



 **What people with autism spectrum conditions and their carers think of services** 

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Wiltshire Service Users' Network (WSUN)

We worked in partnership with WSUN on this project. You can contact them at Wiltshire Service Users' Network, The Independent Living Centre, St George's Road, Semington, BA14 6JQ. Call 01380 871800 or email info.wsun@btconnect.com



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Report summary

What is this report about?

This report highlights the findings from a project that aimed to gather the views of people with autism spectrum conditions and their carers about health, care, and support services in Wiltshire. It was carried out in late 2020/early 2021 by Healthwatch Wiltshire, working in partnership with Wiltshire Service Users' Network (WSUN).

What did we do?

We designed and ran two surveys, one for those with an autism spectrum condition and one for carers. The surveys ran for about 10 weeks. Due to Covid-19, we were not able to meet people face to face but we provided options for the survey to be completed online, over the phone or on paper.

What were the key findings?

- We were told that an appointment with a doctor or nurse can cause considerable anxiety and stress for someone with an autism spectrum condition.
- Difficulties were reported in explaining things to health professionals and in understanding what they were told about their treatment and follow-up.
- Hospital environments were particularly difficult for those with an autism spectrum condition.
- Experience of phone call and video appointments were mixed and depended on the individual concerned. However, responses suggested that these had benefits for some people.
- Most of those with autism spectrum conditions and their carers did not feel that they got enough support related to their condition.
- We were told that most people were supported by unpaid carers. This included parents, partners, other family members and neighbours.
- Other support services were valued but we were told there was not enough information about them or their availability.
- There was mixed feedback about respondents' experiences of diagnosis.

Recommendations

The report draws conclusions from the views and experiences that have been shared with us and makes recommendations based on these. The recommendations make suggestions that aim to improve people's experiences of health and care services going forwards, based on what people have told us.

Introduction

Healthwatch Wiltshire is the independent champion for people using health and care services in Wiltshire. We listen to what people like about services and what they think could be improved and share their views with those who have the power to make change happen.

In late 2020/early 2021 we worked in partnership with Wiltshire Service Users' Network (WSUN), who run the Wiltshire Autism Hub, on a project that aimed to gather insight on the views of people with autism spectrum conditions and their carers about health, care, and support services in Wiltshire. We carried out this work in response to previous feedback from local people about difficulties they had in finding and accessing services that meet the needs of this group.

This work was carried out during the Covid-19 pandemic and in a period of lockdown. As a result, we could not meet face to face and most of the surveys were completed online. We therefore may not have reached those who do not use the internet, and this should be considered when reading the findings.

Our approach

To develop our survey, we researched other work that had been carried out in this area and looked at the type of questions asked. We took advice from WSUN, and other community groups who worked with people with autism spectrum conditions about what they thought might be important aspects of a survey. We found that Healthwatch Worcestershire [had carried out a similar project](#) and had received a good response to their survey. Their questions were felt to be the most 'autism friendly' of those we found, and they kindly gave us permission to use and adapt these.

WSUN worked with several people with autism spectrum conditions, their carers and relatives to develop and test the surveys to make sure they were as accessible as possible. They reviewed both the paper and online version of the survey and made some valuable suggestions. A final survey was then produced taking these into account.

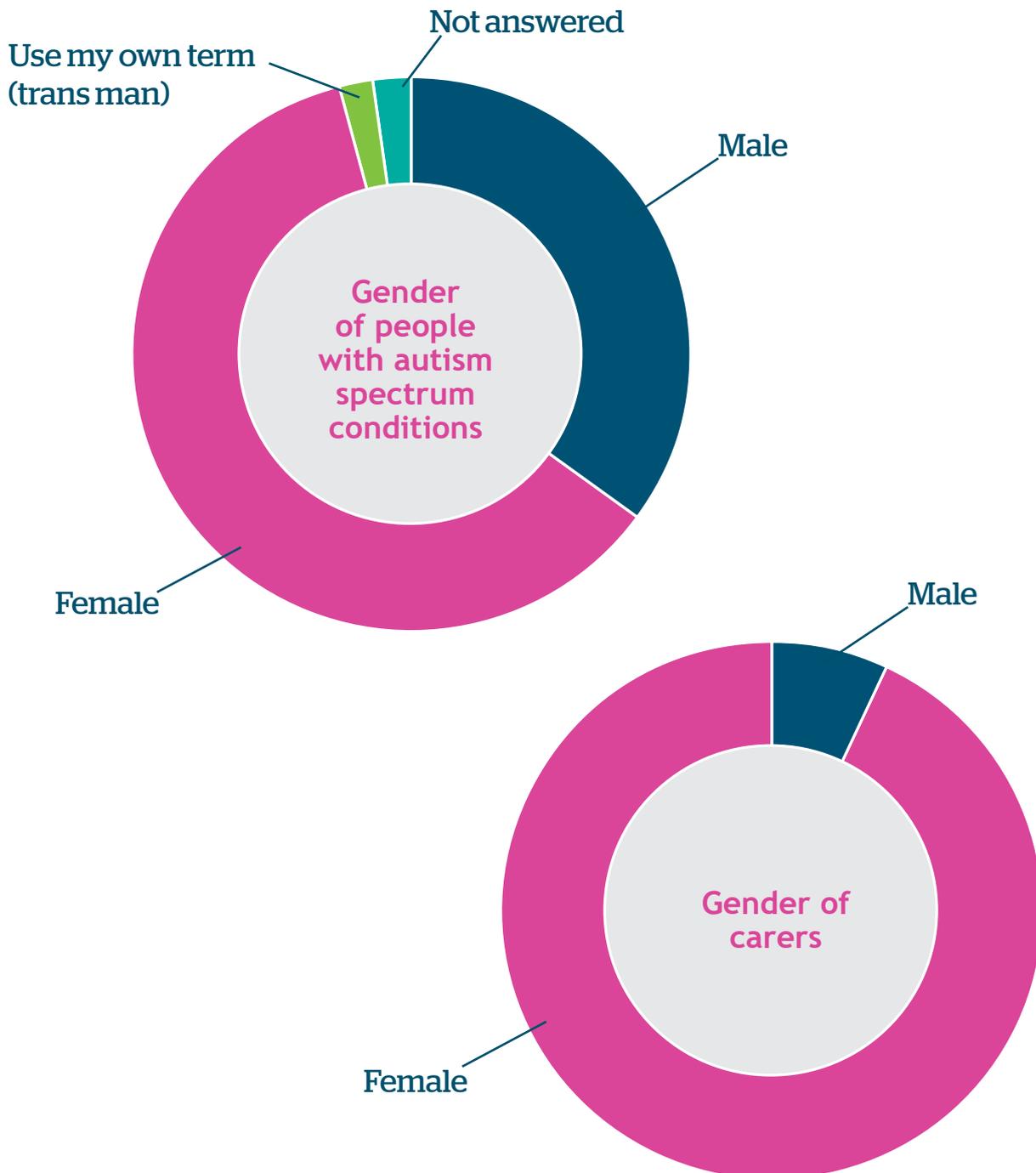
Our survey ran from late February to mid-April 2021. This was during a period of lockdown during the Covid-19 pandemic. We publicised our survey widely throughout Wiltshire via our voluntary and community sector partners. While we were not able to meet people face to face, people were offered the chance to complete the survey online, via a paper copy or be supported over the telephone.

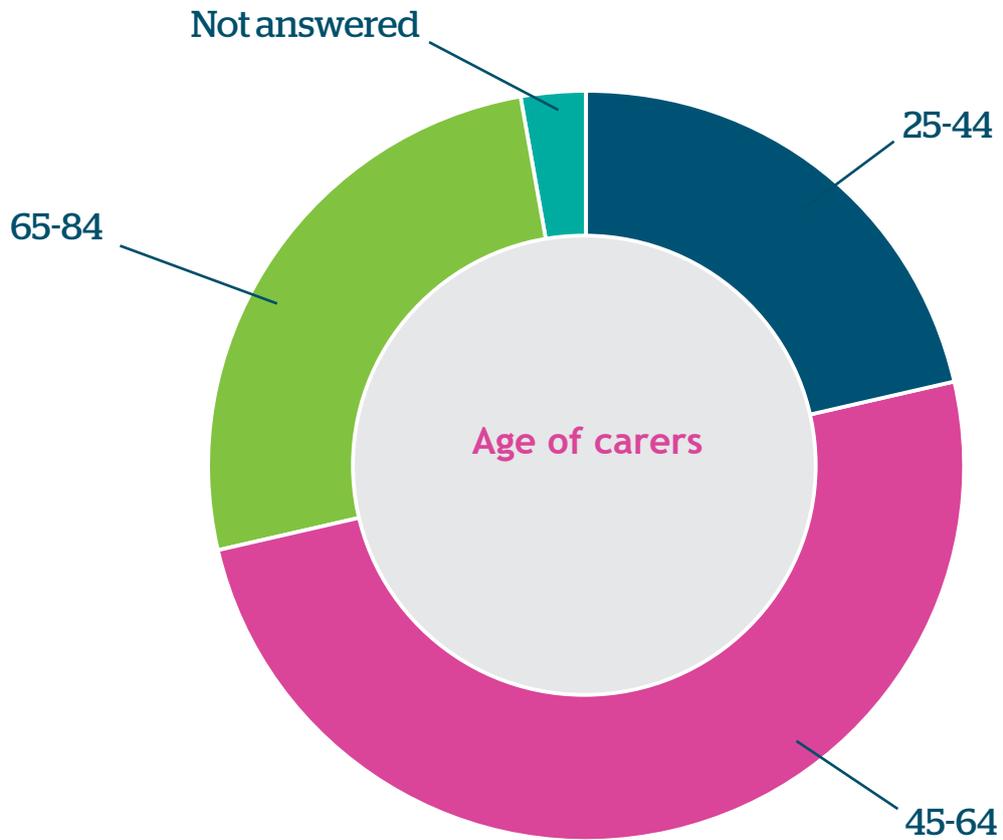
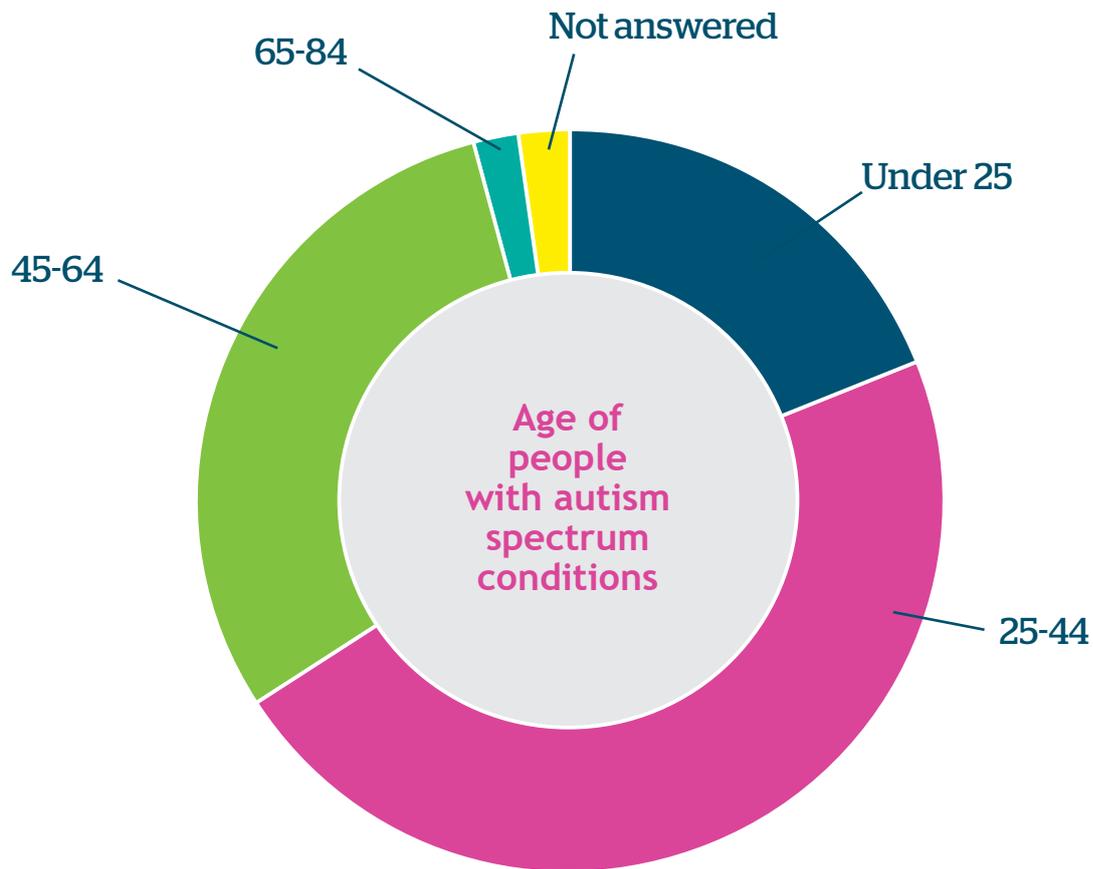
Who did we hear from?

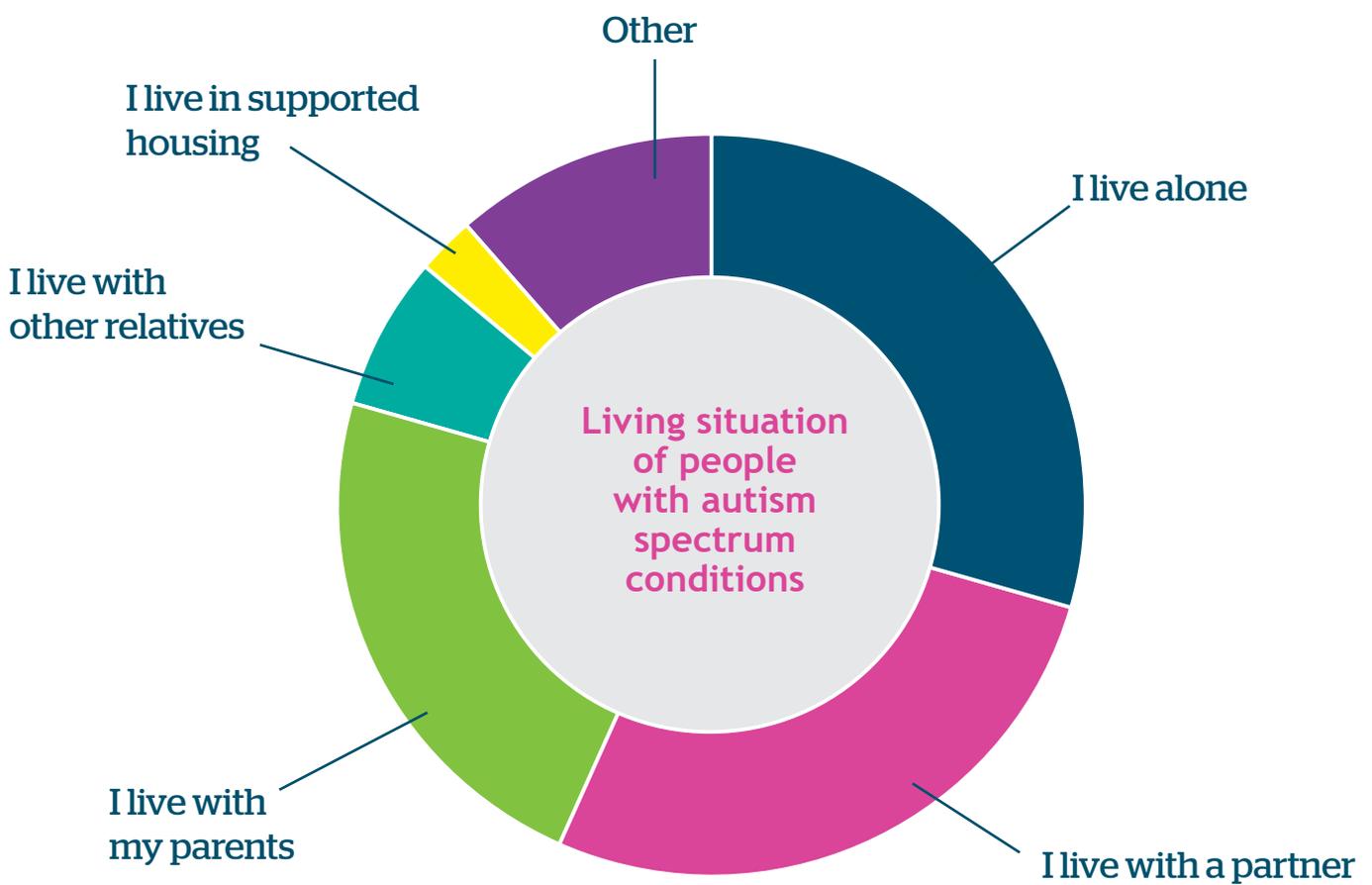
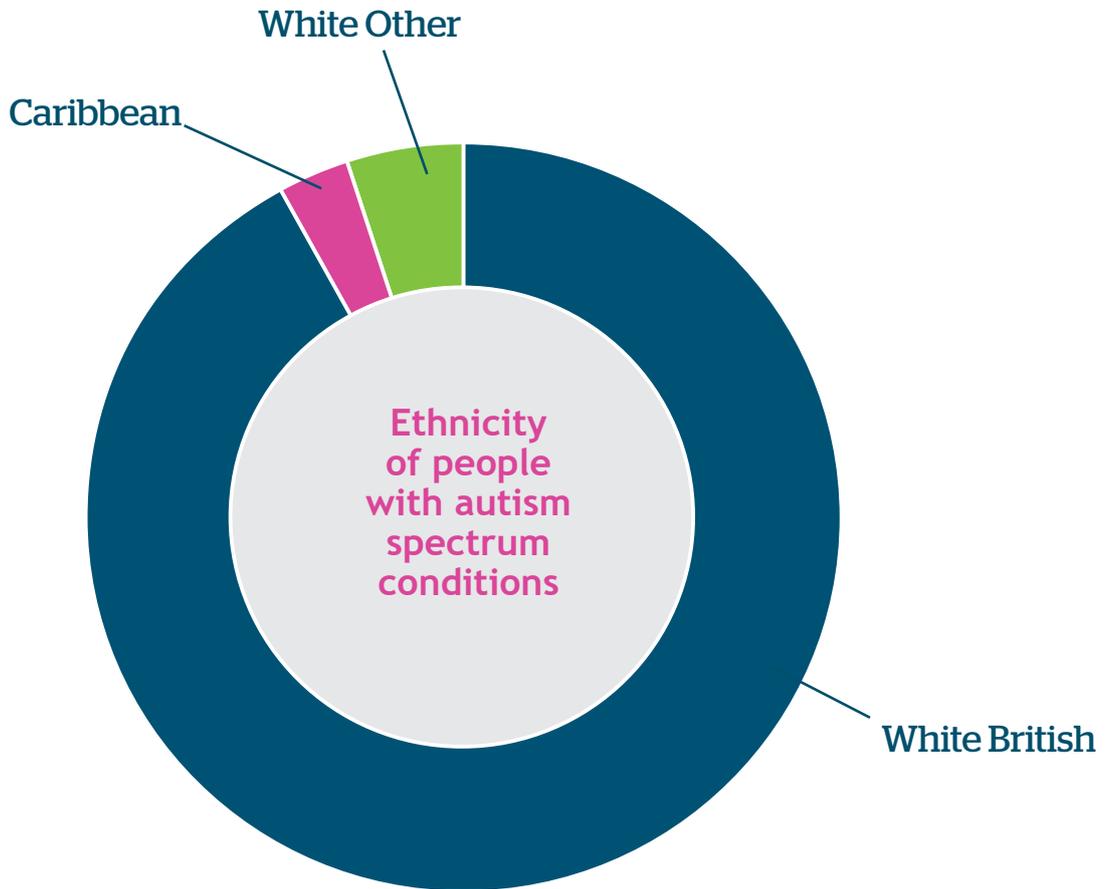
We received a total of 102 completed surveys:

- 43 from adults with an autism spectrum condition.
- 29 from carers of adults with an autism spectrum condition.
- 20 from carers of children with an autism spectrum condition.

Here are some demographics from those we heard from.



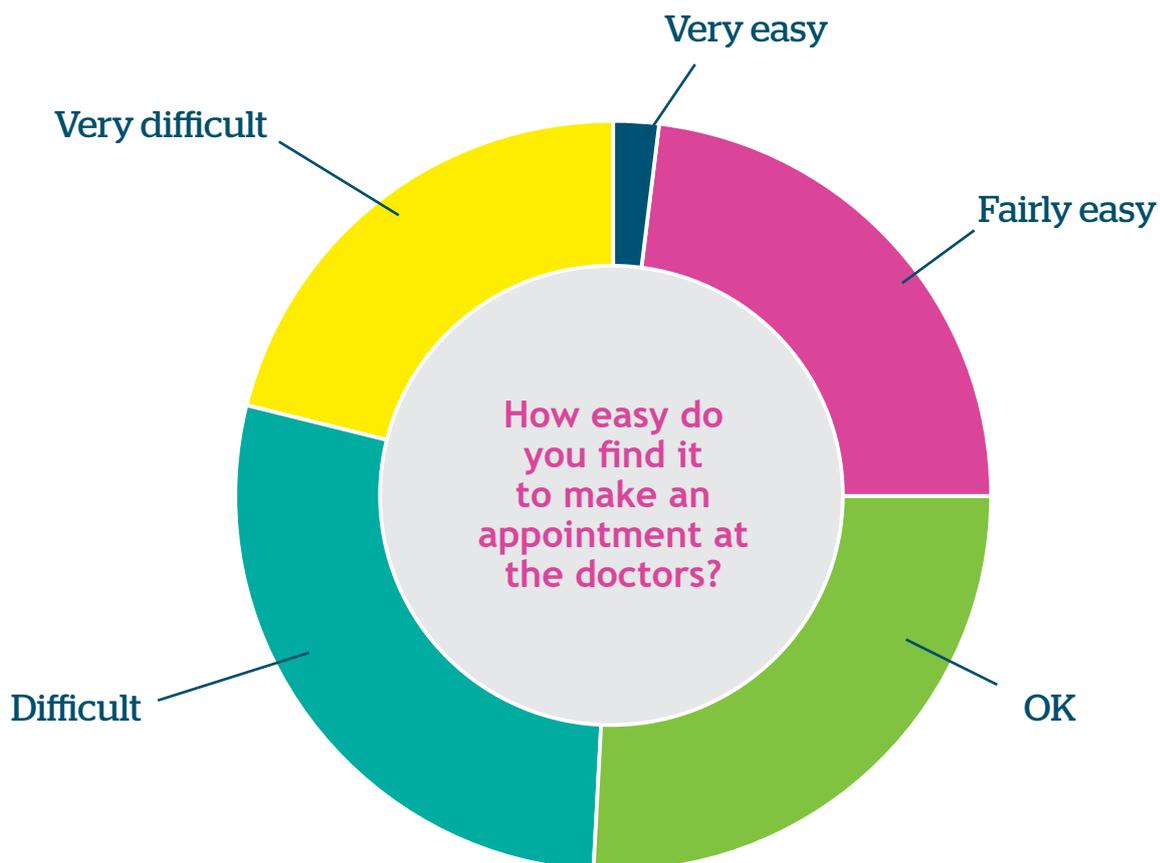




What did people tell us?

GP services

Our survey began by asking for experiences of, and thoughts about using GP services. More people with an autism spectrum condition told us they found it difficult to make an appointment with a GP (49%), than those who said they found it easy (25%).



When asked about what would help with this, most popular was the receptionist being aware the person had an autism spectrum condition, and the second most popular was being able to book online. Being sent a text message confirming the appointment was thought to be useful by just under half of those we spoke to. Other things mentioned included phone systems that were more straightforward to use, quicker waiting times for calls to be answered and clear appointment letters.

Due to moving about, I've used different docs surgeries. My current one is excellent and is signed up to the NHS app so I can book on there. My previous one was much more difficult and had a strange system of appointment releases to get your head around.

Difficulty with phone however once at front of queue receptionist books appointment and sends text which is useful.

Long waiting time on the phone makes me anxious, the music or/beeping is overwhelming. Receptionists aren't always friendly. They don't have awareness that I am autistic. They can't offer me a more accessible booking process or appointments.

If I call mid-morning or mid-afternoon it's easier to get through. I find it easier to make appts at the surgery.

Waiting at the surgery for an appointment was highlighted by both those with an autism spectrum condition and their carers as a difficulty and having a quiet place to wait was the top answer to what would make waiting easier.

We asked how easy people found explaining the reason for their visit. The responses show that more people with an autism spectrum condition said they found this difficult, than those who found it easy. The responses from carers to this question expressed the same sentiment, but even more strongly as the charts below show.





For those with an autism spectrum condition, having a longer appointment time was the top answer given in response to a question about what would help them explain things to the doctor or nurse, followed by having someone present to support them. Carers also identified these as the top two things, although in their case, slightly more said having someone with the person, than said having more time would be of most help. Fewer respondents (25%) said that visual aids and pictures would be useful.

Respondents also mentioned that an awareness and knowledge of autism by practice staff would be helpful. Several people also said that they found writing down their reasons for a visit before an appointment helped them. Carers also stressed the importance of the practitioner listening to the person and to their carers and their responses indicated that this did not always happen.

I feel the appointment always feels very rushed, so I don't have time to get comfortable to be able to address the reasons for my visit.

Very easy because I hand the doctor a pre-prepared note to read, rather than me talking. Covid has made this difficult because I can't hand over a note during a video or phone call, I tend to jot notes down before these calls in preparation.

I try and write things down. Much harder to express over the phone.

Making sure the doctor is aware I have autism before I go into the appointment. So they know I might be difficult to talk to.

I don't always understand the language they use, or what information they want.

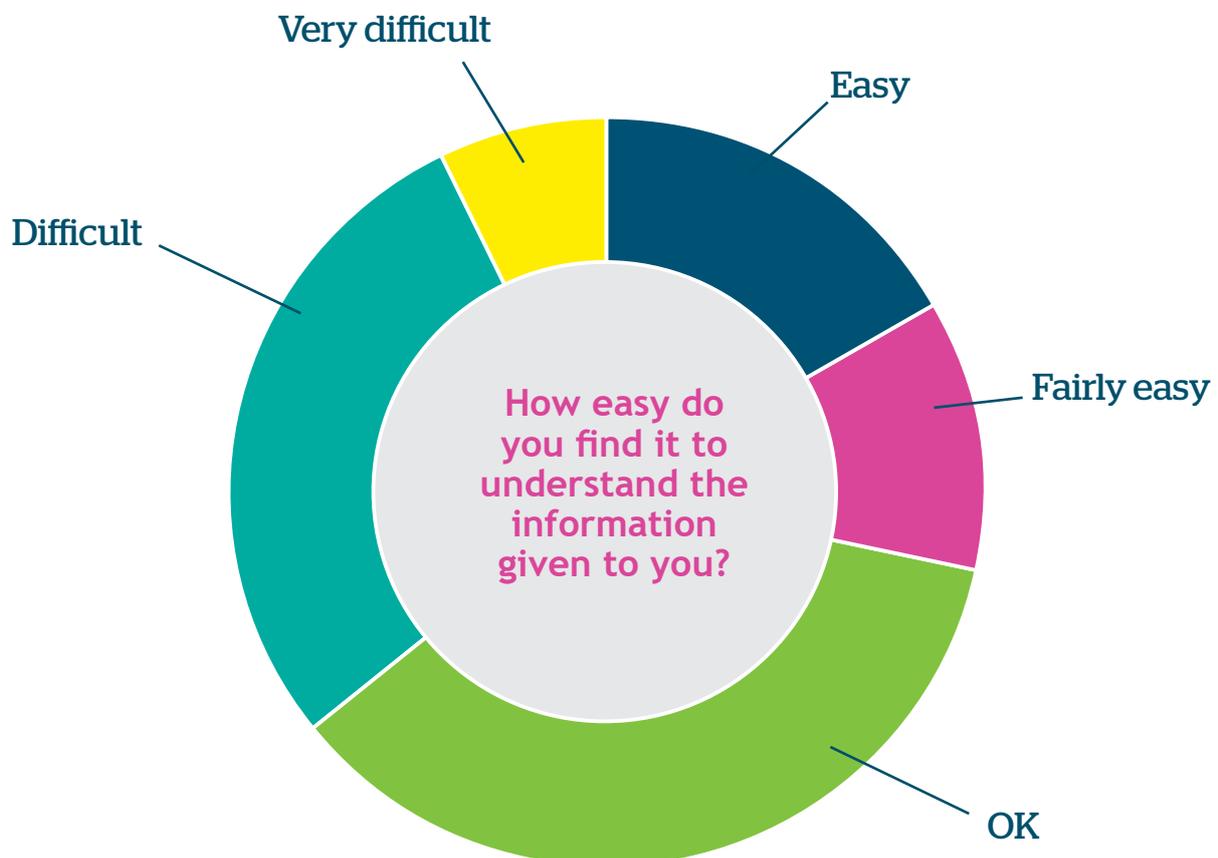
A doctor that listens to the parent would be good.

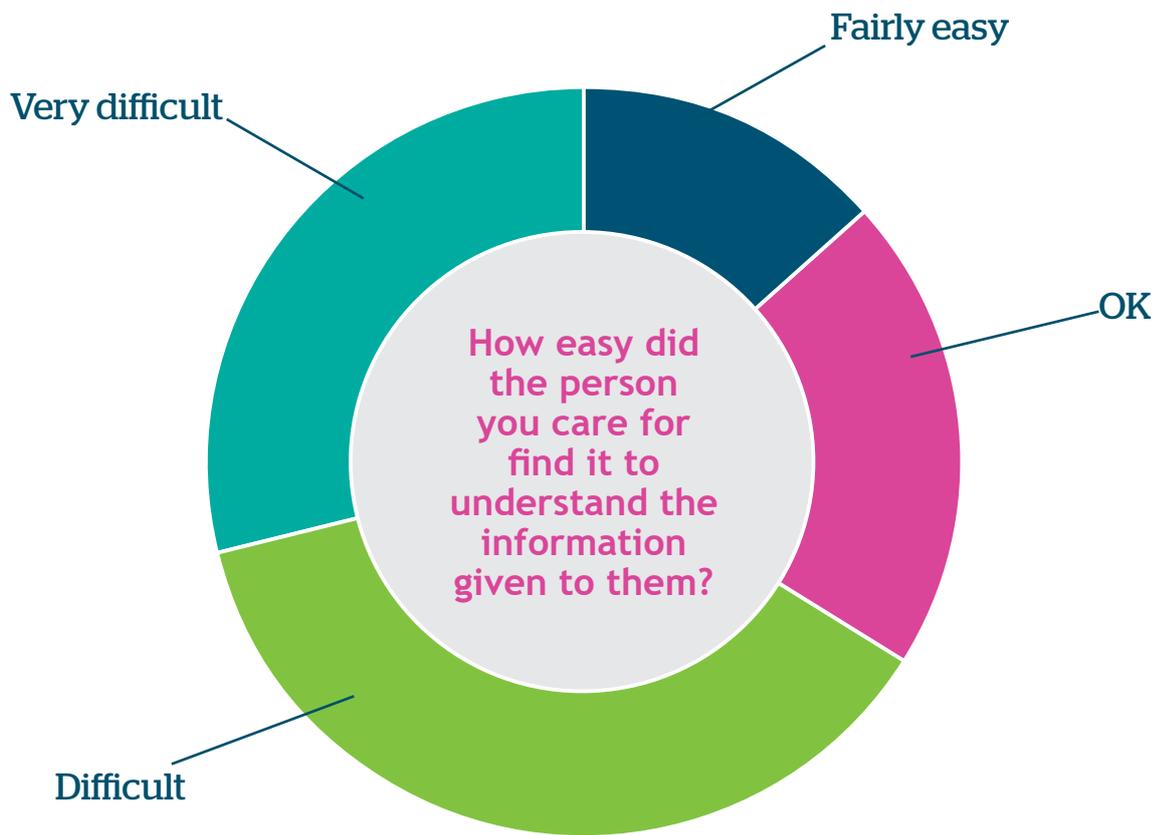
Believe us! If he says he's in pain but doesn't react to pain in a neurotypical way, just believe him.

We then asked how easy it was for people to understand the information that they were given by their GP practice about treatment, medication and follow-on care.

The responses suggested that while this still presented difficulties, it was less of an issue than that of explaining things themselves. Carers' responses also showed the same pattern, although a higher proportion of carers thought that the person they cared for found understanding difficult.

The chart below shows the full breakdown of responses.





When asked to choose what would best help them to understand the information they were being given, being provided with written information. Both those with an autism spectrum condition and their carers frequently mentioned that anxiety during the appointment could make information difficult to process and remember, and that a written summary would be most useful. They felt that written information also supported carers in gaining information that would support them as a carer for the person.

- Because I forget as soon as I walk out of the room. I nod and say yes but 99 out of a 100 I have not stored the information I was given.
- Written information is easy, verbal instructions are difficult to understand and remember.
- It would be nice to be a bit more patient and wrote things down for me.
- Sometimes the nerves overtakes his memory and he can forget what he's been told.

The next most popular choice to aiding understanding was having a longer appointment, followed by having someone with them for support, and third, the use of clearer language. Easy read information and visual information were also mentioned as being helpful by a small number of people.

We asked if there was anything else that people wanted to say about GP appointments. One thing frequently mentioned by those with an autism spectrum condition was the need for staff to understand and be aware of the stress, anxiety and sensory sensitivities that they experience when visiting their GP practice.

Waiting times need to be shorter. Overall environment needs to be less sensory overwhelming and all staff need to have a better understanding of autism. Appointment booking needs to be more accessible and we need support to set up online appointment systems, not just given the option. Otherwise, doctors surgeries are likely to be avoided and important health checks missed. It's so important.

Just to be aware of sensory sensitivities such as smell, light and hearing.

Have a bit more patience and not get irritated.

Having the GP with generally more understanding of autism and how differently autism can look in women and in general.

Carers shared this view, and they also mentioned the importance of practitioners listening to, and involving them.

I would like more empathy with the condition, and patience with the carer who is trying to enlist help.

I find the waiting room can be a very very challenging place for my son with his sensory issues being triggered just because of the number of people in the room. It would be helpful to have a quiet area for us to wait and reduce his anxiety.

Find the best way to contact carers, eg I prefer a text to call the surgery rather than a message that it not always picked up at the time or on the day. Make sure they have consent from the patient to share information.

Please encourage the autistic person to include the carer, some things can be quite embarrassing, but the carer is understanding and knows this. Include them.

Listen to carers. Last time I spoke to a GP I was given ‘advice’ that I would have been stupid not to know about getting my daughter’s sleep pattern regulated – it was patronising and made me feel even more unsupported.

Most nurses and doctors we have seen have been really good, very patient when he asks lots of questions about equipment, etc or tells them about his special interest.

Hospitals

We asked how easy it would be to remember a hospital appointment and 28% of respondents told us that this was easy, 35% said it would be OK and, 37% said it would be difficult.

The top choice of options thought to be useful in remembering an appointment was a text message reminder, with 84% of respondents saying that this would help them. The next most popular thing was that their notes flagged that they had autism, so that those making the appointments were aware of it.

Preparing for a hospital appointment was something that was identified as being difficult, with 51% saying they find it difficult. For carers, 65% said that it is difficult for the person they care for to prepare for an appointment.

Anxiety around unfamiliar journey by car, unfamiliar hospital, waiting rooms, car parking, staff, sensory environment. Appointment letters are overwhelming and not easy to read.

My daughter would be worried about getting there on time, knowing where to go, would it be noisy/busy, would the person seeing me be nice, etc.

When asked what would help them prepare for an appointment, a range of choices were selected. The most popular was a leaflet of the hospital with a map and photos, followed by their notes saying that they had autism so that staff were aware of it.

Carers identified notes saying the person had autism as their top choice and written information about the appointment as the second. Other things that were identified included prompting or instructions on how to book hospital transport, information about timings of appointments, appointments running to time and the use of images as well as words to describe the appointment. The charts on the next two pages show the breakdown of what was thought to help prepare for an appointment.

What would help you prepare for an appointment?

Responses from people with an autism spectrum condition



My notes saying that I have autism.



Leaflet with map of the hospital and photos.



Online map and photos / interactive mobile app.



Video showing the hospital and the department and what I should expect at the appointment.



Written information about what the appointment is for and what will happen.



Easy Read information about visiting the hospital.



Easy Read information about what the appointment is for and what will happen.



Other.

Responses from carers



Their notes saying they have autism.



Leaflet with map of the hospital and photos.



Online map and photos / interactive mobile app.



Video showing the hospital and the department and what I should expect at the appointment.



Written information about what the appointment is for and what will happen.



Easy Read information about visiting the hospital.



Easy Read information about what the appointment is for and what will happen.



Other.

I rarely go to hospital appointments, but the suggestion about the map? Yes please! Hospitals confuse me so much.

It would be a big deal for me as while I do drive, going to a new place and parking at busy hospitals is terrifying.

Information about timings, both potential waiting times and duration of appointment. Prewarning of potential for medical students and explanation for why it can be good for them to sit in on an appointment.

Visuals for procedures. Longer appointments. Staff understanding and sensitivity. Reasonable adjustments (not lots of unnecessary room changes, loads of verbal communication, having to repeat over and over to different nurses/doctors, quiet room).

Our survey responses included lots of further comments about experiences and views of attending hospital appointments. One thing mentioned frequently by both people with an autism spectrum condition and their carers was how difficult a hospital environment could be for them, and the seeming lack of awareness of staff about this.

Issues of confusing environments, busy waiting rooms, noise, formality of staff, and the need to see several different people, were identified as being very stressful. Improved training to increase awareness about autism was frequently mentioned as something that would be beneficial.

I have sat in a corridor rocking back and forth and not one member of staff asked if I was OK. I have asked for quiet area to wait in, only to be told on arrival they didn't know anything about it.

I find going to hospital and a stay very scary. I don't have my routine, I feel out of control. Visiting times reduce my support contact. Staff are not very understanding, especially on wards.

They could reduce physical contact or be more mindful of physically handling patients especially when patients also have a history of sexual trauma. Accommodate for hypersensitivity, eg I only get blood drawn with a butterfly needle because I find it so uncomfortable.

All staff have a learning disability module added to their mandatory training.

If they know you have autism, they treat you like you're stupid.

The environment needs to be easy to navigate and not overly crowded or stimulating. Sensory overload is a big risk creating anxiety and make the experience more difficult.

Becomes anxious, stressed, angry and frustrated at the unknown, noises, sounds and how abrupt and formal staff are.

An autism representative at the hospital, perhaps a volunteer, who could have details of autism patients in that day, wander around, say hello, put them at ease.

In addition, carers also mentioned the importance of them being listened to, involved in appointments and given clear information about what had taken place. Their responses indicated that their experiences of this were very mixed.

Carer to be given duplicate copy of any written communication with the patient. Someone to meet and greet the patient if attending without support.

Believe what we say. Let us know, discreetly, you are aware of his autism.

I've always found our local hospitals have been great when interacting with my son and I during appointments. All I have to do is say my son is autistic and the staff have always been fantastic.

Include the carer, make them a part of the appointment. Make sure they know what their role is and what they need to do.

Phone or video appointments

Our survey asked if people had experience of phone or video appointments for hospital and doctors' appointments and the chart below shows the breakdown of responses.

Have you ever had a doctors or hospital appointment by phone or online by video?

Responses from people with an autism spectrum condition



No, I've never had an appointment by phone or video.



Yes, I've had a doctor's appointment on the phone.



Yes, I've had a doctor's appointment by video.



Yes, I've had a hospital appointment on the phone.



Yes, I've had a hospital appointment by video.

Responses from carers

No, I've never had an appointment by phone or video.

Yes, I've had a doctor's appointment on the phone.

Yes, I've had a doctor's appointment by video.

Yes, I've had a hospital appointment on the phone.

Yes, I've had a hospital appointment by video.

We asked those who had had an appointment by phone or video how it had worked for them and there was mixed feedback. The responses indicated that experiences were largely dependent on the particular needs of the individual. It was clear that there were some individuals for whom phone and video appointments were not suitable.

All three make me feel very insecure and anxious, I do not like talking on Zoom or the phone, I have never even done this with my daughter in Australia as I feel so out of my depth, so that should explain how hard it is for me to do that with doctors or hospital appointments.

It doesn't work at all. Husband cannot express himself and gives one word answers. He cannot concentrate and gets frustrated.

He didn't participate. He finds videos and conversations difficult. He normally goes off and leaves me to talk.

Extremely distressing as I have a severe aversion to the phone and video calls. Phone anxiety is common but video calling also makes me anxious and is a PTSD [Post Traumatic Stress Disorder] trigger.

Face to face is easier as I don't have to talk, I put my problems on a note, hand it to clinician to read, saving both them and me time.

However, there were also several carers and those with an autism spectrum condition who reported a positive experience of phone or online appointments, commenting that they reduced the anxiety associated with travel, the hospital environment and waiting and that they were better able to focus on the appointment.

Having to wake up and get ready to leave the house is very difficult for me so being able to do the appointment in bed was very helpful. It also alleviated the stress of eye contact and constantly observing body language.

Quite liked the phone call – you're in your safe place and get to know the clinician before a possible 1-1 visit.

Yes, it works and saves time going to the surgery. I would like to know what time they will call me.

I have had a video appt with a neuropsychologist on behalf of my son and it worked really well as it meant we didn't need to come into hospital. I've also had several phone appts with a neurologist and that worked well too and saved us a visit where I would be doing all the talking anyway and my son would be sat bored.

It was less stressful as he didn't need to visit the hospital and consequently shorter. Video appointments would be preferable to a phone call so that clinicians can see stress behaviours and adjust their responses accordingly.

I feel with the right training phone or video appointments could be a way to really help autistic people access doctors appointments that they may not have done at all.

Really well. I prefer these. I don't have to worry about fidgeting or think about who I am talking to.

Other support services

Information

Our survey went on to ask about experiences of other support services, beginning by asking about information provided. A large proportion of those with an autism spectrum condition (74%) and their carers (61%) said they felt they did not have enough information about support or services that were available.

In response to asking what information services were most useful, a range of services were named. In order, those most mentioned were Wiltshire Autism Hub/ Wiltshire Service Users' Network, Mencap, National Autistic Society, and using a Google search. For carers, these were Wiltshire Parent Carer Council, Carers Support Wiltshire, and National Autistic Society.

When we asked what information people would find most useful, responses varied. However, one thing mentioned frequently by those with an autism spectrum condition and their carers was a directory or list of support services and groups.

An easy to read directory of what is on and what there is.

Groups for people with autism.

An online tool that would collate all services in your area, organised by postcode. This would be a portal that would have links to all other services available.

Accessible website with useful information all in one place.

Any support groups in my area, specifically for me and not just for parent/carers.

Other potentially useful information identified concerned eligibility for services, benefits, housing, adjustments that can be made to facilitate health, care, and work. In addition, carers mentioned they would like carer/relative specific information about autism, and information about services for young adults who are transitioning from children's services.

Simple, visual one-page roadmaps to key processes such as the Care Act, Financial Assessments for Care, care handovers from hospital to local services.

What support is available to me for work, with examples of reasonable adjustments that can be made.

Help with claiming benefits or housing.

Information pack for relatives or friends when the adults diagnosed with autism. Bullet point leaflet.

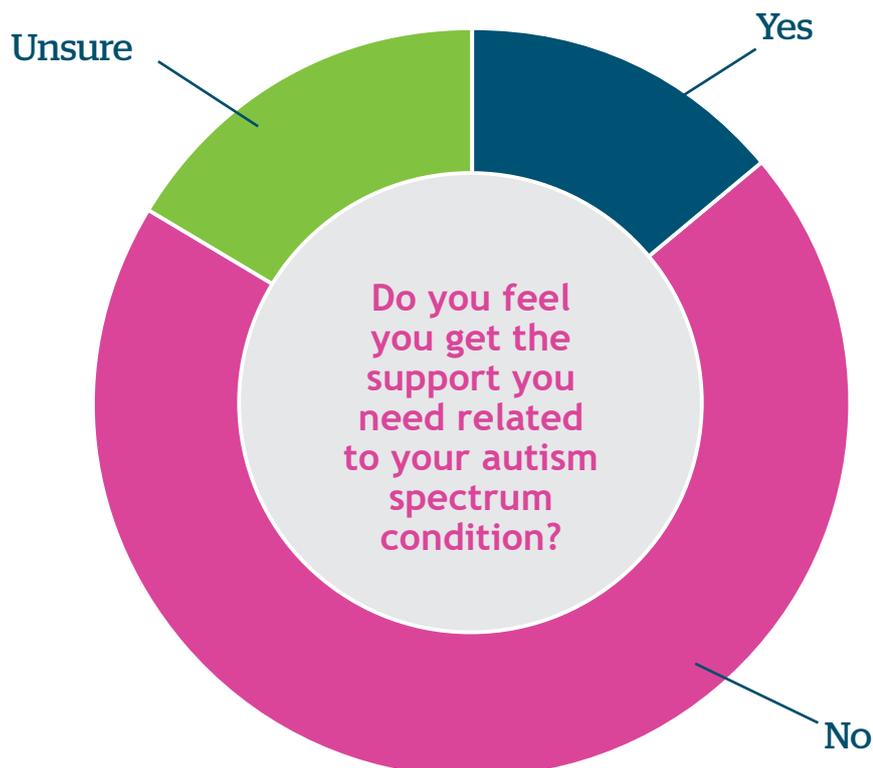
What support is available post 18 and who to contact. Felt like she went from having a wonderful support network to nothing in a matter of a few days.

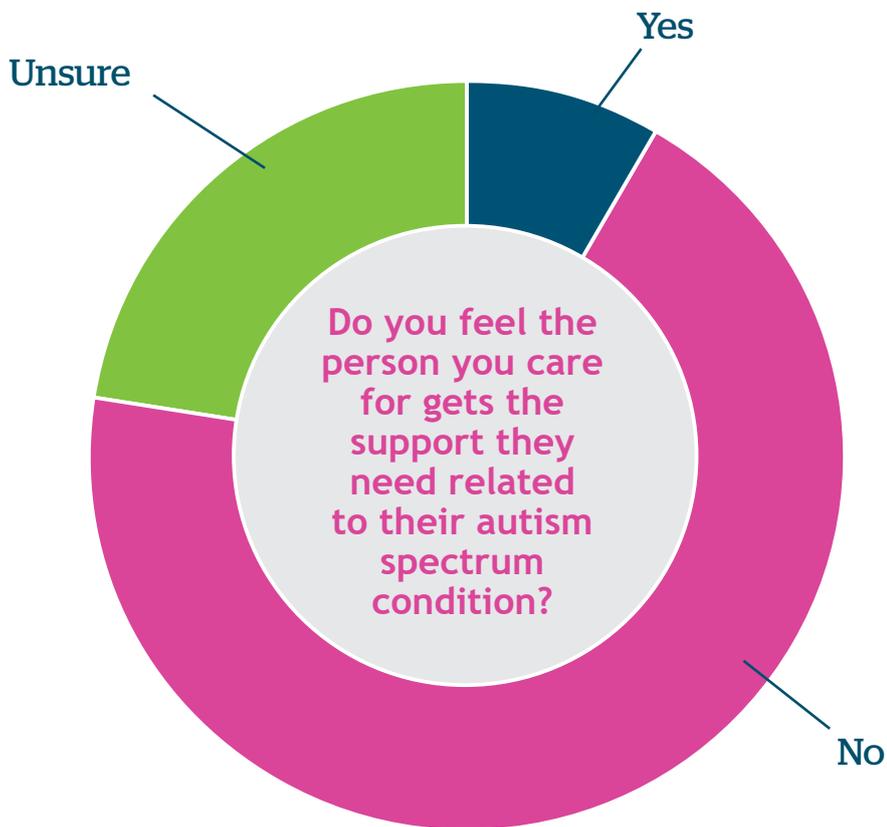
Help with coping with different problems.

When we asked people what they thought the most useful way is to access information about support, those with an autism spectrum condition and their carers identified websites as their top choice, with an app on their phone and social media also being popular options.

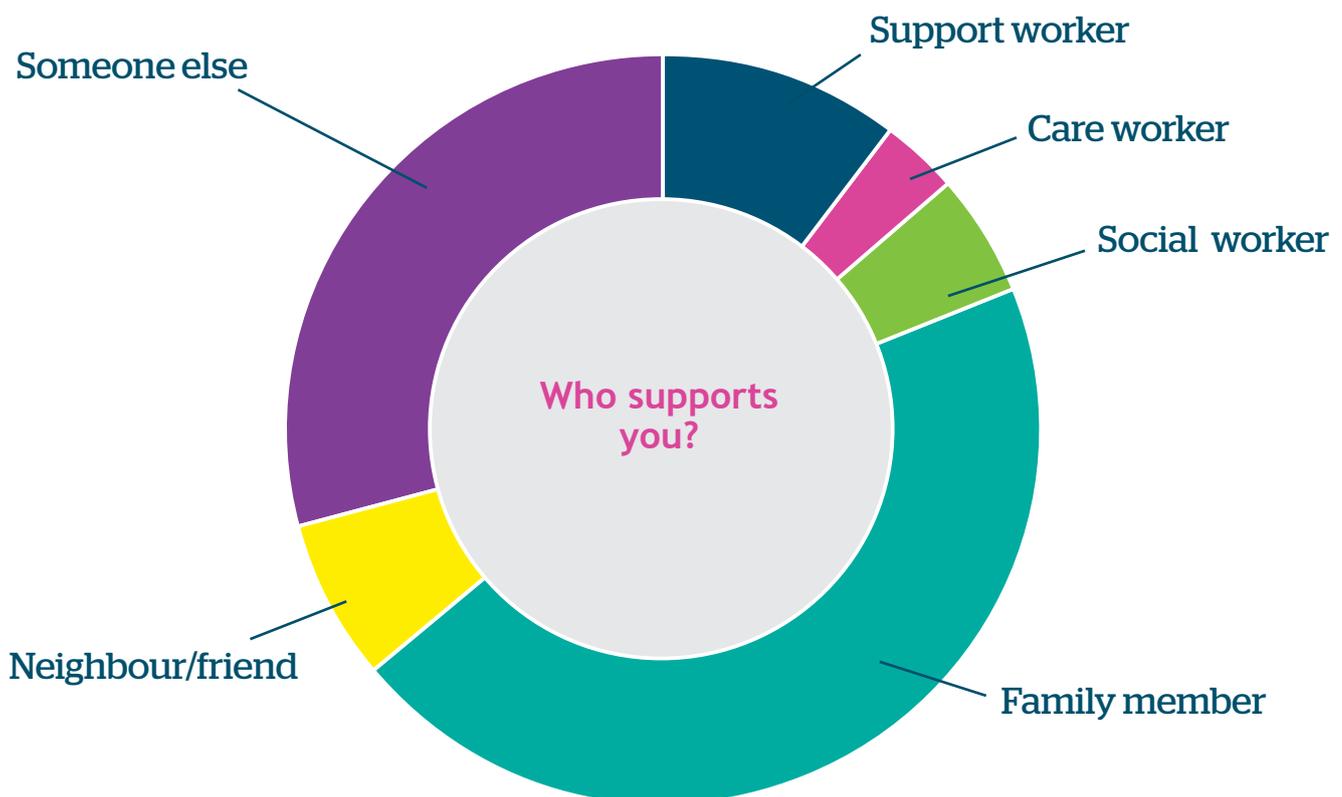
Support

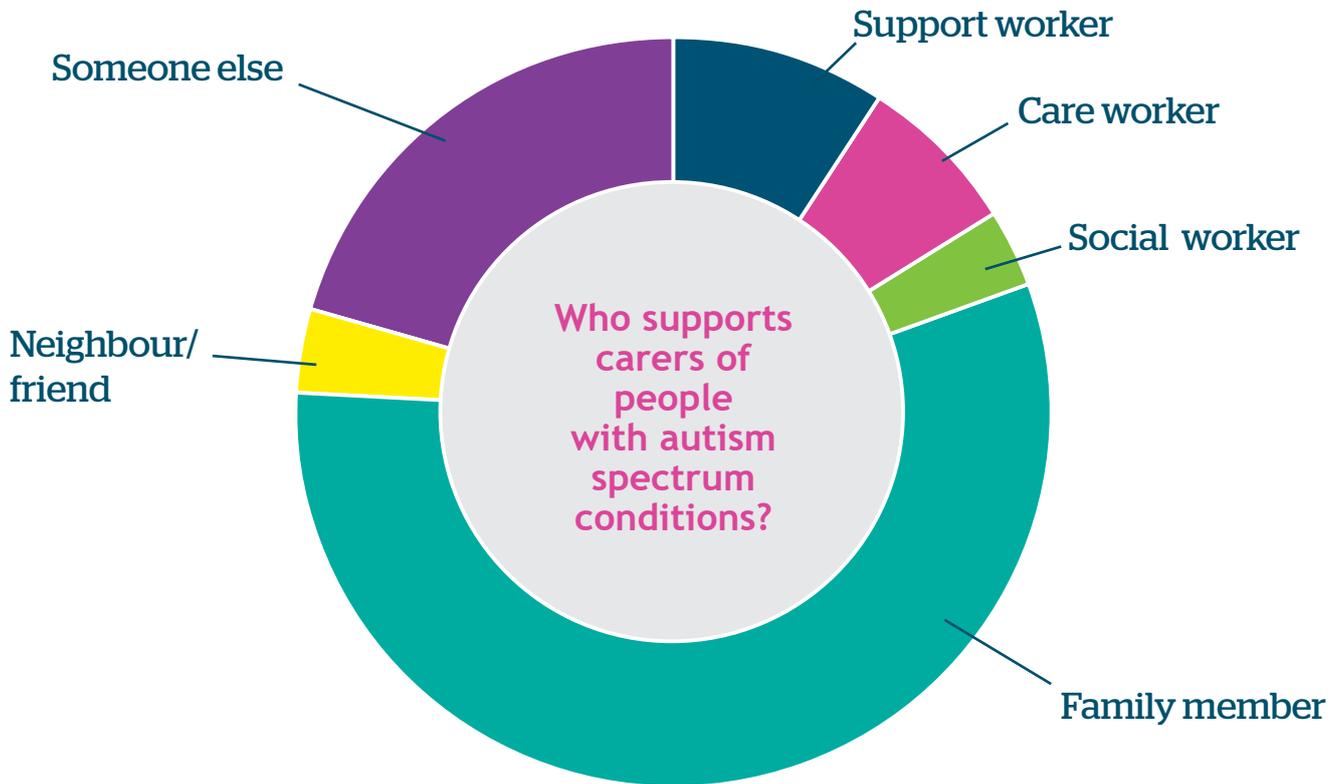
When asked if they felt they received all the support needed, most of our respondents felt that they didn't as the charts below show.



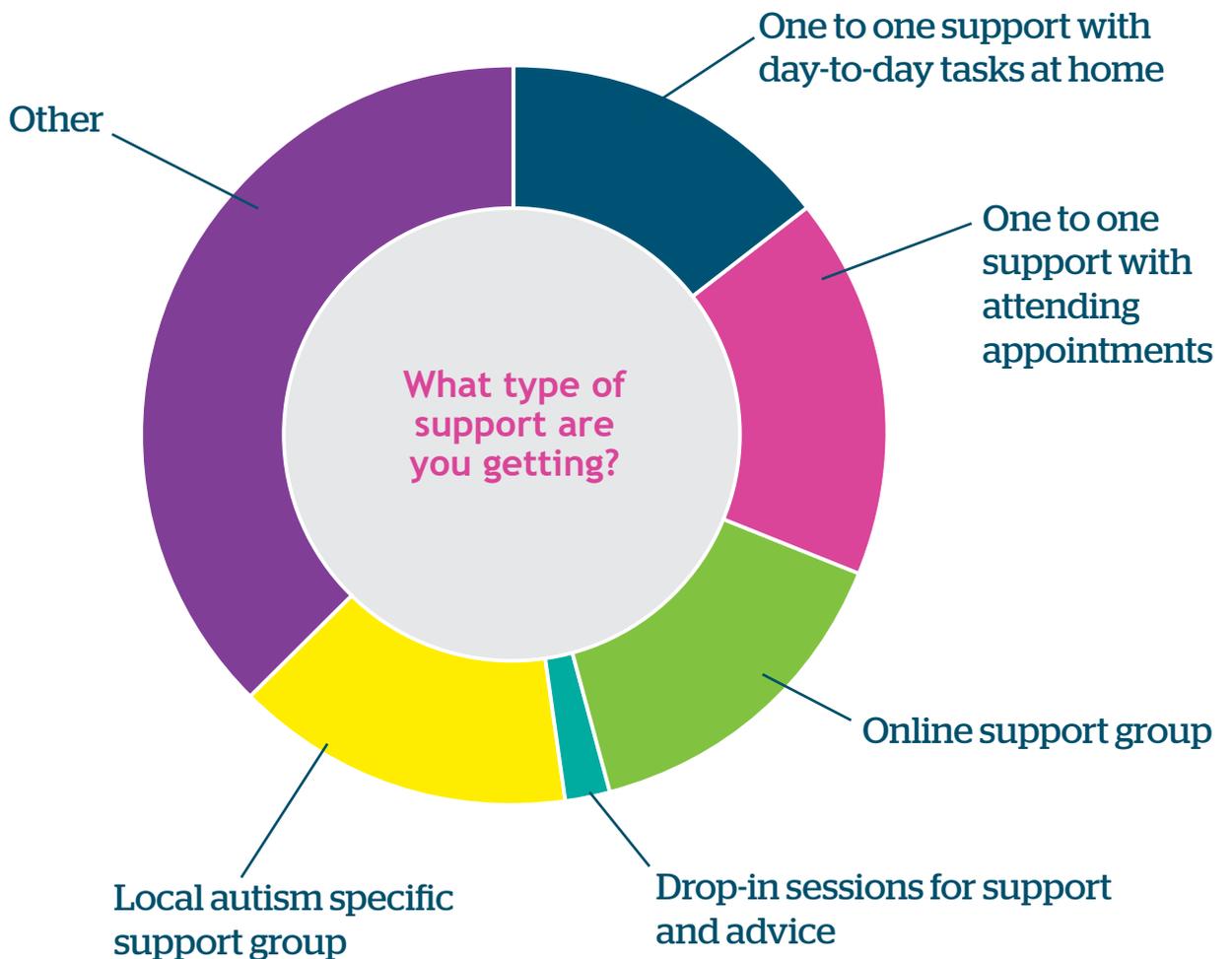


The majority of those we spoke to said that they got their support from family members. The chart below demonstrates the amount of support provided by unpaid family carers. Other sources of support identified were Wiltshire Autism Hub, National Autism Society, a minister, and a private psychologist. Carers most frequently mentioned school staff and Wiltshire Parent Carer Council.

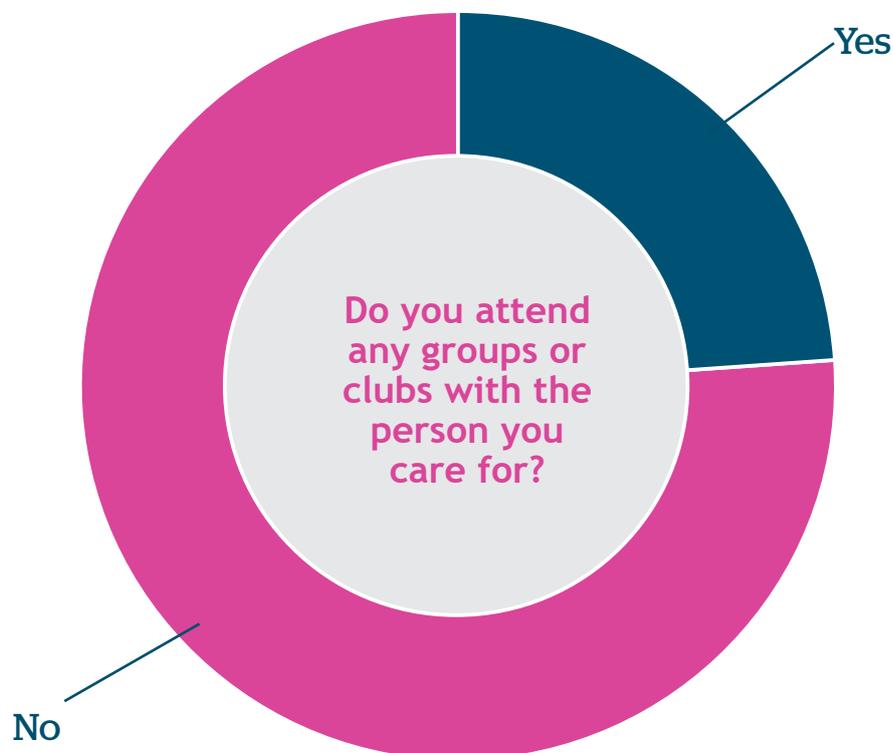
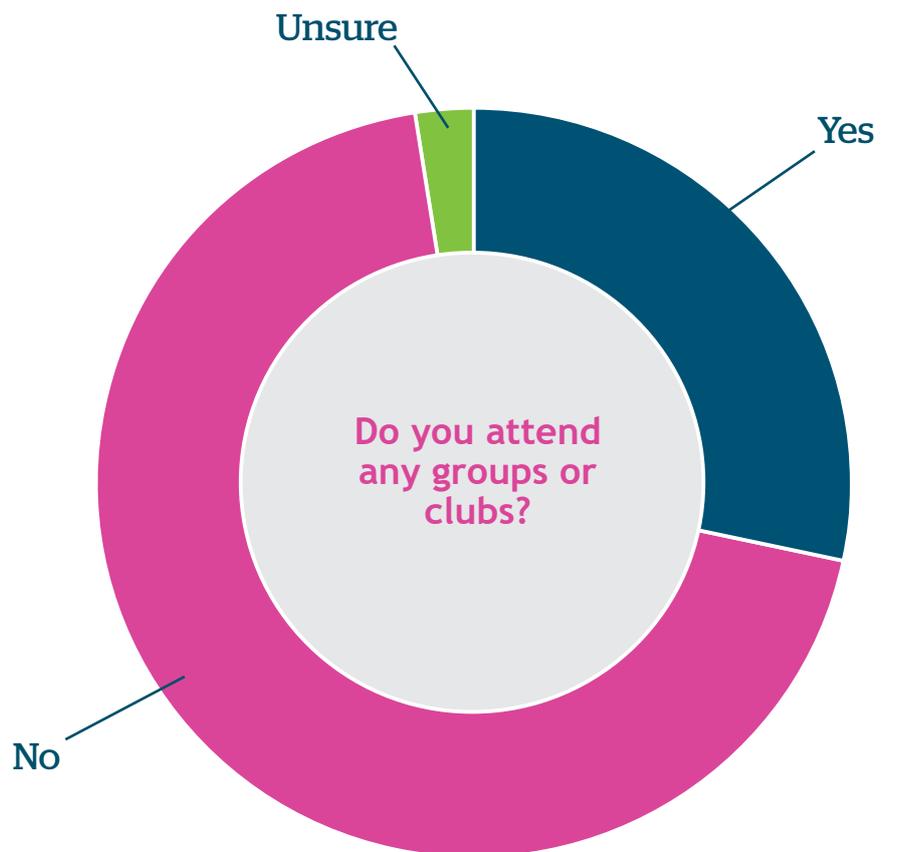




Below is a breakdown of the type of support that people told us they were receiving. Support listed under 'Other' included the church, Wiltshire Service Users' Network, Facebook forums and YouTube.



We asked respondents whether they were attending any groups or clubs and the responses received indicate that most people were not. It is important to note that some groups and clubs were not running due to the Covid-19 pandemic.



When we asked what support was found to be most valuable, we received a range of responses that included support with tasks, and the people and organisations who provided it. Popular choices included having someone to talk to, autism support groups and support with paperwork. Providers were named as family members, the Autism Forum and the Autism Hub.

My partner's support and him making sure he's available to help with school runs or our son's sports clubs as these times can cause me a lot of anxiety.

My parents and my support worker – I could not manage without them. They are my only support.

Talking to people, but I could do with some more support.

Ability to join an autism spectrum condition specific social group and job support from WEST [Wiltshire Employment Support Team].

Support with setting up important things like utility bills and applying for benefits when living on my own for the first time.

Going to autism forum. Having support from the staff. Independence training to learn new routes and places. Have leaflets & booklets for info.

Parent carers of children identified different support that had been valuable. This included support from family, mainstream and specialist schools, community centres and clubs, mentors, privately paid-for therapists and counsellors.

Family and private therapist.

Mentor from Youth Action Wiltshire/Splash and Wiltshire Job Coach.

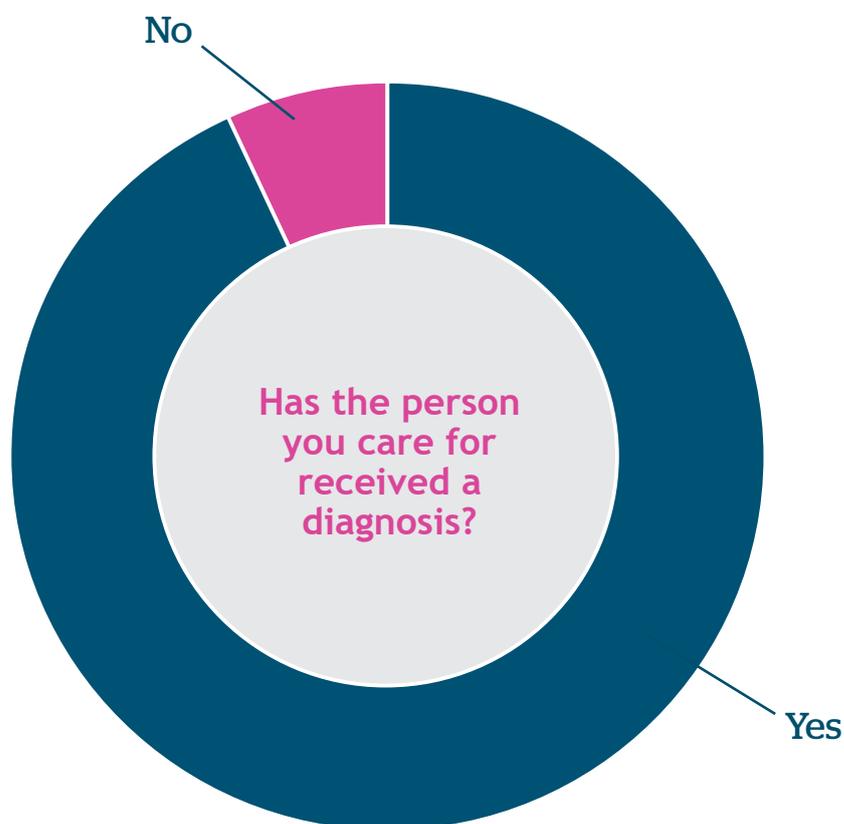
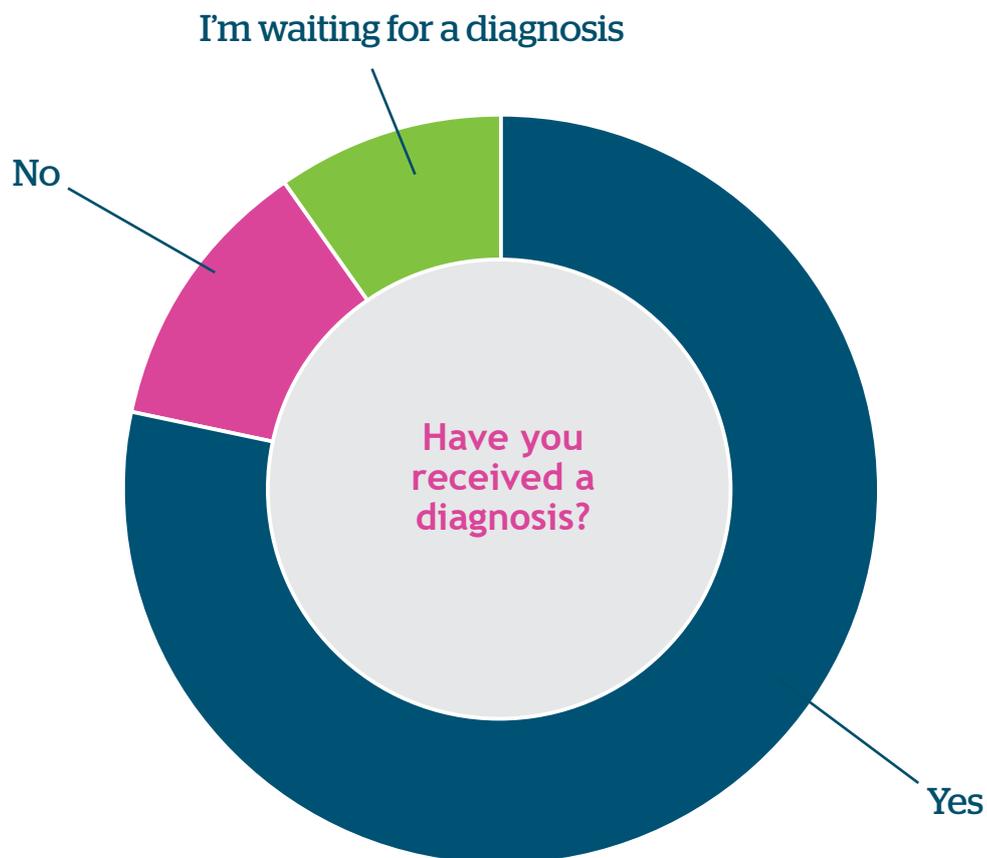
Some additional support through 'Support plan' at school, as well as understanding teaching and support staff for her.

Barnardo's and autism group.

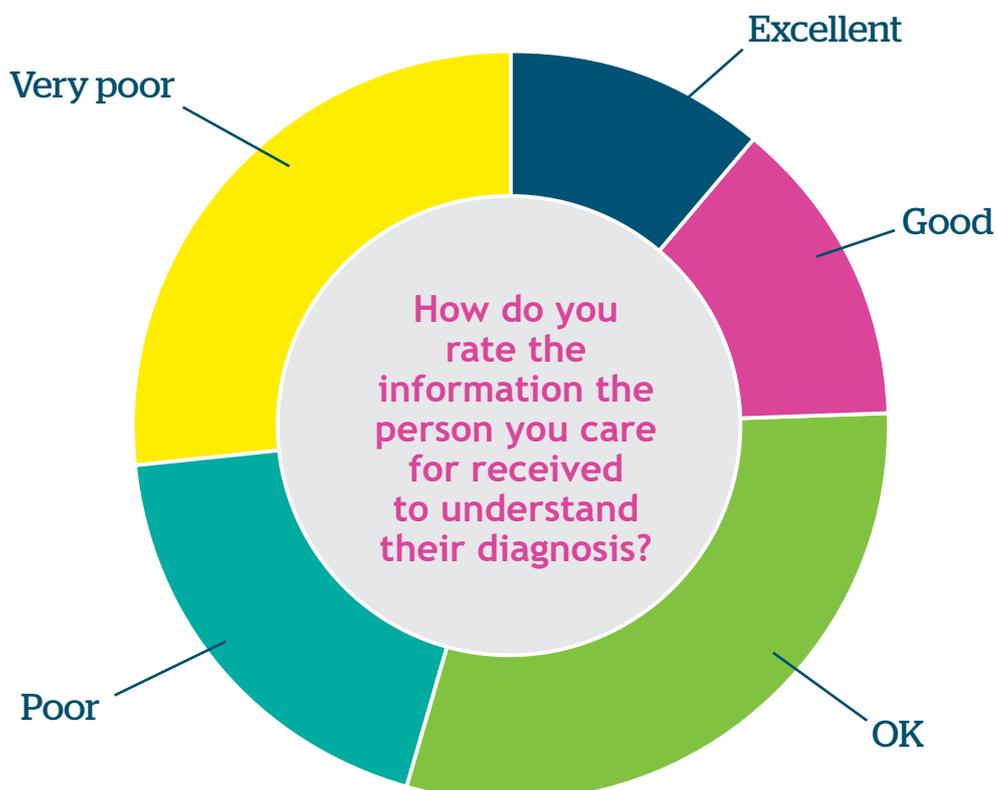
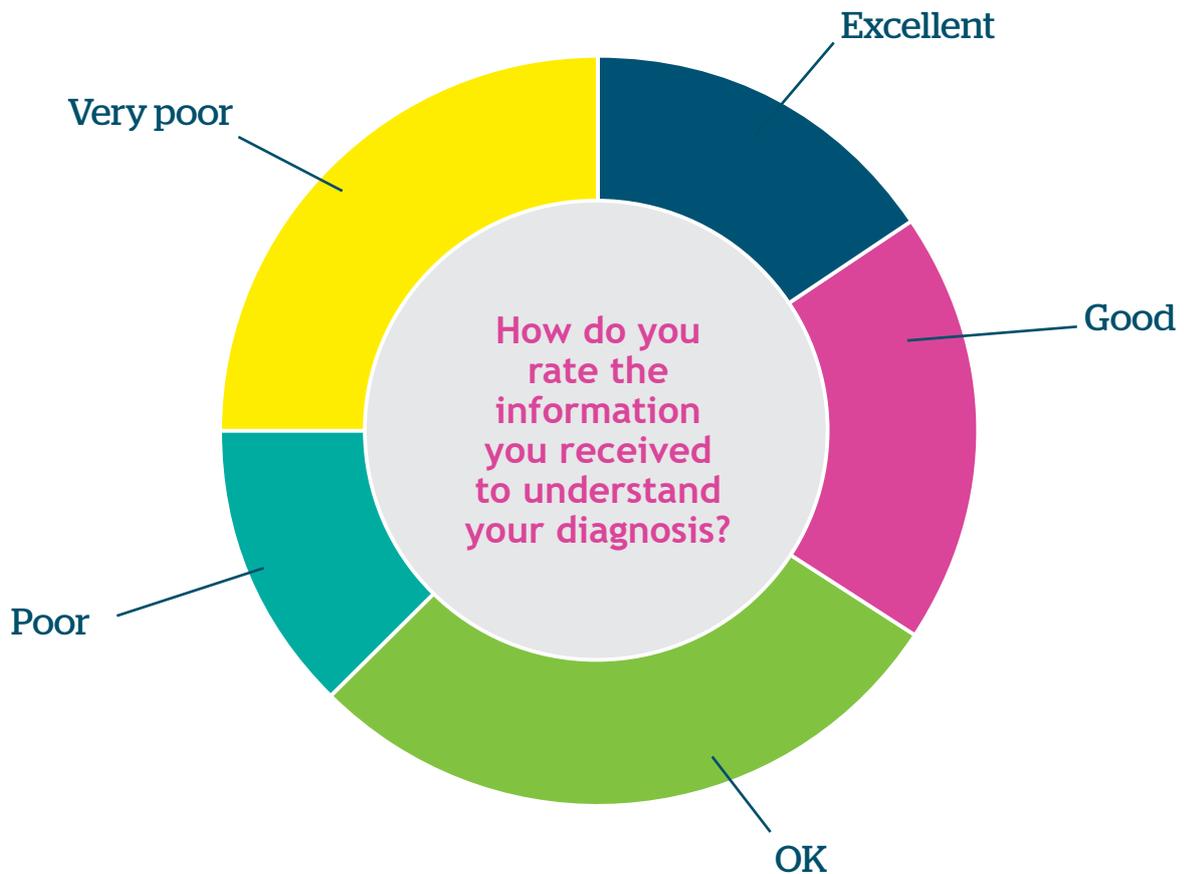
Attending his specialist school has been life changing for my son and our family. Before he was constantly excluded because his needs were not met by a mainstream primary school, this caused him to miss out socially and academically for the majority of his primary school experience.

Diagnosis

The charts below show the proportion of our respondents who said that they had received a diagnosis of an autism spectrum condition.



Feedback about the information that people were given to understand their diagnosis was mixed as the chart and quotes below demonstrate. One thing that was frequently mentioned was that the information pack provided was overwhelming.



The lady that did the assessment was nice and then someone called and went through stuff and that was it. There is no more support.

The clinical psychologist was excellent in her explanation.

Very overwhelming large booklet that I just put away to tackle another time and then misplaced. Needed more than one follow-up appointment. Needed more preparing for PIP [Personal Independence Payment] claim and mentoring.

I did not receive any information not even a written report, he just told me there and then.

The post diagnosis pack was overly voluminous and a bit repetitive.

I had one follow-up appointment with WADS [Wiltshire Autism Diagnostic Service] and it wasn't what I expected. I thought I was going to be told more information specific to Wiltshire, but instead I was just given a big booklet and told to read it in my own time, most of the information was irrelevant and I did not find the booklet useful. I felt the appointment was very pointless, they could have just sent me the booklet instead.

The assessor was amazing with my child, explained everything in detail to me and even called a few weeks after diagnosis to see if we had any more questions.

One booklet. Very overwhelming. Too much information. No follow-up after one post-diagnosis appointment. Just sent on your way.

Both times the diagnosis was well explained, but knowing you have something doesn't tell you how to live with it day to day.

Other things that were mentioned

We asked people if there was anything else they wanted to say about health and care service. Responses frequently mentioned a lack of support following diagnosis and the need for more autism specific support groups.

Give us some hope, somewhere we can meet up with people with similar problems, help us to integrate or learn coping strategies. Virtually everything is left to my poor parents (now both aged over 70).

I received an information booklet at diagnosis about the condition, told there is little for adults on the autistic spectrum and never been supported since. I have mental health issues, including PTSD and simply feel let down and fear contacting any professional after being told by a GP there was nothing else they can do for me nor AWP [Avon and Wiltshire Mental Health Partnership NHS Trust].

They are no care services for people with autism.

There is next to no help for women and girls No groups to go to No drop in session.

Responses from carers highlighted a lack of clear information about what was available, disjointed services and a need for greater awareness of autism spectrum conditions and how they affect individuals.

There is no help or support you have to find everything out yourself. I wish I had known about EHCP [Education and Health Care Plan] before it was too late.

People need 1:1 support within Wiltshire. For people who are high functioning as well as those more impaired. There is no 1:1 support to help someone come to terms with and understand how their condition affects them.

Still a lack of knowledge and understanding of autism spectrum condition within the medical professions.

There is not much 'out there' in the way of real practical support – need a lot more contact/publicity on what is on offer.

I feel there is a gap in services for those who need assistance but can 'manage', once they leave full time education. I have no idea what facilities/amenities are available locally, and I don't even think my son is registered at his GP as having autism spectrum condition.

Conclusions and recommendations

People with autism spectrum conditions and their carers have shared a wealth of useful information which has provided a good insight into their experiences and we are grateful for their input.

There is a clear view that there is a lack of understanding about the impact of autism spectrum conditions, and of what can be done to alleviate the difficulties people experience. Those we spoke to identified a range of ways to improve their experience of health and care services. The need to work with people as individuals was evident from our findings.

Another key theme was the lack of services and groups for people, with most relying on support from family members. Responses from unpaid carers echoed this. The value of this care should not be underestimated and it should also be recognised that providing this care places significant levels of stress on families. Support services were valued where they were present but the overall impression from the survey responses was that they are not part of a much-needed planned and coordinated pathway of support.

We make these recommendations that are based on what we were told:

- Introduce initiatives and training to improve awareness of autism among staff working in GP practices and hospitals.
- Consider offering people with autism a written summary of their appointment, treatment and follow-up.
- Establish a system of recording preferences and/or needs for face to face, phone or video appointments and consider how these preferences can be met as far as possible.
- Establish a system that flags a person's autism spectrum condition in their medical notes.
- Include the findings of this report in pathway reviews for support services in Wiltshire, with the aim of providing improved access to services for people with an autism spectrum condition.
- Consider how information about, and experience of, transition from child to adult services can be improved.
- Investigate a reduction in the volume of general information given at diagnosis and the provision of a more individually tailored pack.
- Work with people with autism spectrum conditions and their carers in taking forward the above recommendations.

Thank you

Thank you to all the people with autism spectrum conditions and their carers who shared their views and experiences with us. Thanks also to WSUN and our volunteers who supported this work.

Responses

 Clare O'Farrell, Director of Locality Commissioning for Wiltshire, Bath and North East Somerset, Swindon and Wiltshire Clinical Commissioning Group (BSW CCG) 

The CCG wants to thank Healthwatch Wiltshire for sharing this report and its associated recommendations.

The report is very timely as we are coming together with system partners as part of the Learning Disabilities and Autism Transformation Programme, and this report will ensure the views and feedback from people, and carers of people that have a diagnosis of autism, are at the forefront of future projects.

We look forward to continuing to work with Healthwatch Wiltshire and Wiltshire Service Users' Network.

 Helen Jones, Director of Joint Commissioning, Wiltshire Council 

Wiltshire Council puts the voice of autistic people and their carers at the heart of what we do, so it is helpful to hear people's experience of using services in Wiltshire and to see how together we can make that experience better.

I would like to give my thanks to Healthwatch Wiltshire and WSUN for producing the report, and to autistic people and carers for contributing to it. I look forward to working with you all as we develop and implement our autism strategy in Wiltshire.

Appendix



Questionnaire for people with an Autism Spectrum Condition

Healthwatch Wiltshire gathers feedback from local people about health and social care services. We are working with Wiltshire Service Users Network on this project.

We want to find out what people with Autism Spectrum Conditions and their carers think about health, care and support services.

We do not require names and the information you provide is confidential, except that anonymised quotes may be used. We use the information to tell those who run services what could be improved or developed in the future.

Please tick to confirm you understand the purpose of the survey and consent to the use of the data as described above.

Going to the Doctors

Making an appointment

1. How easy do you find it to make an appointment at the Doctors? (Tick the box that applies)

————— ————— ————— —————
Very Easy Fairly Easy OK Difficult Very difficult

- Why?

2. What would make it easier for you to make an appointment? (Tick all that apply)

- Booking appointments online
- Being sent a text message with appointment information
- My notes saying that I have Autism (*so the receptionist can see this when you are booking an appointment*)

Other -

Waiting for your appointment at the surgery

3. How easy do you find waiting to see a Doctor or Nurse? (Tick the box that applies)

————— ————— ————— —————

Very Easy Fairly Easy OK Difficult Very difficult

- Why?

4. What would make waiting easier? (Tick all that apply)

- Having a quiet place to wait
- Having an appointment at a quieter time of day
- Something to read or do while you wait
- Someone to support me

Other -

Communication

5. How easy do you find it to explain to the Doctor or Nurse about the reason for the visit? (Tick the box that applies)

————— ————— ————— —————

Very Easy Fairly Easy OK Difficult Very difficult

- Why?

6. What would help to explain things to the Doctor or Nurse? (Tick all that apply)

- Having a longer appointment
- Pictures / visual aids
- Someone to support me

Other -

7. How easy do you find it to understand the information they give you about treatment, medication, or follow-on care? (Tick the box that applies)

————— ————— ————— —————

Very Easy Fairly Easy OK Difficult Very difficult

- Why?

8. What would help you to understand what they are telling you? (Tick all that apply)

- Having a longer appointment
- If they used clearer language
- Being given written information
- Being given Easy Read information
- Someone to support me

Other -

9. Is there anything else that you would like to tell us about going to the Doctors or things they could do to help people with an Autism Spectrum Condition?

Going to the Hospital

10. How easy would you find it to remember an appointment at the hospital?

————— ————— ————— —————

Very Easy Fairly Easy OK Difficult Very difficult

11. What would help you to remember an appointment? (Tick all that apply)

- My notes saying that I have Autism (so they can see this when they send you a reminder about your appointment)
- Text message reminder
- Reminder by post

Other -

12. How easy would it be for you to prepare for and get to an appointment at the hospital? (Tick the box that applies)

————— ————— ————— —————

Very Easy Fairly Easy OK Difficult Very difficult

- Why

13. What would help you to prepare and get to an appointment at the hospital? (Tick all that apply)

- My notes saying that I have Autism (so they can see this when they send you information about your appointment)
- Leaflet with map of the hospital and photos
- Online map and photos / interactive mobile app
- Video showing the hospital and the department and what I should expect at the appointment
- Written information about what the appointment is for and what will happen
- Easy Read information about visiting the hospital
- Easy Read information about what the appointment is for and what will happen

Other -

14. Is there anything else that you would like to tell us about going to the hospital or things they could do to help people with an Autism Spectrum Condition?

Having an appointment by phone or video

15. Have you ever had a doctors or hospital appointment by phone or online by video? (Tick all that apply)

- No, I've never had an appointment by phone or video
- Yes, I've had a doctor's appointment on the phone
- Yes, I've had a doctor's appointment by video
- Yes, I've had a hospital appointment on the phone
- Yes, I've had a hospital appointment by video

If yes, how did this work for you?

Information

16. Do you feel you have enough information about support and other services and groups available for people with an Autism Spectrum Condition? (Tick the box that applies)

Yes

No

Unsure

17. What information service has been most valuable?

18. What other information would you find useful?

19. Which two of these would you find / have you found the most useful way to access information about support and other services for people with Autism Spectrum Conditions?

- Leaflets available at health and community settings
- Leaflets available in schools and colleges
- Website - specific section on local health service website
- Social media - e.g. specific page on Facebook or Twitter
- Local telephone contact number
- Drop in sessions for information
- An information App for your phone or tablet
- Other (please state) -

Support

20. Overall, do you feel that you receive the support that you need related to your Autism Spectrum Condition? (Tick the box that applies)

Yes

No

Unsure

21. Who do you get support from? (Tick all that apply)

Support worker who supports me with day-to-day tasks

Care worker who supports me with personal tasks and/or meals

Social Worker

Family member

Neighbour/friend

Someone else, please say who

22. Do you attend any groups or clubs? (Tick the box that applies)

Yes

No

Unsure

If yes, what groups or clubs do you attend?

23. What support has been most valuable?

24. What other support would you find useful? (Tick all that apply)

One-to-one support with day-to-day tasks at home

One-to-one support with attending appointments e.g. Doctors and Hospital

On line support group

Drop in sessions for support and advice

Local Autism specific support group

Other (please state what)

Getting a Diagnosis

25. Have you had an diagnosis of an Autism Spectrum Condition? (Tick the box that applies)

- Yes (Please continue)
- No (Please move on to question 31)
- I'm waiting for a diagnosis (Please move on to question 31)

26. How old were you when you received a diagnosis?

27. Who referred you for a diagnosis? (Tick the box that applies)

- GP
- Paediatrician
- Other (please state) -

28. Please rate the information you were given about what would happen next. (Tick the box that applies)

————— ————— ————— —————

Excellent Good OK Poor Very Poor

Comments -

29. Who gave you your diagnosis? (Tick the box that applies)

- Wiltshire Autism Assessment Service (Virgin Care)
- Wiltshire Autism Diagnostic Service (AWP)
- Private diagnosis
- Other (please state) -

30. Please rate the information and support you were given to understand your diagnosis: (Tick the box that applies)

————— ————— ————— —————

Excellent Good OK Poor Very Poor

Comments -

31. Do you have any other feedback about health and care services for people with Autism Spectrum Conditions and how they can be improved?

About You:

This information is anonymous, you do not have to answer any questions if you don't wish to.

Your gender:

Your age:

Please tell us the town or village where you live?

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) -

How would you describe your Ethnic Group?

White	Mixed	Asian/Asian British	Black/Black British
<input type="checkbox"/> British	<input type="checkbox"/> White and Black Caribbean	<input type="checkbox"/> Indian	<input type="checkbox"/> African
<input type="checkbox"/> Irish	<input type="checkbox"/> White and Black African	<input type="checkbox"/> Pakistani	<input type="checkbox"/> Caribbean
<input type="checkbox"/> Gypsy/Irish traveller	<input type="checkbox"/> White and Asian	<input type="checkbox"/> Bangladeshi	<input type="checkbox"/> Any other Black
<input type="checkbox"/> White other: _____	<input type="checkbox"/> Any other mixed: _____	<input type="checkbox"/> Chinese	_____
		<input type="checkbox"/> Any other Asian: _____	<input type="checkbox"/> Arab/any other group: _____

Thank you for taking part!
Please return in the Freepost envelope enclosed.

Keep in touch:

If you would like to be added to the Healthwatch Wiltshire mailing list, please provide your email or postal address:

Your details will be held securely and in compliance with data protection laws. They will only be used for the purposes of carrying out Healthwatch Wiltshire activity. Your details will not be shared with any other organisation. You may withdraw your consent to us holding your details at any time by emailing info@healthwatchchwiltshire.co.uk or calling 01225 434218.

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Questionnaire for Carers of people with an Autism Spectrum Condition

Healthwatch Wiltshire gathers feedback from local people about health and social care services. We are working with Wiltshire Service Users Network on this project.

We want to find out what people with Autism Spectrum Conditions (ASC) and their carers think about health, care and support services.

We do not require names and the information you provide is confidential, except that anonymised quotes may be used. We use the information to tell those who run services what could be improved or developed in the future.

Please tick to confirm you understand the purpose of the survey and consent to the use of the data as described above.

Going to the Doctors

Making an appointment

1. How easy do you find it to make an appointment at the Doctors for the person you care for? (Tick the box that applies)

Very Easy Fairly Easy OK Difficult Very difficult

- Why?

2. What would make it easier for you to make an appointment? (Tick all that apply)

- Booking appointments online
- Being sent a text message with appointment information
- GP notes saying that they have Autism and I am their carer (*so the receptionist can see this when you are booking an appointment*)

Other -

Waiting for the appointment at the surgery

3. How easy does the person you care for find waiting to see a Doctor or Nurse? (Tick the box that applies)

————— ————— ————— —————

Very Easy Fairly Easy OK Difficult Very difficult

- Why?

4. What would make waiting easier? (Tick all that apply)

- Having a quiet place to wait
- Having an appointment at a quieter time of day
- Something to read or do while they wait

Other -

Communication

5. How easy does the person you care for find it to explain to the Doctor or Nurse about the reason for the visit? (Tick the box that applies)

————— ————— ————— —————

Very Easy Fairly Easy OK Difficult Very difficult

- Why?

6. What would help them explain things to the Doctor or Nurse? (Tick all that apply)

- Having a longer appointment
- Pictures / visual aids e.g. show me where cards
- Someone to support them

Other -

7. How easy do they find it to understand what they have been told about treatment, medication or follow-on care? (Tick the box that applies)

————— ————— ————— —————

Very Easy Fairly Easy OK Difficult Very difficult

- Why?

8. Is there anything else that you would like to tell us about going to the Doctors or things they could do to help people with ASC and their carers?

Going to the Hospital

9. How easy would the person you care for find it to prepare for an appointment at the hospital? (Tick the box that applies)

————— ————— ————— —————

Very Easy Fairly Easy OK Difficult Very difficult

- Why?

10. What would help them prepare for an appointment? (Tick all that apply)

- Their notes saying they have Autism (so they can see this when they send you information about the appointment)
- Leaflet with map of the hospital and photos
- Online map and photos / interactive mobile app
- Video showing the hospital and the department and what they should expect during the appointment

- Written information about what the appointment is for and what will happen
- Easy Read information about visiting the hospital
- Easy Read information about what the appointment is for and what will happen

Other -

11. Is there anything else that you would like to tell us about going to the hospital or things they could do to help people with ASC and/or their carers?

Having an appointment by phone or video

12. Has the person you care for ever had a doctors or hospital appointment by phone or online by video? (Tick all that apply)

- No, they've never had an appointment by phone or video
- Yes, they've had a doctor's appointment on the phone
- Yes, they've a doctor's appointment by video
- Yes, they've a hospital appointment on the phone
- Yes, they've a hospital appointment by video

If yes, how did this work for them?

Information

13. Do you feel you have enough information about support and other services and groups available for people with ASC and their carers? (Tick the box that applies)

Yes

No

Unsure

14. What information service has been most valuable?

15. What other information would you find useful?

16. Which two of these would you find / have you found the most useful way to access information about support and other services for people with ASC?

- Leaflets available at health and community settings
- Leaflets available in schools and colleges
- Website - specific section on local health service website
- Social media - e.g. specific page on Facebook or Twitter
- Local telephone contact number
- Drop in sessions for information
- An information App for your phone or tablet

Support

17. Overall, do you feel that the person you care for receives the support that they need in relation to their Autism Spectrum Condition? (Tick the box that applies)

Yes

No

Unsure

18. Who do they get support from? (Tick all that apply)

Support worker who supports them with day to day tasks

Care worker who supports them with personal tasks and/or meals

Social Worker

Family member

Neighbour/friend

Someone else, please say who

19. Do they attend any groups or clubs? (Tick the box that applies)

Yes

No

Unsure

If yes, what groups or clubs do they attend?

20. What support has been most useful to them?

21. What other support would you (as a carer/relative) find useful?

Getting a Diagnosis

22. Has the person you care for had a diagnosis of an Autism Spectrum ASC?
(Tick the box that applies)

- Yes (Please continue)
- No (Please move on to question 29)
- I'm waiting for a diagnosis (Please move on to question 29)

23. How old was the person when they received a diagnosis?

24. Who referred them for a diagnosis? (Tick the box that applies)

- GP
- Paediatrician
- Other (please state) -

25. Please rate the information you were given about what would happen next.

(Tick the box that applies)

————— ————— ————— —————

Excellent Good OK Poor Very Poor

Comments -

26. Who gave them their diagnosis? (Tick the box that applies)

- Wiltshire Autism Assessment Service (Virgin Care)
- Wiltshire Autism Diagnostic Service (AWP)
- Private diagnosis
- Other (please state)

27. Please rate the information and support the person you care for was given to understand their diagnosis. (Tick the box that applies)

————— ————— ————— —————

Excellent Good OK Poor Very Poor

Comments -

28. Please rate the information and support you were given to help you understand their diagnosis. (Tick the box that applies)

————— ————— ————— —————

Excellent Good OK Poor Very Poor

Comments -

29. Do you have any other feedback about health and care services for people with ASC and their carers? How they can be improved?

About You:

This information is anonymous, you do not have to answer any questions if you don't wish to.

Your gender:

Your age:

Please tell us the town or village where you live?

About the person you care for:

Their gender:

Their age?

Please tell us the town or village where they live?

What is their living situation?

- They live alone
- They live with a partner
- They live with their parents
- They live with other relatives
- They live in supported housing
- They live in a residential home
- Other (please state) -

How would you describe their Ethnic Group?

White	Mixed	Asian/Asian British	Black/Black British
<input type="checkbox"/> British <input type="checkbox"/> Irish <input type="checkbox"/> Gypsy/Irish traveller <input type="checkbox"/> White other: _____	<input type="checkbox"/> White and Black Caribbean <input type="checkbox"/> White and Black African <input type="checkbox"/> White and Asian <input type="checkbox"/> Any other mixed: _____	<input type="checkbox"/> Indian <input type="checkbox"/> Pakistani <input type="checkbox"/> Bangladeshi <input type="checkbox"/> Chinese <input type="checkbox"/> Any other Asian: _____	<input type="checkbox"/> African <input type="checkbox"/> Caribbean <input type="checkbox"/> Any other Black _____ <input type="checkbox"/> Arab/any other group: _____

**Thank you for taking part!
Please return in the Freepost envelope enclosed.**

Keep in touch:

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