 'Other' option responses included private autistic coaches (often with lived experience), counsellors and therapists, none of whose services were provided by the NHS.

We invited autistic respondents to tell us why they felt this way and 23 respondents provided comments.

Key themes included:

- Poor understanding of autism and how it can affect people. This results in a lack of empathy, appropriate interactions and environment.
- There is a gap in services where someone does not meet the criteria for greater help yet what is offered is inadequate or does not meet their needs.
- Thresholds for mental health support are not suitable for autistic people as they are not designed with their requirements in mind.

Friends and families are empathetic and supportive, not something I have experienced from medical professionals.

Adult mental health team don't have understanding of autism, they raised their voice and laughing in disbelief when I said my partner was my carer, all because I don't have a learning difficulty. They couldn't understand how I could struggle and need support. I never meet the threshold for any support at this level, I am always told "you're not ill enough". My last appointment the staff member stated "you're not even self-harming anymore so of course you're not going to get support" as if this was a negative thing and that is what they would expect me to be doing to even be there.

CBT is often offered, but if therapists are not neuro-affirming and trauma informed and aren't adapting the therapy to the individual neurodivergent person, this therapy and others alike it DBT [Dialectical Behaviour Therapy] are actually more harmful for ND [neurodivergent] people, as they have been based around allistic patients [non-autistic] and the methods encourage autistic masking and exposure to sensory overwhelming environments for example, no amount of exposure will make these environments less sensory overwhelming and traumatic for the individual.

The GP would send me to the local CMHT [Community Mental Health Team] and they would send me to GP so I just went around in circles getting nowhere.

The GP took my worries seriously and was kind and confident. I had a pretty good experience with my GP.

Referred to IAPT who can't support me due to CPTSD [Complex Post Traumatic Stress Disorder], can't access any mental health support as too high needs for IAPT and not high enough for CMHT.

Carers' responses were similar. 48% of carers did not feel they were listened to or that the person they spoke to was helpful, 37% said yes, and 13% were unsure.

There were two responses however that were positive, one of which relates to CAMHS:

Our GP was excellent as they did the referral to CAMHS SPA [Single Point of Access] whilst also booking in follow-up appointments until seen, which was also a godsend as the GP then went on to identify that my daughter was underweight and she actioned her referral to a separate CAMHS team that deals with eating disorders.

Alex's story

Alex*'s relative is in his early twenties, who they describe as being autistic with ADHD and learning disabilities. Alex explained how the young man's life has spiralled out of control since childhood and is now in prison, where he is often self-harming.

Alex says they have not been offered help for their relative, who has no idea of social responsibility and has shown a tendency to risky behaviour. Alex says no one explained the impact of autism, ADHD and learning disabilities to them.

When Alex tried to get help with their relative's mental health, they found it very difficult. The young man is currently taking medication prescribed by his GP. Alex said they do not have anyone to talk to and when they tried, no one listened: "No one gave a damn".

Alex told us their relative had been referred to the Primary Care Liaison Service but the referral did not take place, so Alex and their partner tried to manage on their own. The young man was not offered any other treatment or access to any other service. A social worker told Alex their relative "lives in fantasy land".

Alex feels mental health and social care services are almost non-existent in Wiltshire, that everyone covers up, no one is listening and there is no accountability. They fear their

relative will be in and out of prison.

"I am totally shocked by how the police and social services treat mental health. In prison [the young man] was put with other people [with mental health issues] on the sex offenders' wing. Often beaten, still."

The lack of understanding and support has led to Alex's relative being frequently abused and humiliated, describing police as "a waste of time."

When asked how their experience of getting mental health support could have been improved, Alex replied that truth and honesty would have been helpful to both them and their young relative.

Alex feels the young man is "a product of a lack of responsibility from social care, as many others who are forced into it get left to their own devices. If truth ever made, he is the victim."

Alex says the distress caused by this young man's condition and the lack of effective help has left them: "Just life beaten. Tried an overdose. Failed, [family member] found me."

Alex is also fearful of what their relative might do: "I believe he could seriously hurt someone without help. Prisons are overwhelmed, local authorities ignore."

* Name has been changed.

What could have worked better?

We asked autistic people what could have worked better for them. 27 people gave us their opinions, most of them relating to better communication and empathy that takes account of autistic people's particular sensitivities. Training staff and clinicians so that they understand the impact of autism was also frequently mentioned.

The National Autism Society (NAS) funded the adult social group, and that was the only useful thing for me after being diagnosed, as the charities were only in it for themselves and the diagnostic service had no after care.

Support worker - good, but hasn't been able to adapt her communication style to better support me. I need clear and direct communication, but despite stating this, it's still very chaotic.

More Autism friendly. More understand around mental health problems - My GP surgery has managed in the past to cause or trigger meltdowns/panic attacks and done nothing to help support. Better signposting to places that can actually help - LIFT* was the only place I was signposted to. I had to find Willows and Revival** myself.

More training.

Make the ASD [Autism Spectrum Disorder] service contact and name clear and easy to find and use. If I were to visit the council website now, what number should I call for help? Which service should I contact for help and advice? it's not easy or clear to find or understand.

There is no help. Most other countries have ABA programs etc [Applied Behaviour Analysis]. Unless you have a lot of money in this country you are forgotten and ignored and child left to suffer. Early intervention is vital but denied.

Professional NHS services (GP and IAPT) need to better understand autism and how basic CBT won't necessarily work. Also needs to be a longer number of sessions.

It would be more helpful if someone could have set up services that would actually help me live my life. Like a support worker or carer to take me out of the house and do activities and errands and help me complete household tasks.

* Wiltshire LIFT Psychology, now known as Talking Therapies, is run by AWP and helps people access support for a range of common mental health problems.

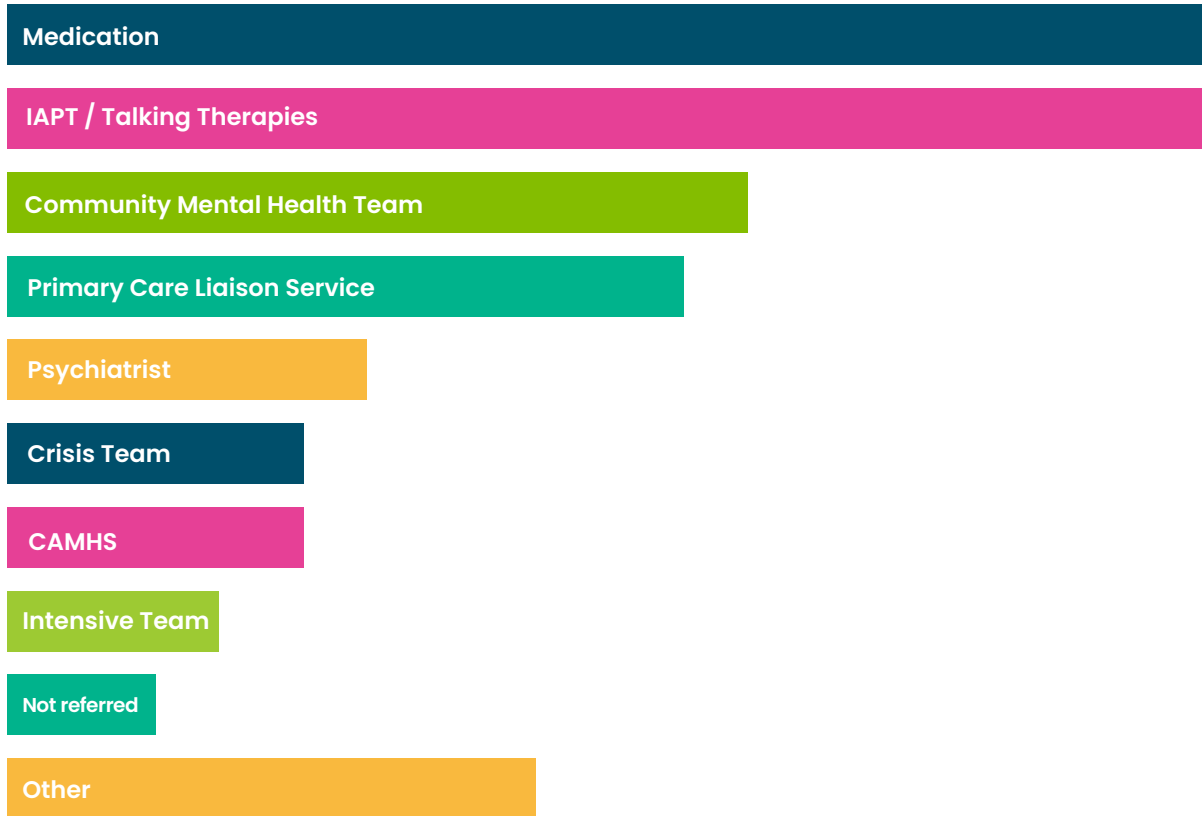
** Willows offers mental health counselling. Revival is the Wiltshire Rape and Sexual Abuse Centre, which offers support to men and women.

81% of carers (21) told us that their experience could have been better/improved, 15% (4) were unsure and 4% (1) persons said it could not. 22 people provided comments on what could have been done better, including:

- 6 For GPs to be able to refer patients to qualified, trained (in Autism) therapists in the community who can support and work with Autistic people who so often have co-occurring conditions - like Tourette's, anxiety, depression and intrusive thoughts, etc. So often now the knowledge to understand Autistic people's needs is not there.
- 6 PCLS need better training so that they recognise someone in need of referral BEFORE they hit crisis, and need to conduct assessments 'face to face'. Those on the spectrum who have other mental health issues need time and support to help them explain themselves to professionals.
- 6 Telephone consultations are not a good substitute for face to face meetings.
- 6 My son can't do Zoom and sometimes this is the only option which is out of the question for him.
- 6 Specific support that is ADD [Attention Deficit Disorder] focused, not just leaflets and support groups but real time in person support for the child and carer/family.
- 6 Services that provide therapy other than CBT and antidepressants which do not work.

Where were people referred?

We went on to ask if people had been referred on to any other service. All 28 autistic respondents answered this question and only 2 said that they had not been referred and tried to manage on their own. The chart below shows the breakdown of where people were referred to. Respondents could choose more than one service.



There were 11 comments left in response to this question. 5 of those said that they were not referred by a professional but that they had self-referred, been told to self-refer, or had asked for a referral.

Other services mentioned include an employee assistance program, MIND and the National Autistic Society.

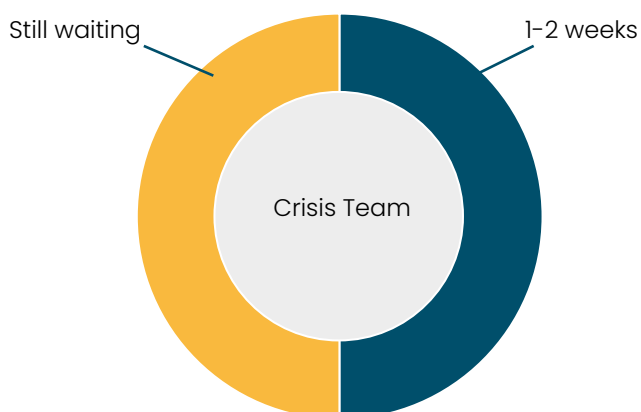
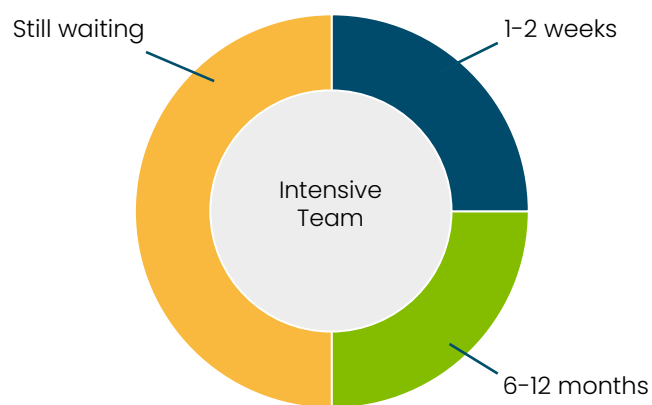
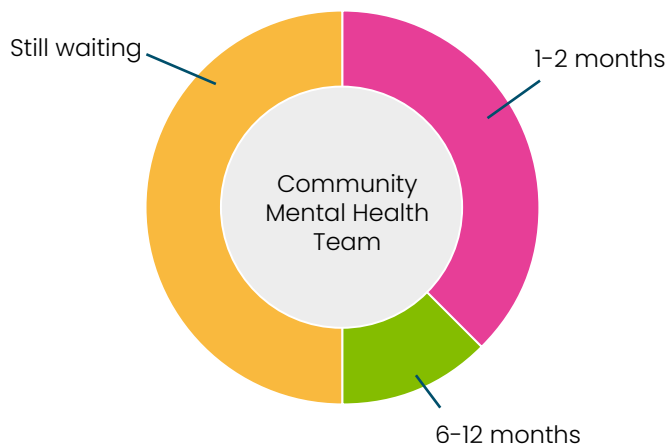
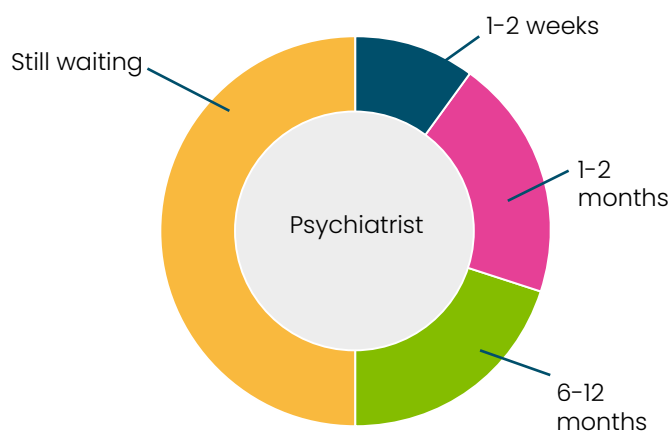
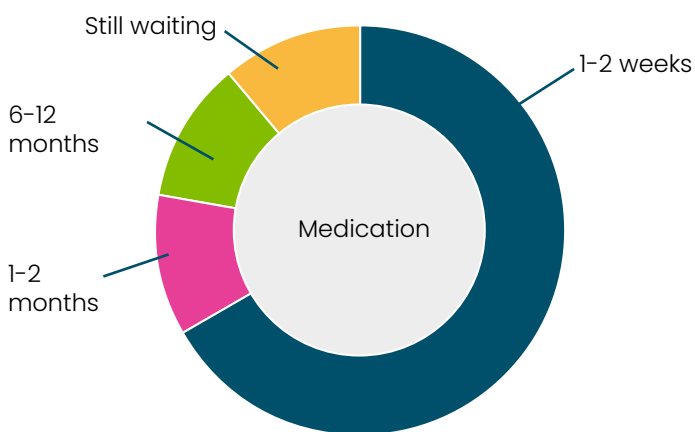
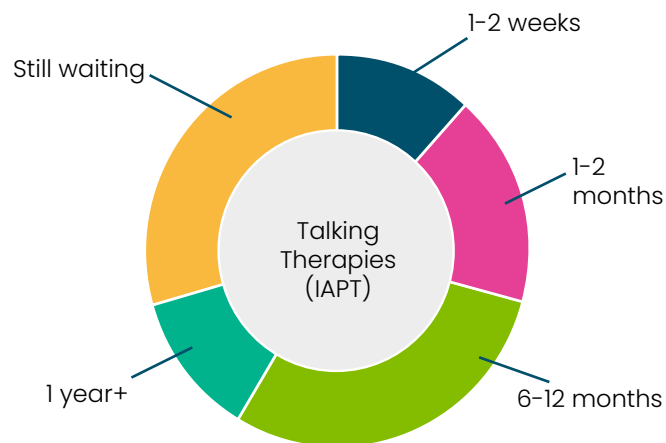
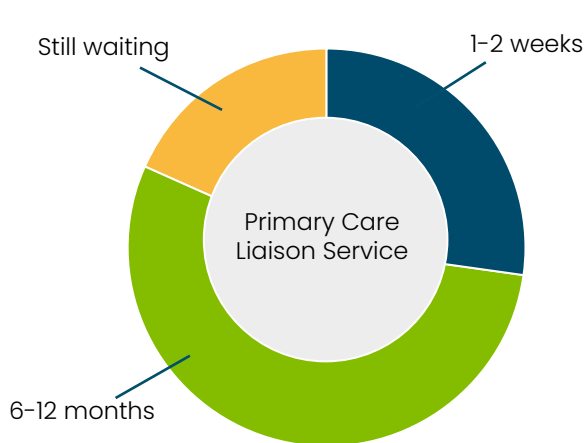
 I was told to contact LIFT. I wasn't referred to them. 

We asked how long the wait was to access the services that they had been referred to. Times varied from 1-2 weeks to over a year depending on the service.

Respondents could select as many options as applied, and 23 of the 25 autistic people who answered this question said that they are still waiting for a service.

The full breakdown is shown in the charts on page 19.

How long did people wait to access services?



Of the 8 comments we received relating to this question, half were positive.

- Super quick response after my father's death by suicide. Thank God! Very kind people.
- LIFT was an online course for me, so I was able to start as soon as I was ready. I doubt it would have been that quick if I was waiting to speak to someone.
- It seems the support was easier to gain if already in the system and you have a named person to contact.
- It was a bit different for me as I was already under CAMHS for sleeping medication - so when the OCD [Obsessive Compulsive Disorder] started I could speak with the Psychiatrist straight away which was amazing as without immediate support and medication I would have got a lot worse quite quickly. She also extended her care when I turned 18 for a few months to ensure the correct level of medication was reached. However prior to this it took about 6 months to get into CAMHS - when they discharged me they said we could re-refer at any time, when we tried they just signposted me to books and then when things got really bad my Mum wrote to the Psychiatrist directly and she got in contact.

How helpful were the services?

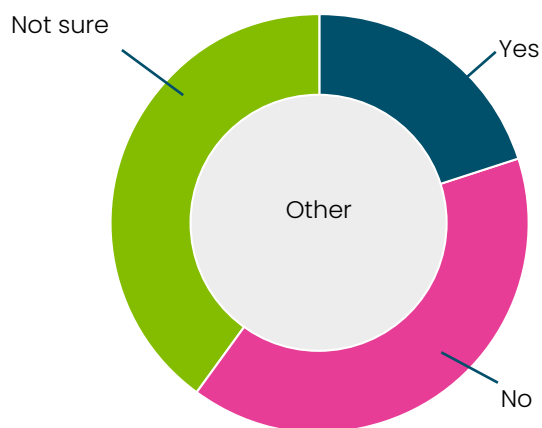
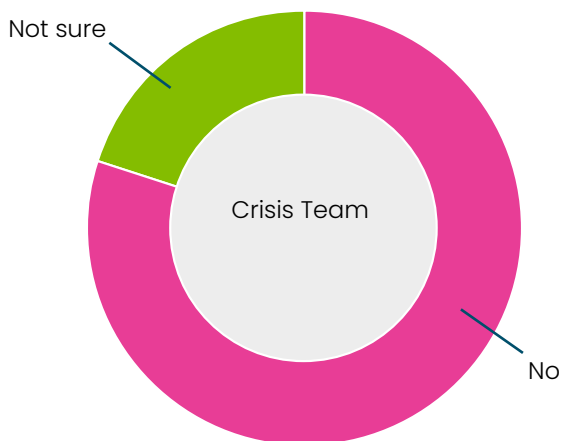
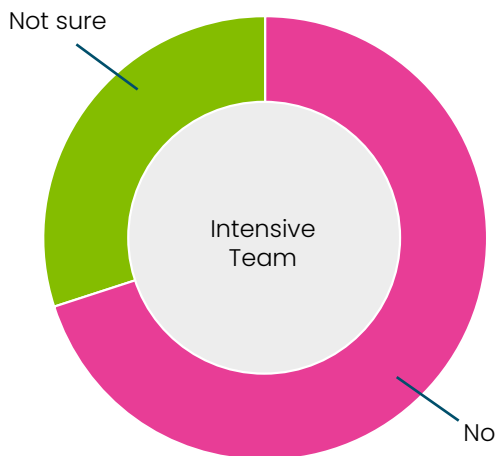
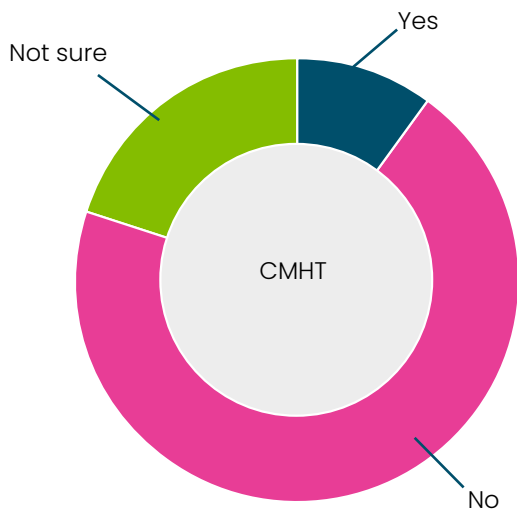
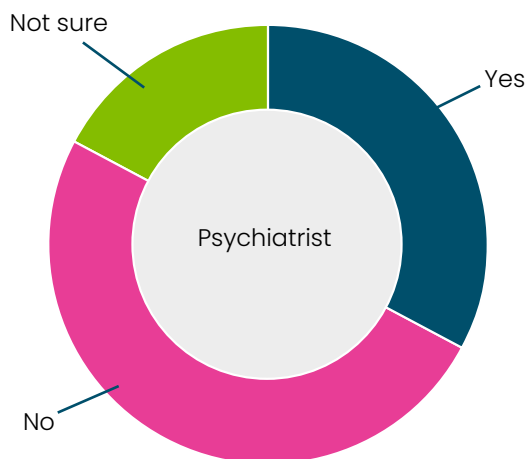
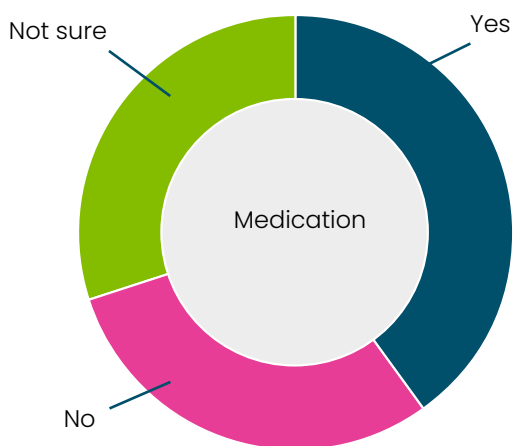
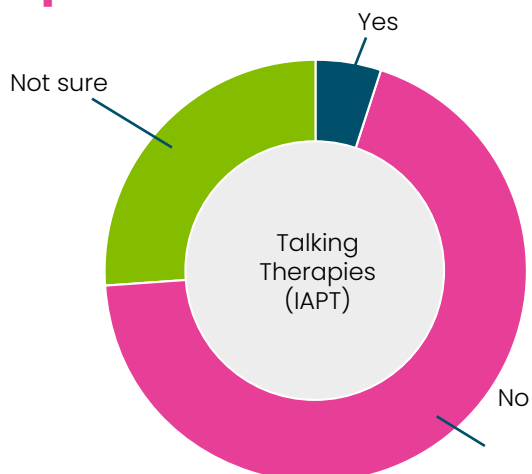
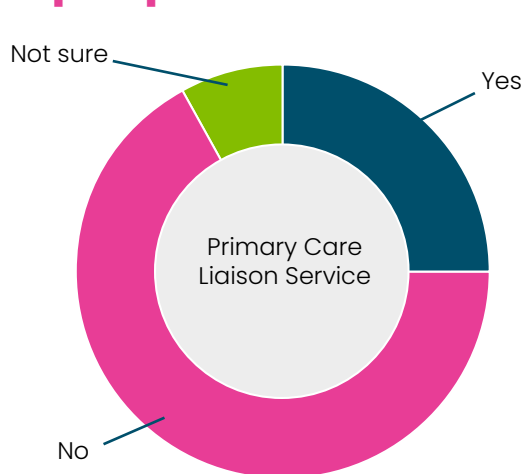
The next question focused on whether respondents found services helpful.

With the exception of medication, which is used by 71% of respondents, services were not seen as helpful by the majority of those who had used them. This suggests that the services available are not suited to the autistic people who responded to this survey.

The pie charts on page 21 illustrate what our respondents told us.

- I have only just reached the top of the list for IAPT and haven't had my first session yet. Medication doesn't work for me, I get too many side effects and it makes me cry more.
- Referrals made but not accepted - constantly fall between the gaps. Not ill enough for PCLS (or told eating disorder the main issue) and too ill/complex for LIFT/IAPT.
- All my support following very shortly after Dad committed suicide... is top of the class. I could not possibly fault it. Everyone cleared their diaries for us.

Did people find the services helpful?



John's story

John*, 50, has an autism spectrum diagnosis and has experienced mental health issues over the last few years. John lives with his wife who has depression, an autistic son and a daughter with ADHD and Obsessive Compulsive Disorder.

He has accessed mental health services in the last 3 years and is currently on medication. He told his GP that he was feeling pointless, hopeless and disconnected. He was referred to the Primary Care Liaison Service who arranged a Zoom triage with a "non-professional" who would send a written report to a professional. He was informed by letter that there was no need for further treatment.

"I was dropped and no further treatment were offered and no GP follow up". He felt he had "failed the initiation process".

He praised his GP but they are now on long term leave: "She was wonderful. She sorted out my medication she saw me every two to three weeks to make sure I was maintaining at least a status quo. If not, she would try to inspire me. I

felt that I was important to someone other than my family."

John said he does not have the energy to go through the process again to reach the same conclusion.

"Unless I say the words 'I want to end my life' I'm not important enough. I have told Health Professionals that I have wished to never have existed and I have wished myself out of existence. No matter, I will continue my existence with a sense of hopelessness. Apparently mental health is about saving lives not improving lives."

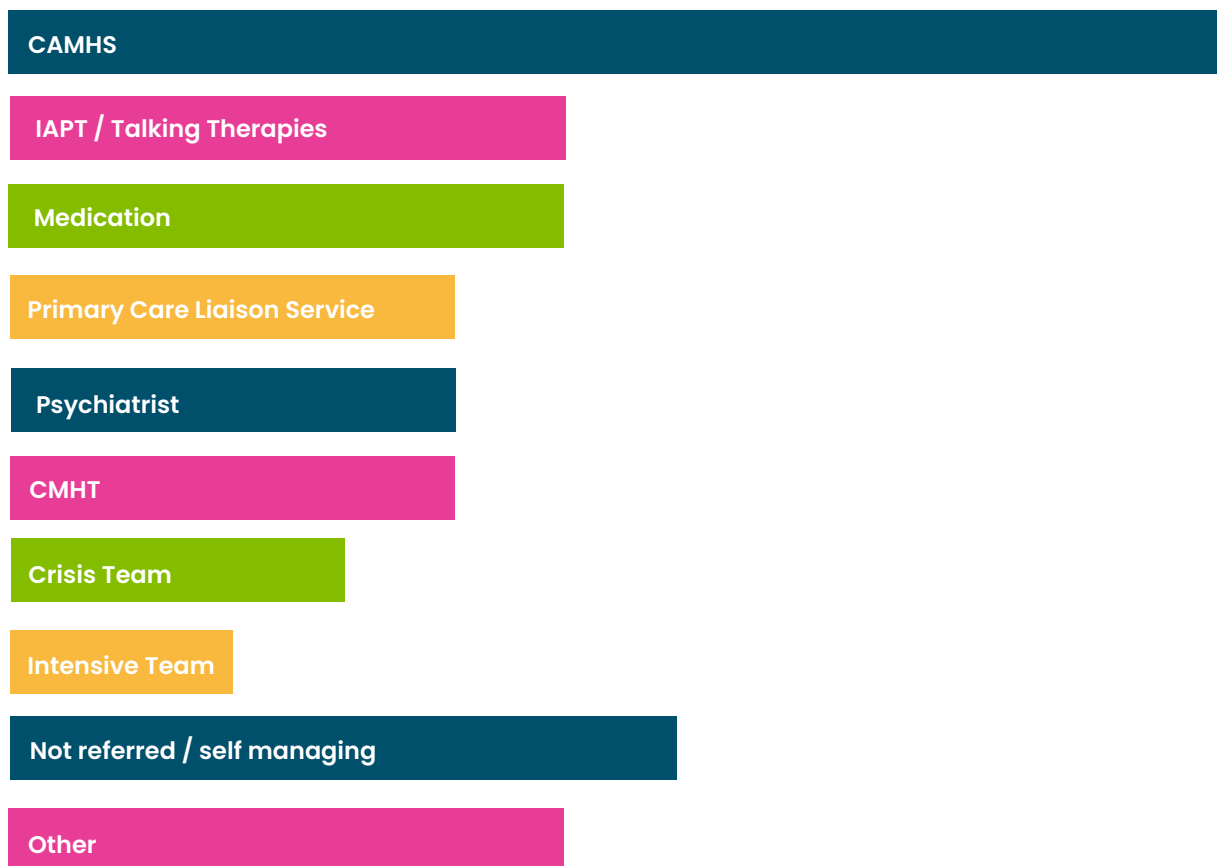
He says he has given up trying to find help.

"I realised the process of getting [help] just makes my mental health worse. I already have depression, anxiety and I'm autistic. I can't make telephone calls without extreme levels of anxiety possibly panic attacks and days, possibly weeks, of trying to build up the courage to do so."

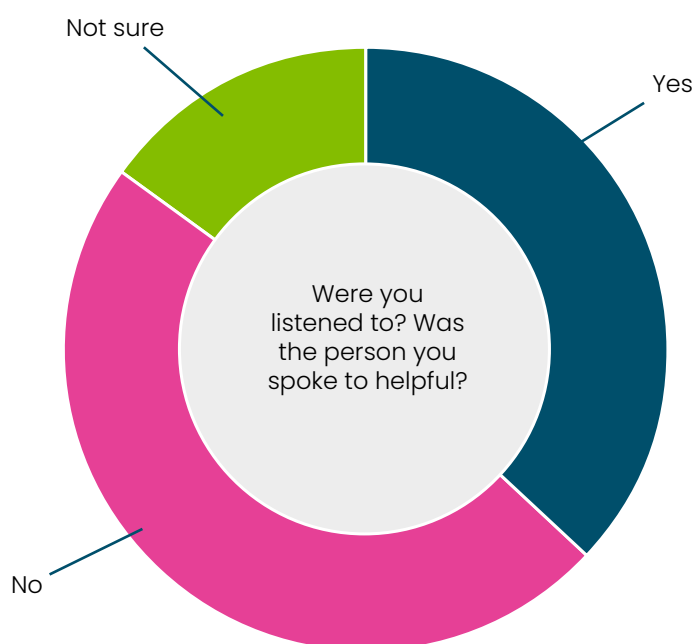
* Name has been changed.

Carers' views of referrals

We asked carers about the services their loved ones were referred to and their views on how helpful these referrals were. The chart below shows that most (42%) were referred to CAMHS. 23% were not referred and tried to manage on their own.



The majority of carers told us they did not feel that their request for help was listened to or that the person they spoke to was helpful. All 27 carer respondents answered this question and 23 left comments explaining why they held this view.



Most comments (17) were negative, though 5 people qualified their comments by stating that the GP had tried to be helpful but they felt let down by the mental health services. Three people said the system was under pressure and did not have capacity. Two comments were positive, 3 were mixed and 1 comment said their children had refused to cooperate. The key themes were:

- The difficulty in accessing mental health services
- The high thresholds imposed for eligibility
- The unsuitability of talking therapies
- Being bounced around the system with no one taking responsibility for finding support.

Our GP was very good, but the CAMHS telephone appointment (before we had the referral to the eating disorder team) was disappointing. I came away with the feeling that as my daughter was not going to commit suicide, (although when asked I did say that I know she has suicidal thoughts I didn't think she would, but she then again, I never thought she would self-harm and she was) that the rest of the telephone conversation was a 'checklist'.

The result of this call was a recommendation to self-refer to Wiltshire Speech & Language services for the selective mutism and to Barnardo's Decider Skills* course. I came away feeling let down and not really listened to as all I was asked was a list of question which then pointed to certain outcomes. However, the response from the CAMHS eating disorder team has been very different. We have felt listened to and because it is face to face, the people we meet can actually see the impact on my child's mental health.

From the GP yes, from CAMHS absolutely not. They were absolutely awful and completely untrained in mental health.

I have been trying to get mental health support in the form of therapy on and off for years now with no avail. Over the past 15 months alone my child has been passed from pillar to post, despite having a multi-agency approach with ESA meetings [Early Support Assessment]. We have been in a constant loop. School have said they can't include it within the EHCP [Education Health and Care Plan], the local authority have said CAMHS need to meet the need, my daughter isn't complex enough for CAMHS, CAMHS have sent us to family counselling trust and Barnardos therapy/support. Both these charities have come back and said she is too complex for them to support and to go back to CAMHS and we keep going round in circles. Meanwhile my daughter's mental health continues to worsen.

When we asked carers if the person they care for was offered any other treatment or access to any other service to help them with their mental health, 69% (18) said they had not, 19% (5) were and 3 people were unsure. 10 carers shared comments about their experience.

Referred to child psychologist for autism assessment, dietitian and paediatrician for general health check due to low weight.

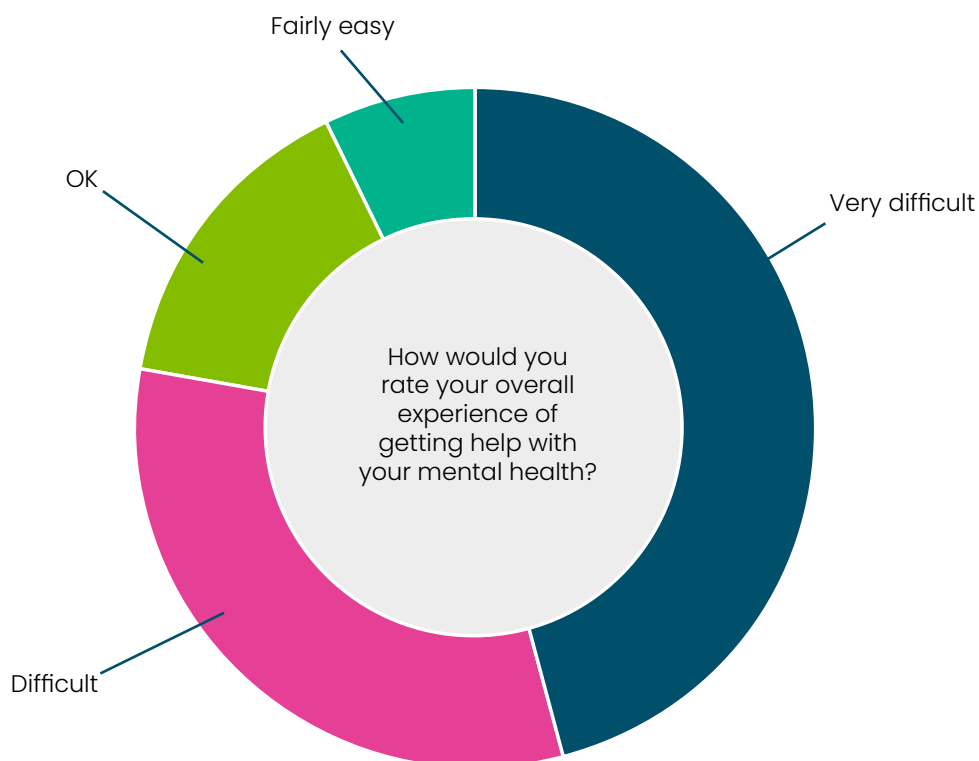
He was placed in a psychiatric hospital for a short stay which did not help his mental health but kept him alive.

Leaflets! And support groups which always fall in the working day, also zoom based courses - these need to go back to face to face.

* A programme based on cognitive-behavioural therapy for children and young people and their families.

Autistic people's views of the overall experience

When we asked people about their experience of getting help for their mental health, 79% (22) of those autistic people rated their overall experience as difficult or very difficult. No one found it easy. 21% (6) thought it was ok or fairly easy.



All 28 of the autistic respondents left a comment as to why they rated their experience as they did. 23 comments were negative, 4 were mixed or neutral and 1 was positive.

I find it difficult to explain my difficulties. When you've spent over 40 years being told it's your fault as not trying hard enough, being used and abused by people, in a bid to not end up homeless and on the streets, how can you explain it all in a 10 minute GP meeting? Even in CBT therapy they made me feel worse, as told me it was my fault from thinking wrong and were annoyed with me when I wasn't normal at the end of their therapy, and I was still scared about finding life difficult with no support. They made me feel as if I was making it up to get benefits.

Too many gaps in services. Not enough understanding of Autism. Hard getting referrals for OT [Occupational Therapy]/social care, despite repeatedly saying struggles in these areas impacting mental health.

Because no one can help me and I just get offered medication despite everyone being in agreement that I need a specialist to do therapy.

Waiting lists. Lack of variety of treatment. Not very individual to people's needs.

Long waiting periods, lack of understanding, extremely high thresholds for support, no appropriate autism friendly mental health support available. Experiencing discrimination. Being undermined and laughed at. Until significant changes are made I will seek private support at financial hardship to myself and continue to use peer support groups and neuro-affirming DBT workbooks that are run and adapted by autistic people to fill the gap mental health services aren't giving us. But I am concerned if my mental health got [worse] where I would go for support.

I fall between the cracks, too many experts who don't have a clue about autism.

On arrival, I found my care was not continued and I was just isolated. I did have some sessions with a mental health nurse at the surgery for a short time... I did a CBT course, but it was a total waste because I had forgotten what I had done by the time I walked out the door. My requests for support always fell on deaf ears, so I went private and they [were abusive] so I gave up. I always tell people there is no mental health [support] in Wiltshire, it is invisible.

I say OK as I was lucky to be in the system - If I hadn't or without my Mum I think I would have got very ill quickly.

The GP was kind and listened and was supportive and helpful. We discussed increasing medication, and this was enough to stabilise me and, overall, I had a good experience.

Carers' views of the overall experience

We asked the same questions of carers and family members and they rated their overall experience in a similar way. 89% (23) of the 26 carers who answered said it was difficult or very difficult getting help for the person they care for, while 11% (3) thought it was fairly easy or ok. They all provided comments explaining their ratings.

It's taken over 1-2 years for the Initial assessment and now on a waiting list to actually get the counselling and support.

Lack of services and support for young adults with autism.

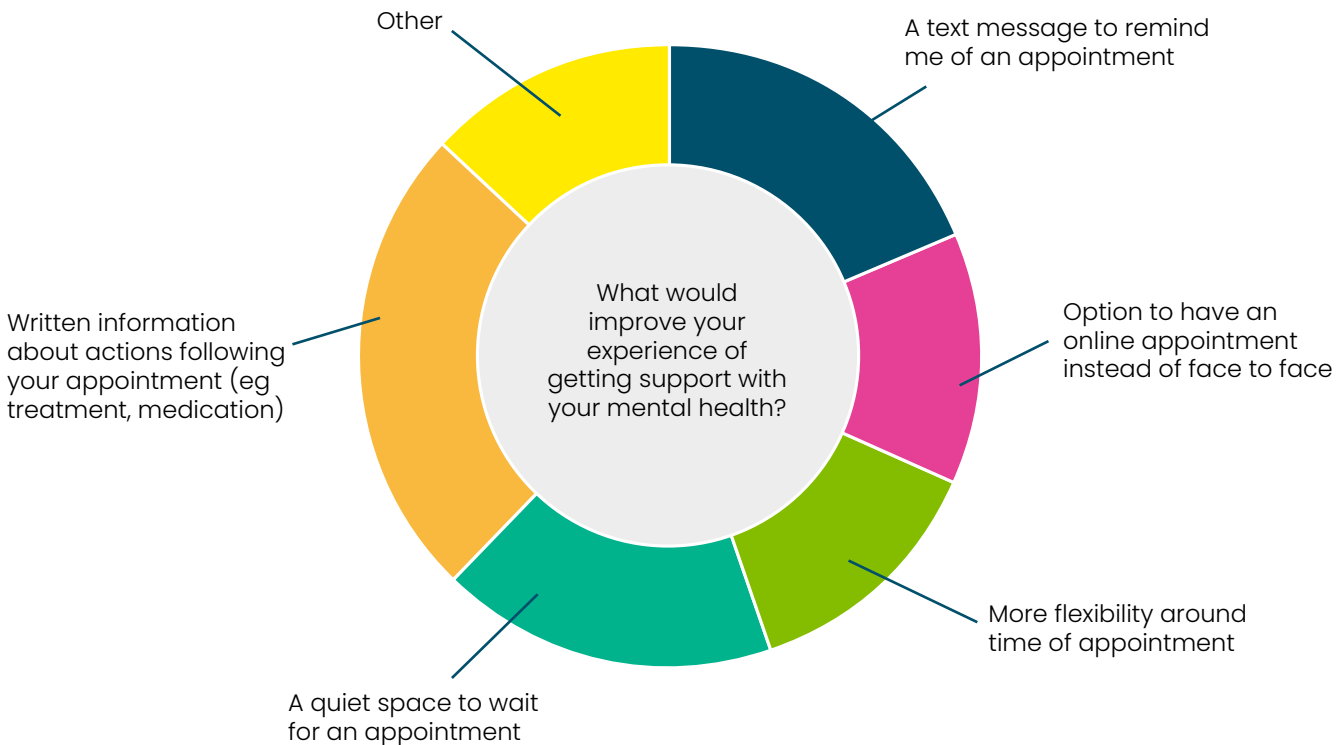
Initially long time to get into CAMHS but once in then good support.

There was nothing available suitable to help someone on the autistic spectrum with the difficulties being expressed. Just told in an emergency to contact Police/999 which is not the answer.

Recommendations for making it easier to get support

We asked if there are any specific practical recommendations people could suggest to improve their experience of getting support with their mental health.

25 autistic people answered this question. We suggested five options which we had gathered from previous engagement as a “starter”. They could select as many as they liked. We also requested they add any other recommendations. Their responses showed a marked preference for written records following any advice given.



‘Other’ suggestions made by autistic people included:

- Using email or text rather than phone to communicate and to ask questions, avoiding long waits on phone and difficulty in expressing thoughts.
- More online booking.
- Staff who understand/are aware of autism.
- Written information about what to expect after you’ve been referred, eg estimated wait time for assessment, what the assessment will involve, type of support the service can provide.
- A central autism service who know about all of the services available to those with autism/ADHD and can assess each person with a diagnosis/seeking a diagnosis; for care act assessments, benefits, occupational therapy, etc.
- Make services easier to find and contact, eg improve signposting from websites.
- Tailor care and treatment plan to individual rather than to CMHT services.
- Better/more variety of options and therapies more suited to autistic people’s needs.

Being able to email places to ask for help. I find using the phone very difficult. I would much rather email to begin with.

There is no flexibility to what CAMHS offers (if you are unwell enough to meet the threshold-it has been said that two suicide attempts are currently the threshold for support). Only talking therapies are available, whereas a more creative therapy approach is needed for a lot of children (eg art, play, nature therapies).

Carers also made some recommendations which they thought could make it easier for them to get support for the person they care for and for themselves.

- Easier access to community mental health teams, before crisis situation.
- Better coordinated service with better communication between services so serious mental health signs in a child are neither being missed or dismissed.
- Less reliance and signposting to apps and websites/online material, more face to face treatment.
- Enable better resourcing and access to CAMHS to reduce long waits.
- Access to a specialist multidisciplinary team with modern treatments.
- Autistic-led training to all mental health staff.

For the carer to have a 1:1, face to face discussion (with OR without the patient) so that the full depth of the illness / problem can be understood - and for the professional... to be skilled in active listening. Finally - for professionals to take a proactive approach with the patient rather than a reactive one.

CAMHS to be more accessible and deal with urgent cases quicker. It was a complete waste of time as by the time we got the appointment for assessment my son had thankfully got better and the assessment was a complete waste of NHS money as he was discharged. This was because the school counsellor stepped in. Had we not had access to this my child may no longer be alive. My worry is if he relapses once out of education.

Please listen and understand that if an Autistic person presents themselves as coping, it does not mean that they are. Offer help in a timely manner, it's been 3+ years and we have reached a dead end, no one seems to be able to provide specialised therapy for her. After researching, looking and asking practically everyone, I was recommended a charity called Rethink Mental Health who are now trying to help us.

I am also a carer for another daughter too and the toll this has all taken on me has been immense. When your child tells you they would be better off dead because help isn't coming so I have to ask her if she feels like killing herself or is making plans to on those more difficult days, it's been desperate at times and in turn, I have felt desperate to help her many, many times.

Anything else you would like to say?

Finally, we asked if there was anything else people would like to tell us about their experience of getting help with their mental health. Autistic people told us that it was a distressing and difficult process and several said that they had given up trying to get help.

Shockingly bad. Huge gaps in services. Very disjointed services depending on where in Wiltshire you live. Still not enough understanding of autism and the need for reasonable adjustments.

It has been appalling I would rather commit suicide than deal with them again.

The process for asking for help is not user friendly. However, once contact is (finally) made with appropriate support service(s) the people providing the support are very helpful.

I have given up trying to find help as I realised the process of getting it just makes my mental health worse, I already have depression anxiety and I'm autistic. I can't make telephone calls without extreme levels of anxiety, possibly panic attacks and days possibly weeks of trying to build up the courage to do so.

19 carers provided a wide range of comments. 17 were negative, 1 positive and 1 mixed. All asked for more help. Several mentioned that their own mental health was under huge stress as they "battled" to find support for their loved one and the impact on family life. Being forced to seek private treatment due to lack of services was also mentioned.

Although I understand that there are immense pressures on the NHS, the wait for vulnerable people in dire need of help is appalling. One therapy is not helpful for everyone and assuming it is (because someone has decided it is) can cause more harm than good. If CBT doesn't work for you (as it doesn't for many autistic people) then there is no offer of alternative help and you are cast adrift to cope on your own.

I think that we as parent/carers know our children better than the GPs and Mental Health Teams. They always come across as they know better than the parent. Parents/carers should be taken seriously for what support our child needs.

The system has failed my son - and I, as now I am struggling with my own mental health due to the ongoing struggle to cope with my son's.

Please change things and as quickly as possible because lives will be lost because the support is just not there. I am a pro-active parent, I have to be, but even I am tired of it all.

We have lived in several different places in England and Scotland. As far as health services for autistic people are concerned, Wiltshire is by far the worst in terms of specialist services, eg IAPT was unaware of how to adapt materials and refused to offer face to face appointments.

Didn't get support until she overdosed.

It's difficult, first refused by CAMHS and then accepted when referred again. Our daughter is stuck in limbo, with suicidal and self harm issues and really no further 2 years on. The services and waiting time are appalling.

Whilst I understand the need to identify children who are more at risk of suicide than others, the current service [CAMHS] gives the impression that unless you are about to attempt suicide, you are on a waiting list to get help and it will be a long wait.

Conclusions

It is clear that autistic people and their carers have struggled to access support for their mental health, and this has had a serious impact on them as individuals and their families.

Many people have spoken about falling between the gaps of services, no suitable service being available or having to pay privately for support. The lack of suitable support has a long term impact on autistic people and their families/carers, with some becoming suicidal or a potential danger to others.

Most people went to their GPs as their first point of contact to get help and considered them to be helpful, but faced long waiting times for onward referrals to other services. People were also frustrated at being referred and re-referred between services.

One of the most frequent recommendations from respondents was the need for training among medical and clinical staff and emergency services on autism and greater awareness and empathy.

Communication difficulties faced by autistic people, coupled with a lack of flexibility from services – such as only offering phone calls rather than face to face appointments – created a barrier for autistic people to be able to access help.

Carers said the Child and Adolescent Mental Health Service (CAMHS) was overwhelmed and the waiting times very long, while waiting times for an autism diagnosis were seen as unacceptable, with little support or guidance post diagnosis.

Reasonable adjustments to the way services are delivered could make a big difference to autistic people's ability to access support once they are accepted for treatment. This request for adjustments was heard in the previous project undertaken by Healthwatch Wiltshire and WSUN in 2020/21 looking at how autistic people access health and care services.

The survey responses make clear the unsuitability of IAPT/talking therapies and the lack of appropriate mental health support that takes into account the particular needs of autistic people. Several respondents asked for a more creative approach to providing help and support that works for their needs rather than the standard offer.

Recommendations

Based on our findings we make the following recommendations:

- Deliver autism training for all mental health staff, preferably led by an autistic person or someone with lived experience, that provides practical advice and techniques for engaging with autistic people. This would be in addition to training to raise awareness of autism (such as the Oliver McGowan Mandatory Training).
- Provide more staff for CAMHS and mental health services who understand autism.
- Consider the recommendations that have already been made in our previous report and consult with autistic people to put in place reasonable adjustments and more flexibility, to make it easier for autistic people and their carers to access mental health support and maintain treatment.
- Create mental health solutions/therapies that are more suited and helpful to autistic people, recognising their neurodivergence.
- Recruit ASC specific professionals to help at times of crisis with respite/practical support/network co-ordination and support for the carer.
- Recognise that an autistic person may mask their condition - assess them more than once or ask a carer/family member for their input and views.
- Provide options for how people contact a service - offer online/email contact to those who have difficulty making phone calls, and vice versa.
- Tailor the service to their individual needs rather than be diagnosis-led: Provide more face to face contact if it's easier for the autistic person.


Thank you!

Thank you to all the autistic people and their carers who shared their views and experiences with us. Thanks also to WSUN, our partner organisations, and our volunteers who supported this work.

Response

Gordon Muvuti

Director of Place Swindon and BSW Executive Director for Mental Health, Bath and North East Somerset, Swindon and Wiltshire Integrated Care Board (BSW ICB)

 The findings and outcomes of this mental health focused Healthwatch Wiltshire report shine a spotlight on the importance of continuing to improve access and service provision for people with autism and their families and carers in Wiltshire.

The views and experiences of people who have accessed services are paramount in guiding service transformation, and this report highlights where people want to see improvement in current service provision.

We will ensure that their recommendations form part of our review of the Wiltshire Autism Strategy as well as the further development and implementation of our BSW ICB Learning Disabilities & Autism, and Mental Health transformation programmes.

We are grateful to individuals, their families, supporters and carers, for providing their input to this report and we will continue to develop our co-production approach in order that their voices and experience drive the changes we want to see across our system.



Appendix 1

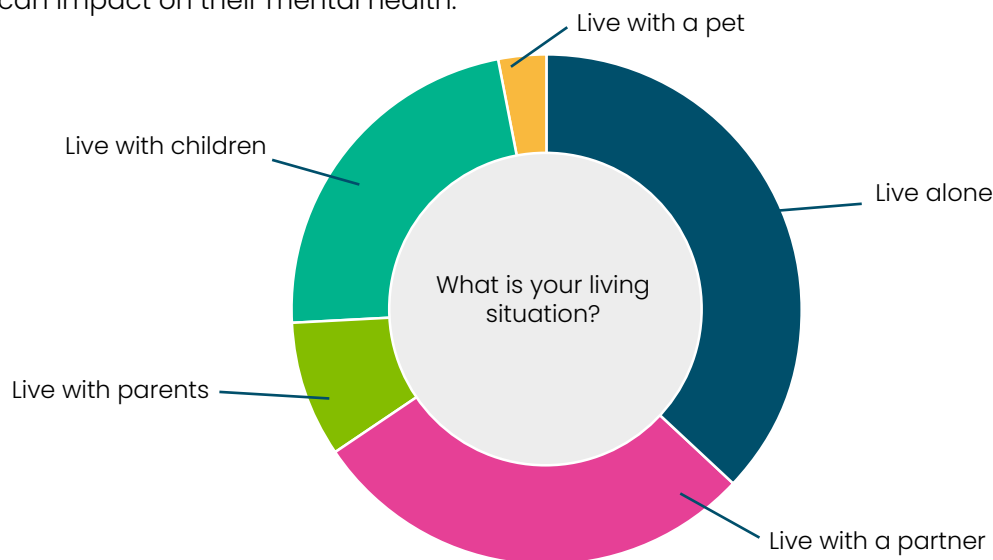
Demographics

People who responded on their own behalf

96% of people who responded on their own behalf described their **ethnicity** as White British and 4% as White Other.

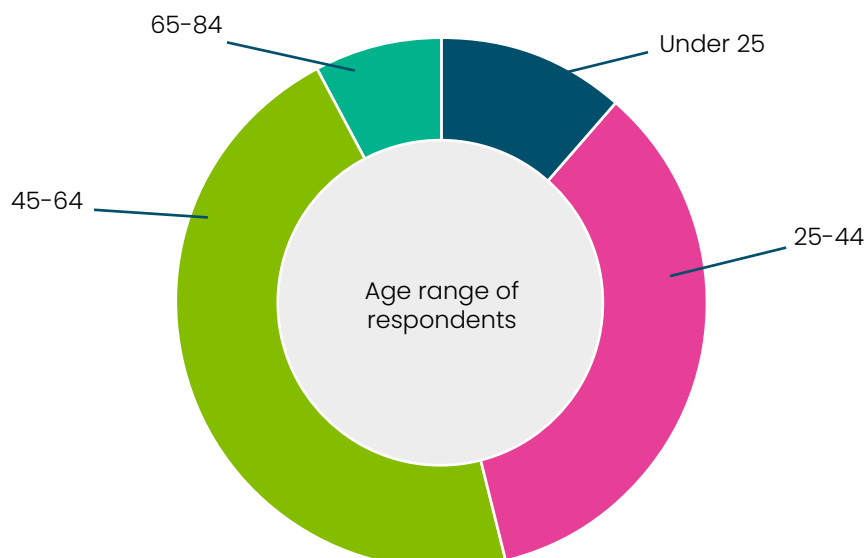
In terms of **gender**, 16 respondents described themselves as female, 10 as male, 1 as non-binary and 1 as pansexual.

When we asked people about their **living situation**, the responses were quite evenly balanced between those who live alone (13) and those with a partner (10). Three people said they live with their parents and 1 person told us they lived with their dog. 8 respondents also told us that they lived with their children who were autistic, had learning disabilities or had additional needs. Their reason for commenting on this is that this can impact on their mental health.



Respondents to the survey are **located all across Wiltshire**. It should be noted that 2 respondents are no longer based in Wiltshire.

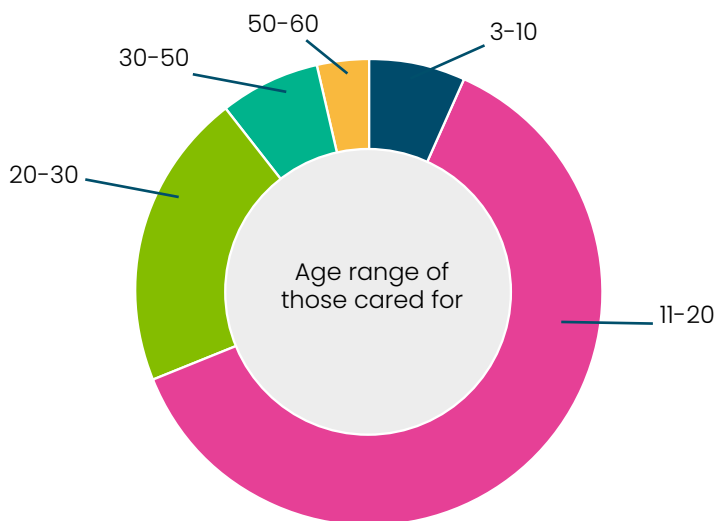
The **age range** of respondents was similarly wide and representative with the majority of autistic people who completed the survey being within 45 to 64 years.



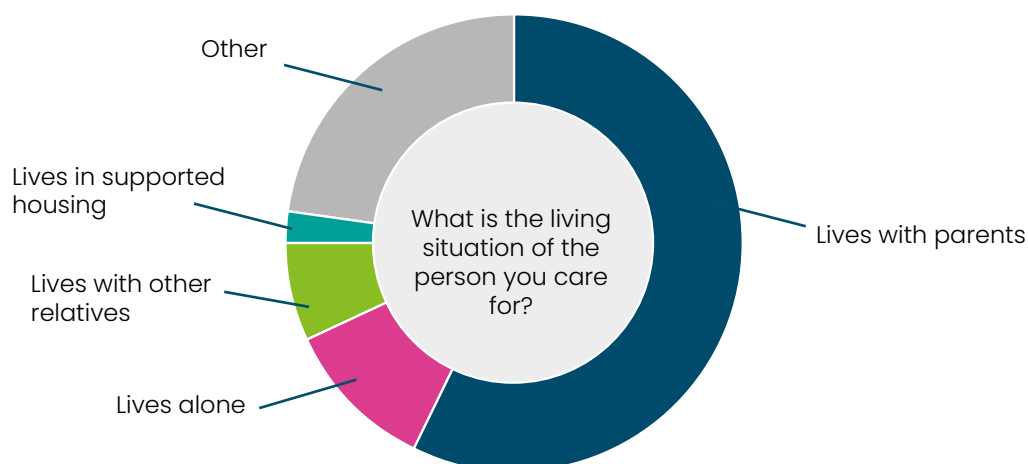
People who responded on behalf of a person they care for/loved one

Interestingly, when we asked about the **gender** of the person for whom they care, the results were very different, almost opposite, from those who responded directly for themselves, with 9 female, 15 male, 2 trans male (one did not answer). One person answered on behalf of their two male and two female children, hence the number discrepancy.

The **age range** of those cared for was generally younger than those who responded to the survey on their behalf.

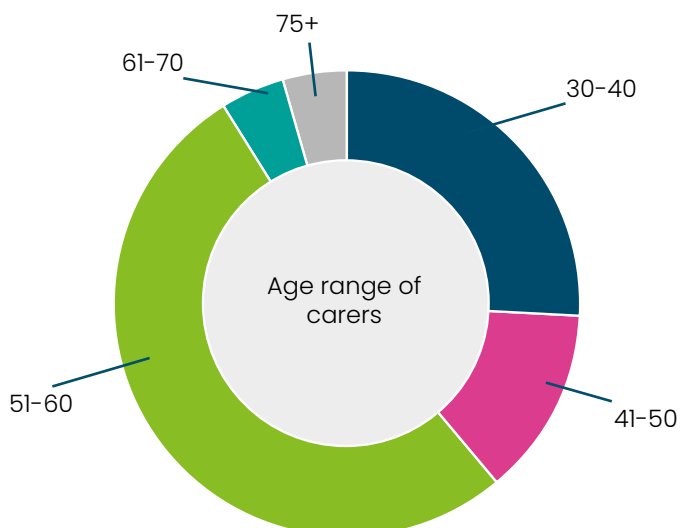


In terms of their **living situation**, carers' answers showed that most people (15) are living with their parents, which fits with the younger demographic being described. None are living with a partners, 4 live alone of whom 1 is identified as receiving direct payments, 1 lives in supported housing and 2 live with other relatives. The responses under 'Other' category include 1 person who is currently in prison and 2 who said "they are living with me" but did not specify the relationship.



About the carers

When we asked the carers about themselves, they told us 24 of them are female, 1 male and 1 person declined to say. Their age range went from 31 years to 75 years.



Appendix 2



Autistic people's experience of accessing mental health services and support in Wiltshire

1. Your experience

Healthwatch Wiltshire gathers feedback from local people about health and social care services. We are working with Wiltshire Service Users Network who support the Wiltshire Autism Hub for Autistic people aged 14 years or more and living in Wiltshire.

We want to find out autistic people's experience of accessing mental health services in Wiltshire over the last three years. The information you provide is confidential, however we may use anonymised quotes. We will use the information to tell those who run the services what could be improved or developed in the future.

1. Please can you tell us which of these options describes you? (Please tick all boxes that apply)

- I believe I am autistic/self-diagnosed
- I have an autism spectrum diagnosis
- I am waiting for diagnosis
- I am waiting to be referred for diagnosis
- I also have learning disabilities

2. How would you describe your current mental health? *

- I feel my mental health is currently stable
- I am worried about my mental health and need help
- I've had issues with my mental health recently (within 3 yrs)

3. Please can you tell us whether you have needed help with your mental health? (Please tick all boxes that apply)

- I am currently getting help from mental health services
- I have had help from mental health services in the last 3 years
- I am currently taking medication to help with my mental health (prescribed by the GP)
- I have not accessed mental health services but I am concerned about my mental health and I am thinking of asking for help

4. Who did you talk to in order to get help? (Please tick all that apply)

- My GP
- My Support Worker
- Friend/Family member
- Hospital Staff
- I don't have anyone to talk to
- Other (please specify in the Comments box below)

Comments:

5. If you are considering asking for help with your mental health who would you talk to?

- My GP
- My Support Worker
- Friend/Family member
- Hospital Staff
- I don't have anyone to talk to
- Other (please specify in the Comments box below)

Comments:

6. For each person you spoke to, can you say whether they were helpful? (Please tick all boxes that apply)

	Yes	No	Unsure
GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support Worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friend/Family member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Yes	No	Unsure
Hospital Staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify in Comments box below)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

For each person you talked to, can you please tell us why you felt like this?

7. What could have worked better/been improved?

8. Were you referred to further services? (Tick all that apply)

- Primary Care Liaison Services
- IAPTs - Talking Therapies (previously known as LIFT)
- Medication
- Psychiatrist
- Community Mental Health Team
- Intensive Team
- Crisis Team
- Child and Adolescent Mental Health Services (CAMHS)
- You were not referred and tried to manage on your own
- Other (this could include other organisations, e.g. Wiltshire Wildlife, Rethink, Mind, peer support groups etc)

If you answered 'Other' please tell us what other service/s you were referred to:

9. How long did you wait to access any of these services? (Tick all that apply)

	1-2 weeks	1-2 months	6-12 months	1 year +	Still waiting
Primary Care Liaison Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Talking Therapies (previously known as LIFT)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychiatrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community Mental Health Team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Intensive Team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Crisis Team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you answered 'Other' please specify:

10. For each service you accessed, can you say whether it was helpful? (Please tick all boxes that apply)

	Yes	No	Unsure
Primary Care Liaison Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IAPTS (Talking Therapies - previously known as LIFT)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychiatrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community Mental Health Team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Intensive Team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Crisis Team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (see previous question for examples)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

For each service you accessed, can you tell us why you felt like this?

11. How would you rate your overall experience of getting help for your mental health?

- Very easy
- Fairly easy
- OK
- Difficult
- Very difficult

Why?

12. Are there any specific practical recommendations you could suggest to improve your experience of getting support with your mental health? (Please tick any of the examples in the list below if applicable)

- A text message to remind you of an appointment
- The option to have an online appointment rather than face to face
- More flexibility around time of appointment
- A quiet space to wait for your appointment
- Written information about actions following your appointment (e.g. treatment, medication dosage etc)
- Other (please use box below)

Other suggestions

13. Is there anything else you would like to tell us about your experience of getting help with your mental health?

2. Demographics

This section asks you some personal questions about you so that we can identify any issues that affect different groups of people. This information is anonymous, and you do not have to answer any questions if you don't wish to.

14. Your gender (how you identify)?

15. Your age?

16. Please tell us the town or village where you live?

17. What is your living situation?

I live alone

I live with a partner

I live with my parents

I live with other relatives

I live in supported housing

I live in a residential home

Other (please state):

18. How would you describe your Ethnic Group?

White

- British
- Irish
- Gypsy/Traveller
- White Other

Asian/Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian

Mixed

- White and Black Caribbean
- White and Black African
- White and Black Asian
- Any other mixed

Black/Black British

- African
- Caribbean
- Any other Black
- Arab/any other group

Carers/Relatives experience of assisting autistic people to access mental health services and support in Wiltshire

1. Your experience

Healthwatch Wiltshire gathers feedback from local people about health and social care services. We are working with Wiltshire Service Users Network who support the Wiltshire Autism Hub for Autistic people aged 14 years or more and living in Wiltshire.

We want to find out the carers/relatives experience of helping the autistic person they care for access mental health services in Wiltshire over the last three years. The information you provide is confidential, however we may use anonymised quotes. We will use the information to tell those who run the services what could be improved or developed in the future.

1. We would like you to tell us about the person you care for. Please can you tell us which of these options describes this person? (Please tick all that apply)

- They believe they are autistic
- They are awaiting diagnosis
- They are waiting to be referred for diagnosis
- They also have learning disabilities
- Other (please specify):

Comments:

2. Please can you tell us whether the person you care for has needed help with their mental health? (Please tick all boxes that apply)

- They are currently accessing mental health services
- They have accessed mental health services in the last 3 years
- They are currently taking medication to help with their mental health (prescribed by the GP)
- They have not accessed mental health services but they are concerned about their mental health and are thinking of asking for help

Comments:

3. Who did you/would you talk to in order to get help for the person you care for? (Tick all that apply)

- Their GP
- Their Support Worker
- Friend/Family member
- Hospital Staff
- I don't have anyone to talk to
- Other (please specify in box below)

Comments:

4. Did you feel that your request for help was listened to? Was the person you spoke to helpful?

- Yes
- No
- Unsure

Can you please tell us about your experience?

5. Is there anything about this experience that could have worked better/been improved?

- Yes
- No
- Unsure

Comment

6. Did the person you talked to initially refer the person you care for to a further service? (Tick all that apply)

- Primary Care Liaison Services
- IAPTs (Talking Therapies previously known as LIFT)
- Medication
- Psychiatrist
- Intensive Team
- Crisis Team
- Community Mental Health Team
- Child and Adolescent Mental Health Services (CAMHS)
- You were not referred and tried to manage on your own
- Other (please specify which other service/s in the comments box below)

Comments:

7. How long did the person you care for wait to access any of these services? (Tick all that apply)

	1-2 weeks	1-2 months	6-12 months	1 year +	Still waiting
Primary Care Liaison Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IAPTs (Talking Therapies previously known as LIFT)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychiatrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Intensive Team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Crisis Team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community Mental Health Team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Child and Adolescent Mental Health Services (CAMHS)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other 1-2 weeks 1-2 months 6-12 months 1 year + Still waiting

If you answered 'Other' please specify:

8. Was the person you care for offered any other treatment or access to any other service to help them with their mental health?

- Yes
- No
- Unsure

If Yes, please can you tell us what treatment or service they were offered?

9. How would you rate getting help for the person you care for?

- Very easy
- Fairly easy
- OK
- Difficult
- Very difficult

Why?

10. What would improve your experience of getting support for the person you care for? Are there any specific recommendations you could make that would make it easier for you to get support for the person you care for, and possibly for yourself as a carer?

11. Is there anything else you would like to tell us about your experience of getting mental health support for the person you care for?

2. Demographics

This section asks you some personal questions about the person you care for and about you so that we can identify any issues that affect different groups of people. This information is anonymous, and you do not have to answer any questions if you don't wish to.

12. What is the gender of the person you care for (how do they identify)?

13. What is the age of the person you care for?

14. Please tell us the town or village where the person you care for lives?

15. What is the living situation of the person you care for?

- The person I care for lives alone
- The person I care for lives with a partner
- The person I care for lives with their parents
- The person I care for lives with other relatives
- The person I care for lives in supported housing
- The person I care for lives in a residential home

Other (please state):

16. How would you describe the ethnic group of the person you care for?

- White
- British
- Irish
- Gypsy/Traveller
- White Other
- Asian/Asian British
- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian
- Mixed
- White and Black Caribbean
- White and Black African
- White and Black Asian
- Any other mixed
- Black/Black British
- African
- Caribbean
- Any other Black
- Arab/any other group

3. About You

17. What is your gender (how do you identify)?

18. What is your age?

19. Do you identify as autistic?



We are committed to the quality of our information. Every three years we carry out an in-depth audit so we can be certain of this.

healthwatch Wiltshire

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