

# Autism Spectrum Conditions Report

V. 1.0

March 2018



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*Please see our website for appendices including copies of surveys and questionnaires*

## Section A

### Introduction

Healthwatch Worcestershire gathers feedback about publicly funded health and care services and uses this to make recommendations to those who run the services about how they could be improved from the patient perspective.

We have been gathering feedback from people with Autism Spectrum Conditions and their carers about their experiences of accessing healthcare services, information, support and diagnosis. We have also been looking at the current levels of awareness and understanding of Autism Spectrum Conditions within health services in Worcestershire and ways in which services are currently supporting and making adjustments for those on the Autism Spectrum.

#### I. Autism Spectrum Conditions

Autism is a lifelong developmental condition, which affects the way people perceive the world and interact with others. In particular:

- Social communication - difficulties interpreting verbal and non-verbal language
- Social interaction - difficulties recognising and understanding others' emotions and intentions and expressing their own emotions
- Thinking in a flexible way - preferring routine, predictability and specific interests
- Experience over or under sensitivity to sound, touch, smell, taste, light, temperature or pain
- High levels of anxiety

Although Autism was first identified by Leo Kanner in 1943 and Asperger Syndrome by Hans Asperger in 1944, it was not until the 1990's that Lorna Wing and Judith Gould developed a more formal diagnostic criteria. There has therefore been an increased awareness, identification and diagnosis of Autism over the last 20 years.

Autism Spectrum Conditions includes Autism, Asperger Syndrome, Pathological Demand Avoidance and other names that have been previously been given as a diagnosis. It is now recognised that even though people may be affected in different ways and have a variety of different intellectual abilities, they all share common difficulties.

Due to the increase in understanding, we now know that approximately 1 in 100 people have an Autism Spectrum Condition. Between 44% to 52% of people with an Autism Spectrum Condition have a learning disability and many people with Autism experience mental health difficulties.

*Information from National Autistic Society website - [www.autism.org.uk](http://www.autism.org.uk)*

## II. Worcestershire - a local context

In 2015 Worcestershire's All Age Autism Strategy was approved by the Health and Wellbeing Board. The strategy sets out the objectives and outcomes for Autism services and support in Worcestershire in line with the national Adult Autism Strategy 2015 and the requirements set out in national guidance: Fulfilling and Rewarding Lives 2010.

The Strategy identified eight key priorities and an action plan for each of these.

1. Pathway for diagnosis and support
2. Awareness raising and training
3. Securing successful and seamless transitions
4. Improving access to education, training and employment
5. Independent living - improving access to universal, health, social care and housing services
6. Local planning - partnership working and data collection
7. Listening to children, young people and adults and their carers
8. Supporting community based organisations and groups

The strategy was developed with and is monitored by the Autism Strategic Partnership Board, which was set up and supported by Worcestershire County Council. This is made up of adults with Autism Spectrum Conditions, family carers, key professionals in Health and Social Care and Voluntary Sector representatives.

Annual updates about the progress of the All Age Autism Strategy are given to Worcestershire's Health and Wellbeing Board. The next update is due to be made in May 2018.

## **Demand and waiting times for diagnosis pathway**

The Umbrella Pathway is the Worcestershire pathway for assessment of children for Autism Spectrum Conditions. This involves assessments from two or more professionals including: Community Paediatrician, Speech and Language Therapist, Clinical Psychologist, Occupational Psychologist, Specialist Teacher for Autism, Educational Psychologist. Following the assessments and completion of reports, a decision is made by a panel about whether the individual meets the criteria for a diagnosis. There has been a dramatic increase in referrals to the Umbrella Pathway since 2010, meaning that of those who completed the Umbrella Pathway in November and December 2017, the average time on the pathway was over a year (327 days).

- Information taken from *Assessment of children and young people who may have Autism* - Report to Overview and Scrutiny Performance Board, February 2018

The Family Psychologist service is currently commissioned to deliver the adult diagnosis pathway in Worcestershire. In addition to diagnosis assessment, they provide six follow up one-to-one sessions with the individual. There has also been an increase in adults seeking a diagnosis and in March 2017 the average waiting time to the point of diagnosis was 41 months. One off additional funding and a temporary hold on new referrals was implemented to help to progress those still waiting for diagnosis. An approximate waiting time for diagnosis is predicted to be 11 months over the coming year.

- Information from All Age Autism Strategy for Worcestershire: Action Plan Update 2017

## **III. Why this issue?**

Work on Autism Spectrum Conditions was chosen as one of Healthwatch Worcestershire's business priorities following feedback received through our previous engagement and surveys and from members of our Reference and Engagement Group, who represent and support people with an Autism Spectrum Condition and their families. Concerns had been raised with us about: waiting times for diagnosis for children and adults, lack of awareness and understanding of Autism within health services and difficulties in accessing appropriate information and support.

When we asked members of the public and representatives of local patient, service user and carer groups who attended Healthwatch Worcestershire Annual Conference in June 2016 what they wanted us to choose as a Business Priority, work around Autism Spectrum Conditions received the highest number of votes.

## IV. Our work

Healthwatch Worcestershire carried out work to gather feedback and experiences from people with Autism Spectrum Conditions and their Carers, to identify progress made and further action needed in implementing the All Age Autism Strategy.

In particular we have focussed on the following elements of the priorities set out within the Strategy -

- *Priority 1:* We will have a clear pathway for diagnosis and support for children, young people and adults with Autism Spectrum Conditions.
- *Priority 2:* We will identify gaps in knowledge and understanding and make sure that all organisations can access high quality awareness raising and training.
- *Priority 5:* We will make sure that children, young people and adults with autism spectrum conditions have access to universal and health and social care services.
- *Priority 8:* We will promote the use of support groups in local communities and ensure they can access information about local services that are available.

Over the last 18 months we have undertaken a variety of work including:

### **Gathering feedback from people with Autism Spectrum Conditions:**

- 34 people completed our survey
- 15 young people completed Easy Read surveys
- 29 people took part in group and individuals discussions as part of our engagement

### **Gathering feedback from Carers of people with Autism Spectrum Condition:**

- 101 Carers completed our survey
- 40 Carers took part in group and individual discussions as part of our engagement

We have worked with and visited a number of organisations and groups to inform, guide and promote the work we have been doing and enable us to carry out engagement, including: ASPIE, National Autistic Society Companions Group, Bromsgrove Autism Parent Support Group, Your Ideas, Autism West Midlands, Sky Malvern Support Group, Bromsgrove District Housing Trust Autism Youth Group, Blossom Vale additional needs parent support group, Parents Voice, Worcestershire Parent Carer Forum, Aid for Asperger, SpeakEasy N.O.W. and Fortis Living.

## **Requesting feedback from Health services**

We requested feedback about the levels of awareness and training of Autism Spectrum Conditions amongst staff and any adjustments they make to support patients with Autism Spectrum Conditions from:

- GP Practices across Worcestershire
- Worcestershire Health and Care Trust
- Worcestershire Acute Trust
- Care UK
- West Midlands Ambulance Service

## **Parent feedback on Umbrella Pathway**

Providing parent and carer feedback to inform work being done by commissioners and Worcestershire Health and Care Trust to develop information about the Umbrella Pathway.

This included collating and reporting feedback about experiences of the Umbrella Pathway gathered through HWW engagement and Parent and Carer Survey 2016; helping to organise and facilitate a Parent Feedback Session and gathering further parent feedback on revised leaflets and information about the Umbrella Pathway.

*- Feedback and action plans relating to this work can be found on our website.*

We have also been participating in meetings of the Autism Strategic Partnership Board.

## Section B

# Feedback from people with Autism Spectrum Conditions

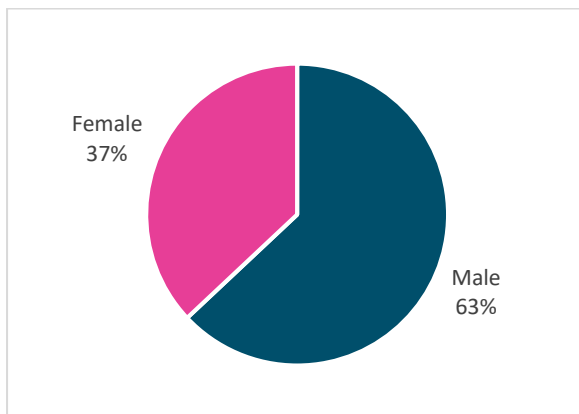
We gathered feedback from people with Autism Spectrum Conditions about their experiences of going to the doctors, going to the hospital, finding useful information, getting the right support and getting a diagnosis.

- 34 completed our survey
- 15 children and young people completed our Easy Read survey
- 29 took part in group and individual discussions as part of our engagement

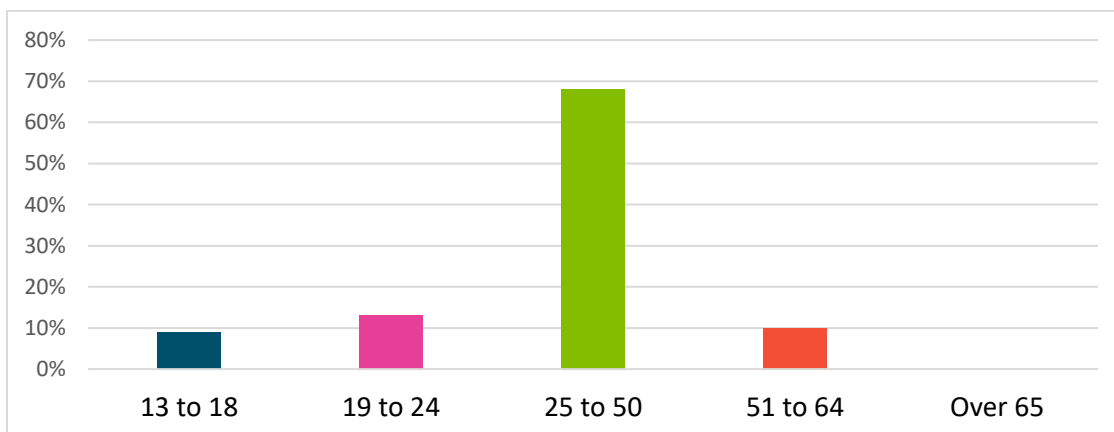
### 1. Survey for people with Autism Spectrum Conditions

34 people with Autism Spectrum Conditions completed our survey - 22 completed paper copies and 12 completed this online.

**Gender of respondents:**

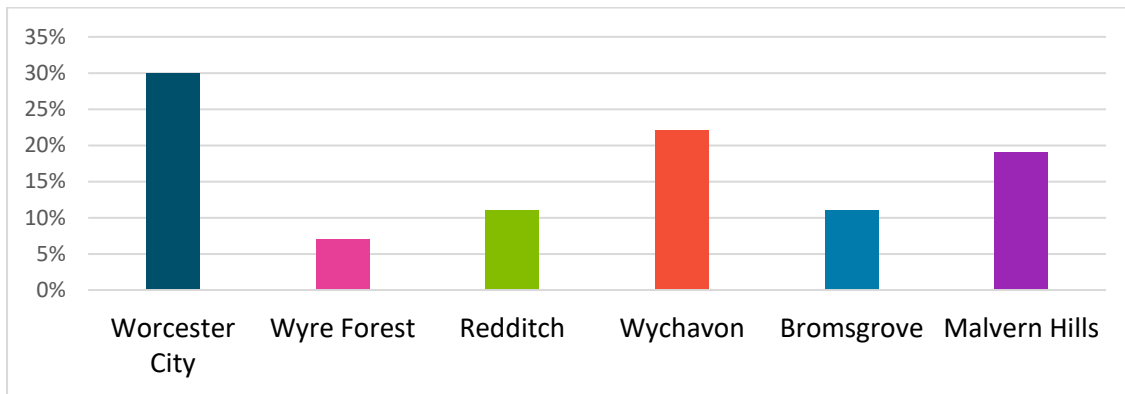


**Age of respondents:**



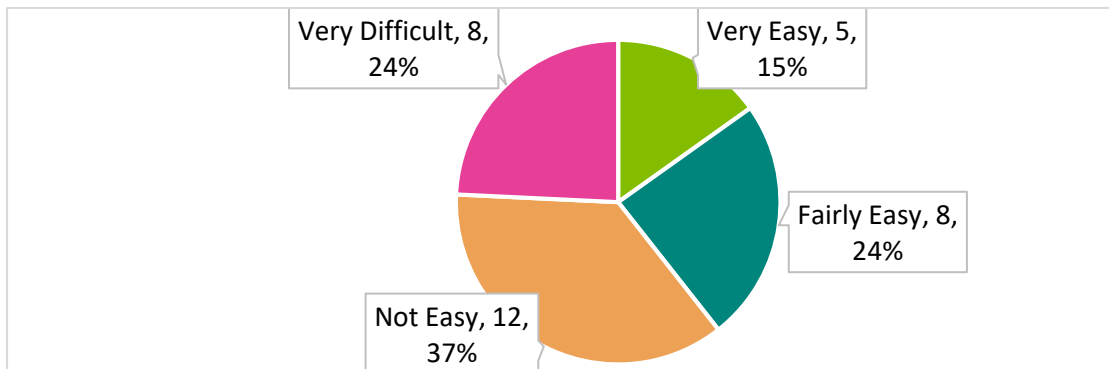


## Where respondents live:



## Going to the Doctors

### 1.1. How easy do you find it to make an appointment at the Doctors?



## Additional Comments

The most common explanation for why people found it difficult to make an appointment were due to anxiety or difficulties using the telephone

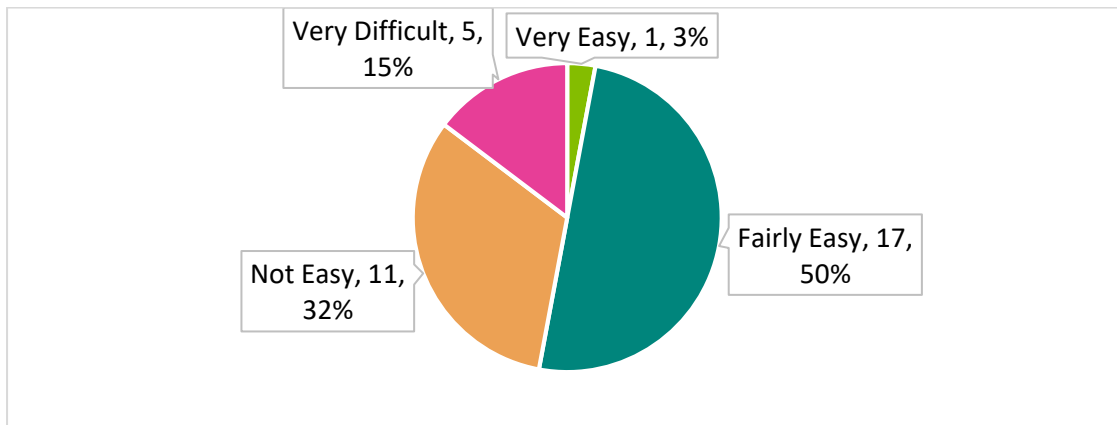
'I hate using the phone, I avoid it. I get tongue tied asking for an appointment and explaining why. I am not assertive enough / skilled to get what I require'

'cannot always have an appointment with my trusted doctor. I feel the receptionist don't understand my needs well and don't know another way to make appointments'

### 1.2. What would make it easier to make an appointment?

- Booking appointments online (18 people)
- 'My notes saying I have Autism so the receptionist can see this when booking an appointment' (15 people)

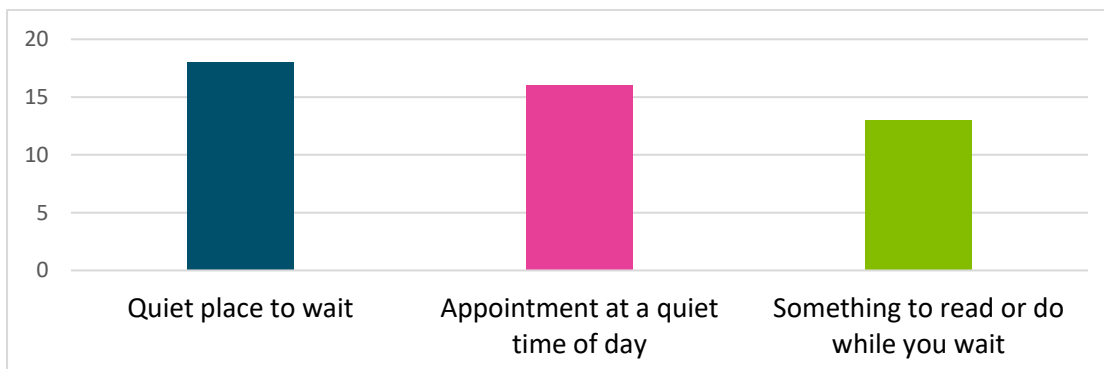
### 1.3. How easy do you find waiting to see a Doctor or Nurse?



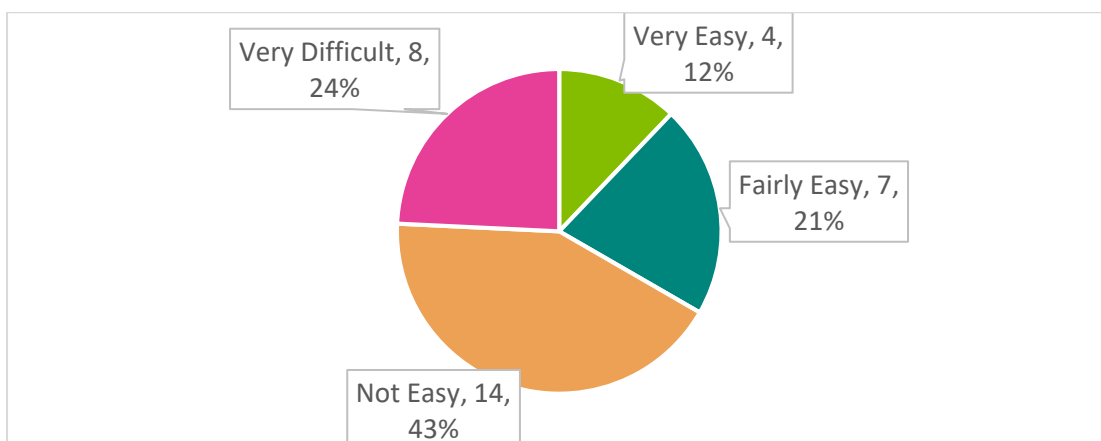
#### Additional Comments

14 people commented that waiting made them feel anxious due to: the length of time they had to wait, being in a crowded environment, noise or not knowing when it is their turn.

### 1.4. What would make waiting easier?



### 1.5. How easy do you find it to explain to the Doctor or Nurse about the reason for your visit?



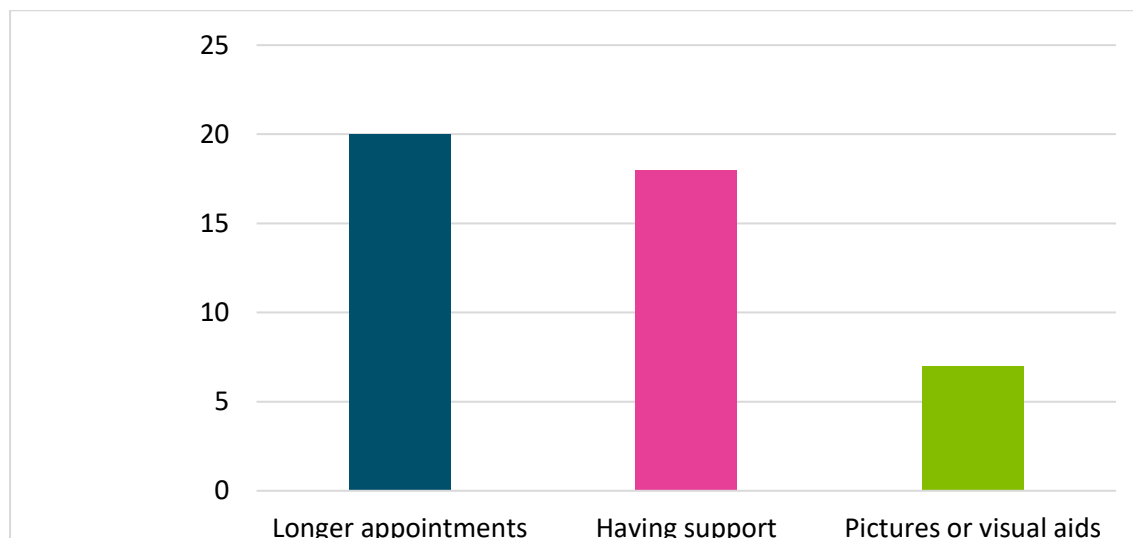
## Additional Comments

11 people told us this was due to difficulties with communication, especially knowing what to say. Three of these comments said that they felt the Doctor was not listening or was rushing them and this impacted on their ability to explain what was wrong. Others said that anxiety made it difficult to explain.

'I can never think of the right words to say'

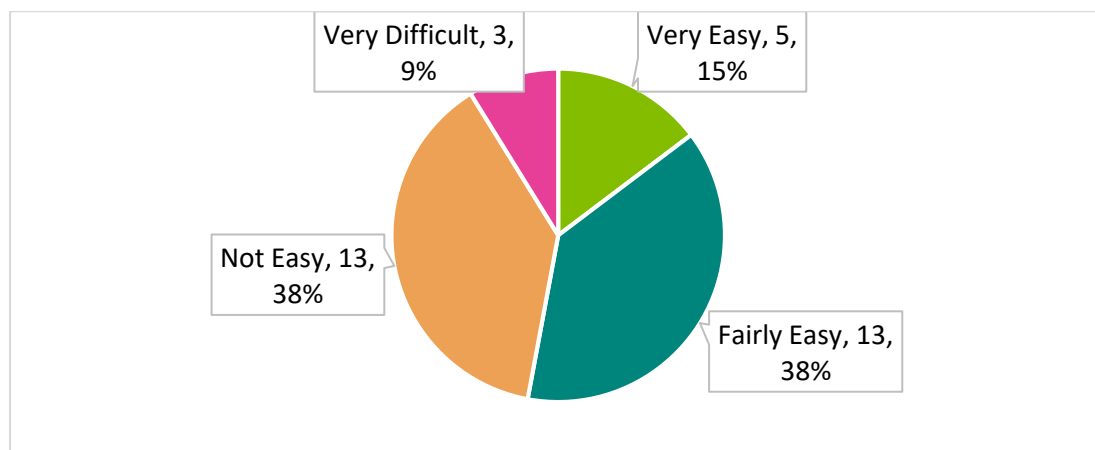
'I don't find communicating with anyone easy, but Doctors are always in a rush and this flusters me'

### 1.6. What would make it easier to explain things to the Doctor or Nurse?



Other suggestions included being able to see the same Doctor and the Doctor having an understanding of Autism Spectrum Conditions.

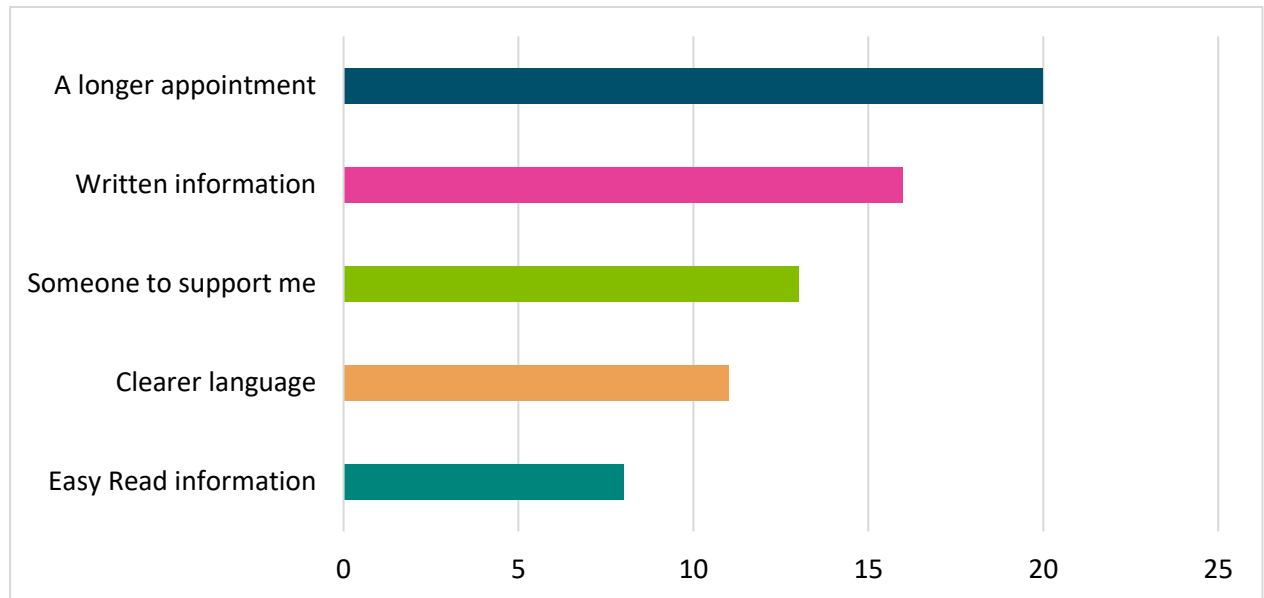
### 1.7. How easy do you find it to understand what they tell you about treatment, medication or follow on care?



## Additional Comments

Nine people said that they found it difficult due to the Doctor using words they did not understand, complex language or speaking too quickly.

### 1.8. What would help you to understand what they are telling you?



### 1.9. Additional comments about going to the Doctors

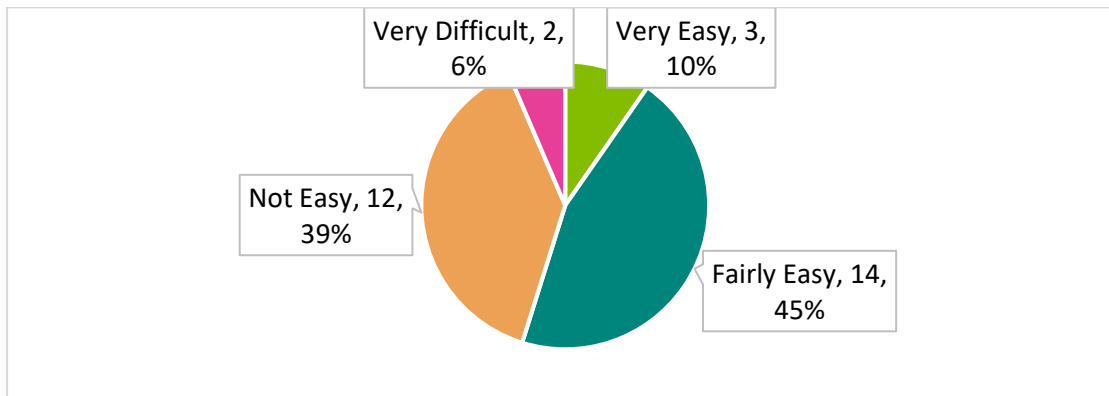
The majority of the additional comments expressed a need for a better understanding of Autism Spectrum Conditions. Including comments specifically about the need for understanding of sensory issues, for example bright lights, noises and crowds.

‘the information screen when it dings. It makes me anxious as it goes off every couple of seconds’

Other comments made related to: the receptionists having a better understanding of how to communicate with people with an Autism Spectrum Condition; having clearer information; having shorter waiting times; having Autism only clinics; the practice knowing that they have Autism and the lack of services available for people with Autism Spectrum Conditions.

## Going to the Hospital

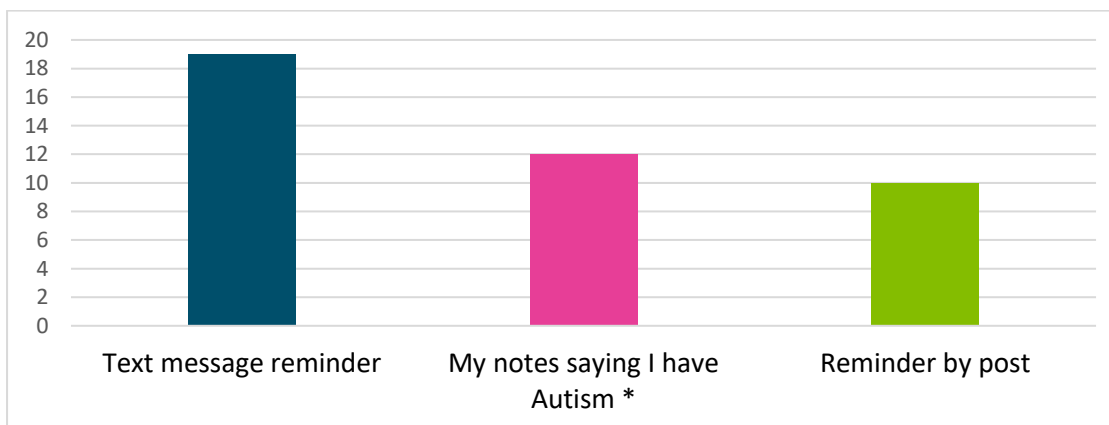
### 1.10. How easy would you find it to remember an appointment at the hospital?



#### Additional Comments

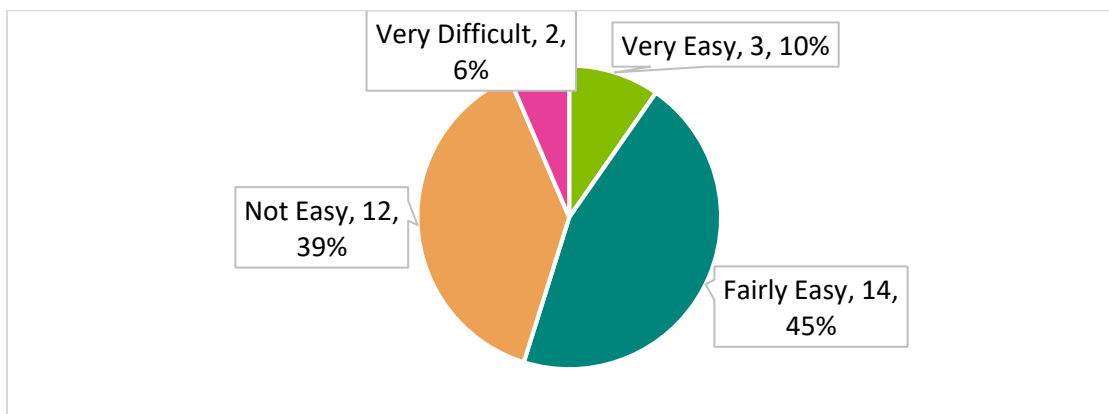
The main reasons given about why it was difficult to remember appointments were about being forgetful or finding it difficult to remember things.

### 1.11. What would help you to remember an appointment?



\*So that they can see this when they send a reminder

### 1.12. How easy would it be for you to prepare and get to an appointment at the hospital?



### Additional Comments

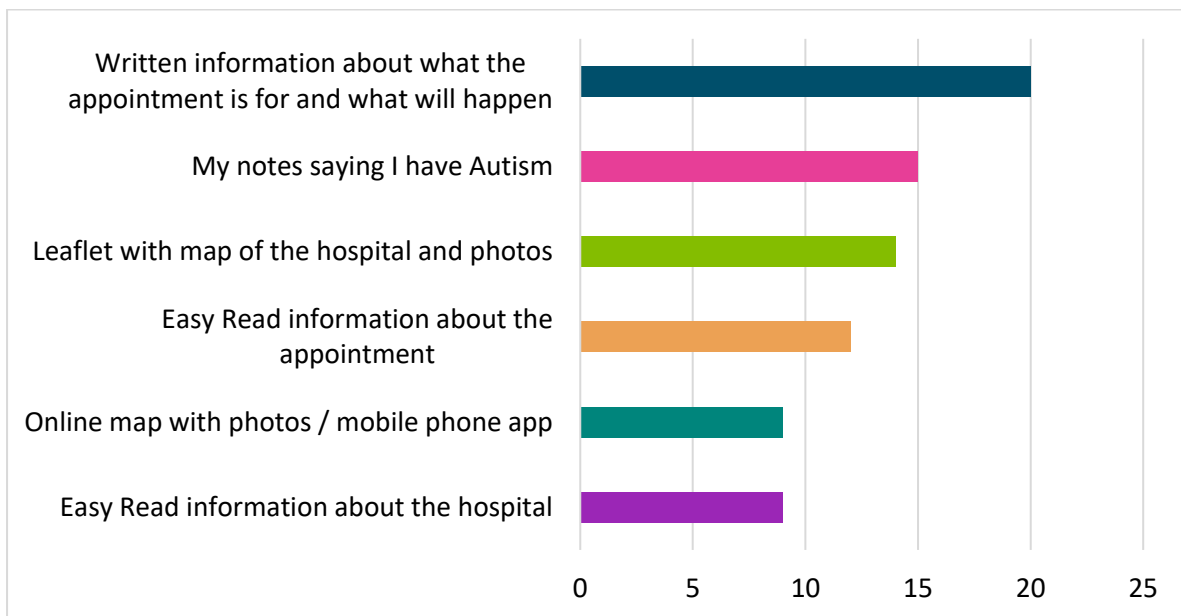
People said that they found this difficult due to difficulties with journey planning and time keeping or anxiety.

‘struggle planning journey and what to prepare’

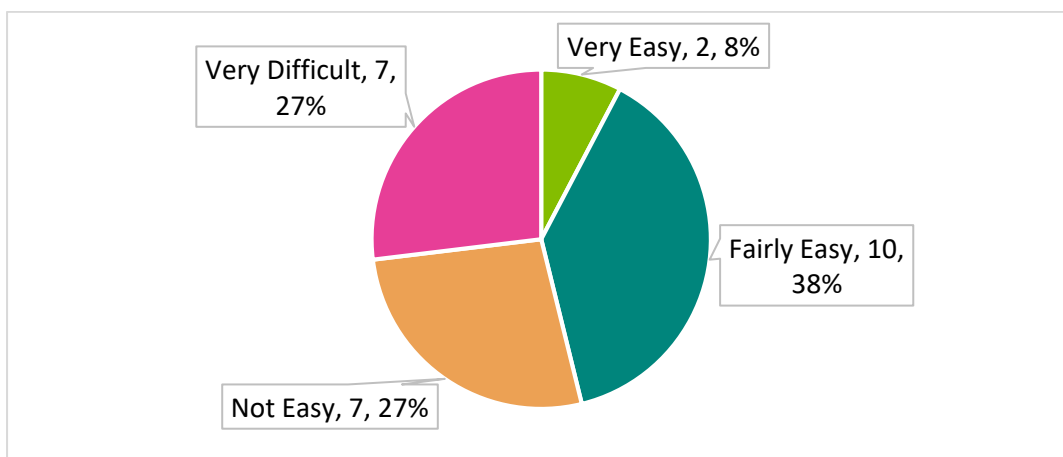
‘nerves - fear of the unknown’

‘I get way too nervous and then the anxiety kicks in’

### 1.13. What would help you prepare for and get to an appointment at the hospital?



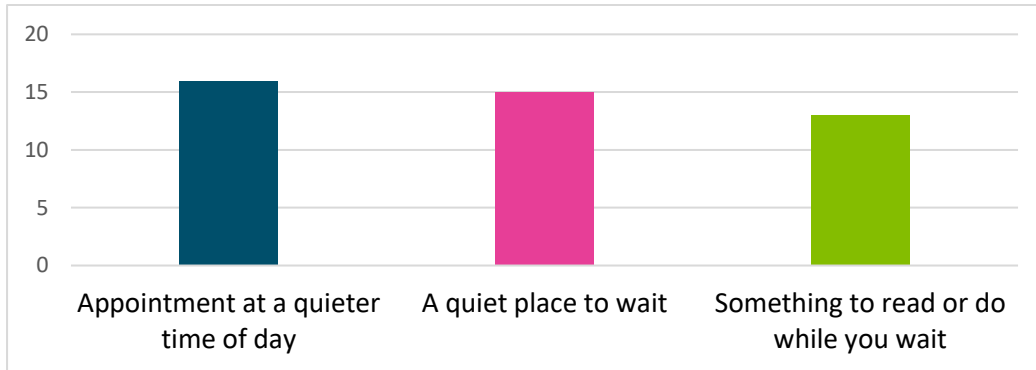
### 1.14. How easy do you find waiting for your appointment at the hospital?



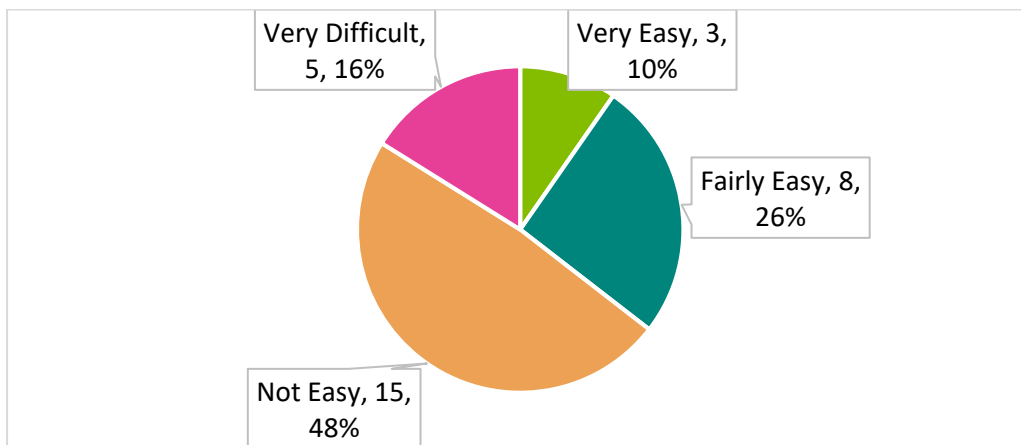
### Additional Comments

Reasons given for finding it difficult to wait for an appointment included: hospitals being busy and crowded, they do not like waiting and that they would feel anxious.

#### 1.15. What would make waiting easier?



#### 1.16. How easy do you find it to explain to the Doctor or Nurse about the reason for your visit?



### Additional Comments

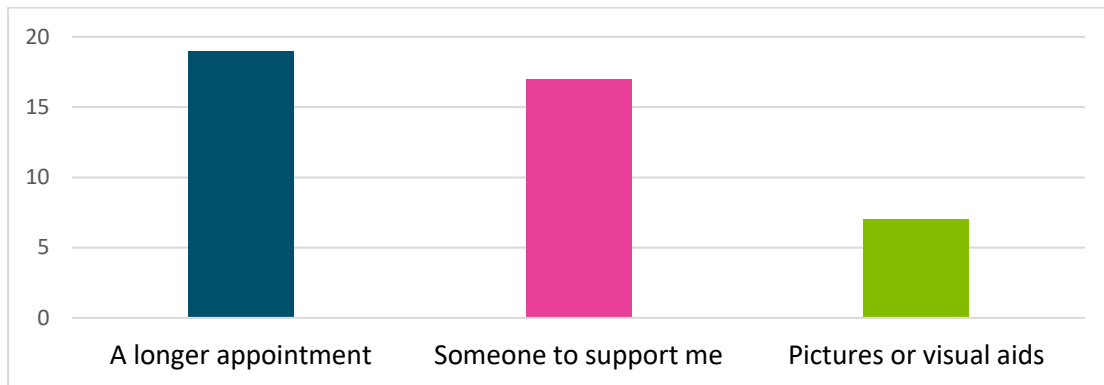
The main reasons given were difficulties knowing what to say or explaining themselves. Other reasons were: feeling rushed or under pressure, not knowing the person and sensory issues relating to the environment.

‘hard to filter the detail and say in a nutshell why I am there’

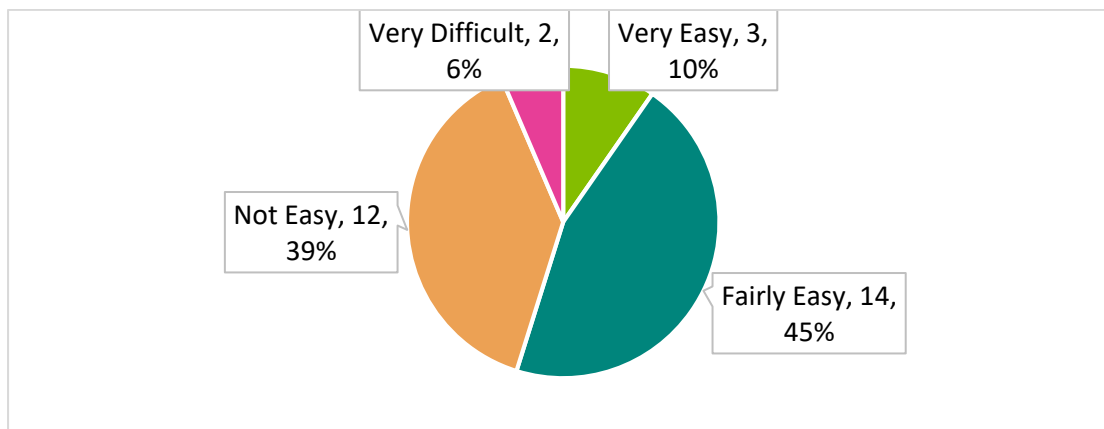
‘you might not know what the clinician wants to know, exactly, and you would need specific questions and prompts, no use of jokes / humour, ambiguous language, subtleties in context.’

‘They don’t understand what it’s like with the bright lights, noises’

**1.17. What would help you explain things to a Doctor or Nurse?**



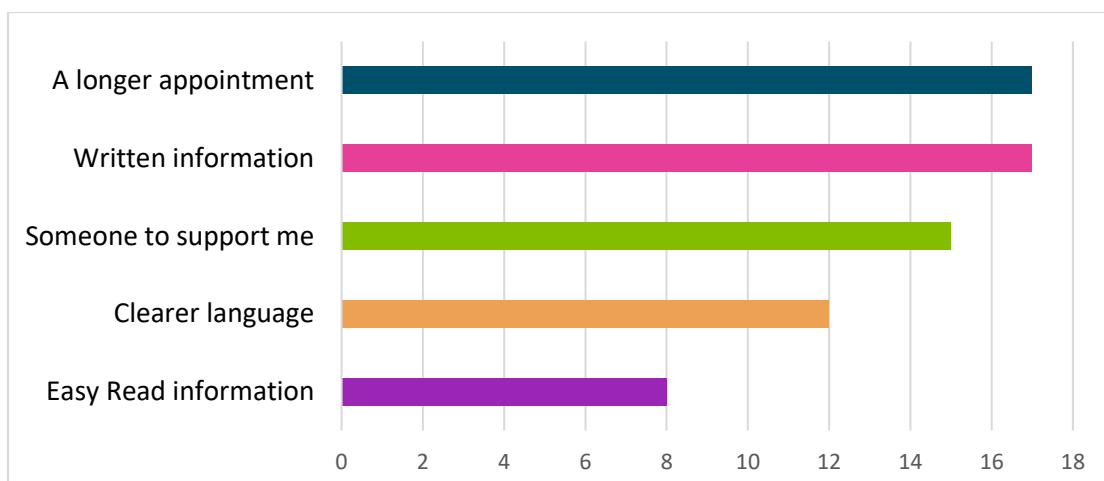
**1.18. How easy do you find it to understand what they tell you about treatment, medication or follow on care?**



**Additional Comments**

Reasons given for not understanding included: the information is too difficult to understand, difficulty with remembering and being anxious.

**1.19. What would help you to understand what they are telling you?**





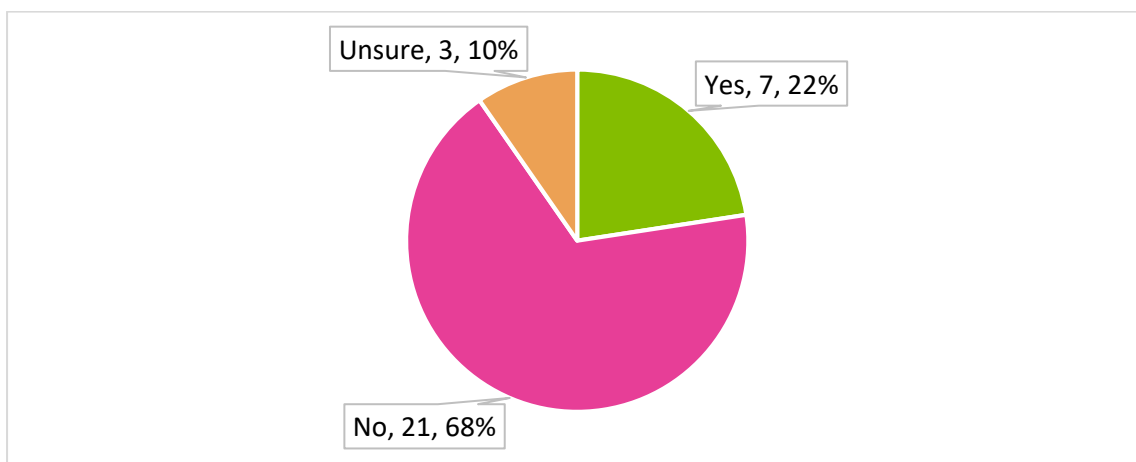
### 1.20. Additional comments about going to the hospital

Additional comments were made about difficulties relating to the environment, waiting times, anxiety and the need for increased awareness and understanding of Autism.

‘All doctors need to understand more about my condition and that I am not naughty or argumentative for fun. I just like to be at home where I am safe.’

### Information about support and services

#### 1.21. Do you feel you have enough information about support and other services and groups available for people with an Autism Spectrum Condition?



#### 1.22. What has been the most valuable?

Eight people told us that attending a support group or social group had been valuable.

Three people said that they had received information from the Psychologist when they received their diagnosis. One person mentioned a Facebook closed support group.

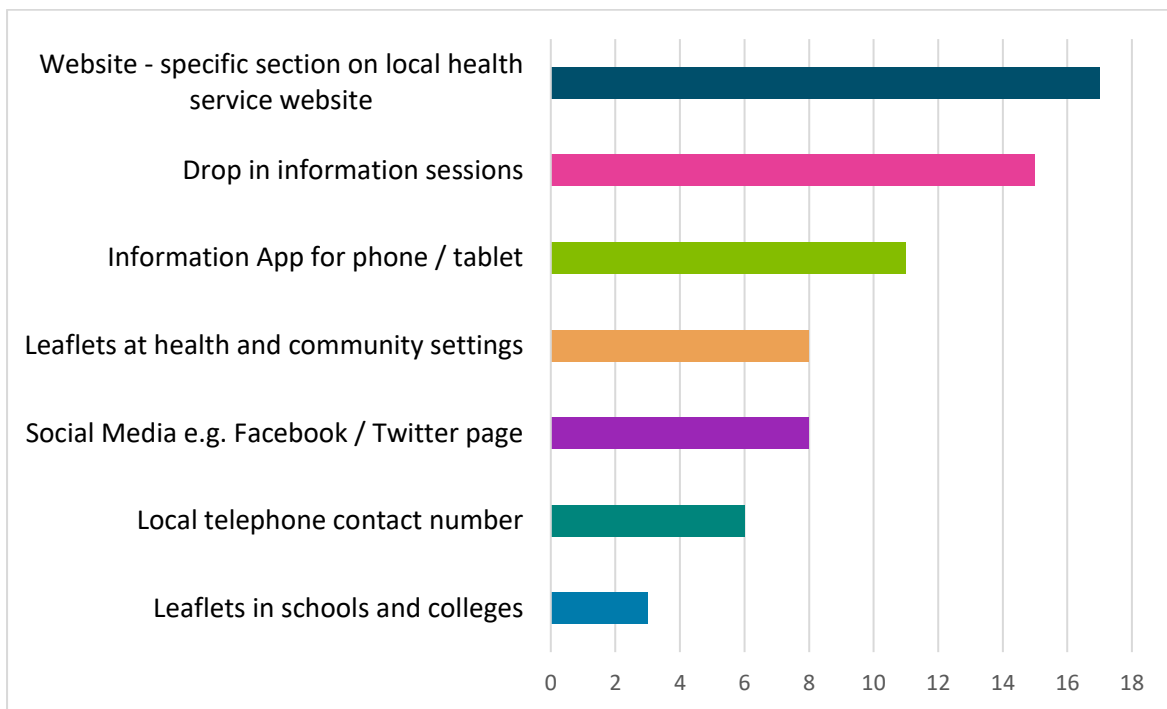
#### 1.23. What other information would you find useful?

Four people said they would like information about the support that is available. One of these mentioned that generally this kind of information is aimed at parents or carers of people with ASC rather than the individual themselves.

One person said that they would like information to support their partner and family and coping strategies for being a parent with Autism.

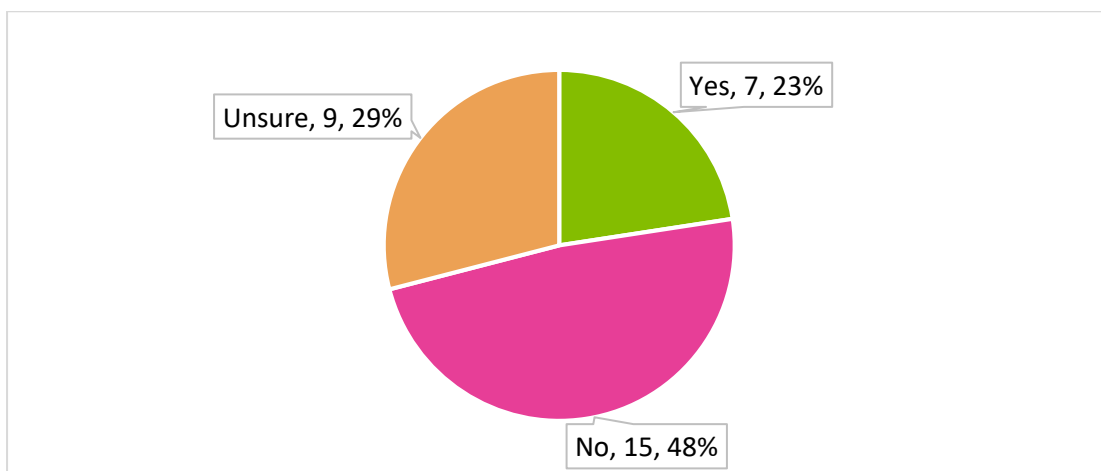
Other suggestions were having more groups available, leaflets and up to date information available on line.

**1.24. Which of these would you find / have you found the most useful ways to access information about support and other services for people with an Autism Spectrum Condition?**



**Support for people with Autism Spectrum Conditions**

**1.25. Overall, do you feel you receive the support that you need related to your Autism Spectrum Condition?**



### 1.26. What support has been the most valuable?

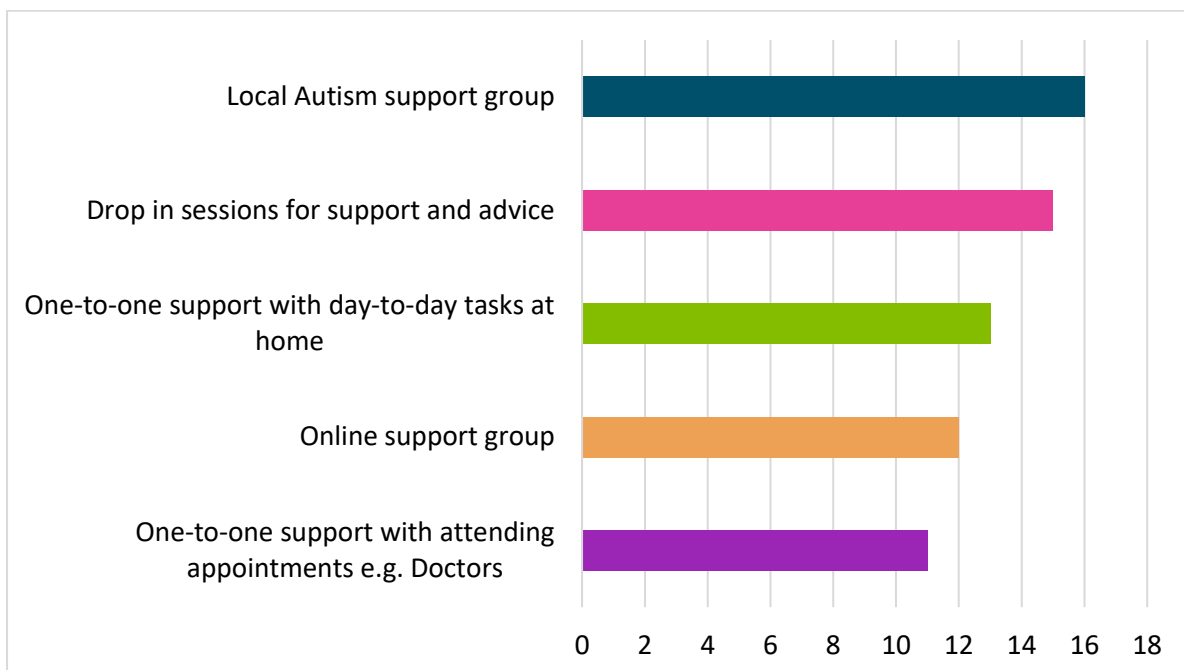
Six people said that having Doctors or health professionals who understood had been the most helpful support.

Four people said that their family or friends had been most valuable.

Three people made comments about the fact that they had not received support or support had not been helpful.

Other support that was mentioned included: social or group support and one to one support and in one case from a mentor at university. One person felt that receiving the diagnosis itself had been the most valuable.

### 1.27. What other support would you find useful?



Someone also suggested that they would find it helpful to have support for parents who themselves have Autism.

## Diagnosis

### 1.28 Experiences of diagnosis

Ten of the people who completed the survey had received a diagnosis within the last three years. They reported mixed experiences of the process. Some saying that this had been quick and they had received information about the process. While others reported a long wait for a diagnosis and did not feel they received support during this time. Some had paid to gain a diagnosis privately due to the waiting times for a diagnosis. Four had received a diagnosis via the Family Psychologist Service. A few were unsure who had provided their diagnosis.

## Additional Feedback

Twelve people made additional comments about how services can be improved for people with Autism Spectrum Conditions.

Five of these were relating to the need for increased services and support:

‘We know what support we need to enable us to live more fulfilled lives and allow us to function better, but we seem to always be fighting for it and never getting anywhere’

‘everyone waits too long for a diagnosis and then there are only limited support services available.’

Additional comments were also made about the need for increased awareness and understanding:

‘I think everyone needs to understand more including Doctors, nurses, schools and shops, they can help spread the knowledge’

Other comments included: the need for adjustments to be made to enable easier access to health services and wanting to meet people with Autism Spectrum Conditions who work to share experiences.

## 2. Feedback from young people with Autism Spectrum Conditions

We gathered feedback from children and young people with Autism Spectrum Conditions who attend groups run by Your Ideas, Autism West Midlands and Sky Malvern Support group. 15 children and young people, between the ages of 12 and 24, completed the Easy Read version of our survey.

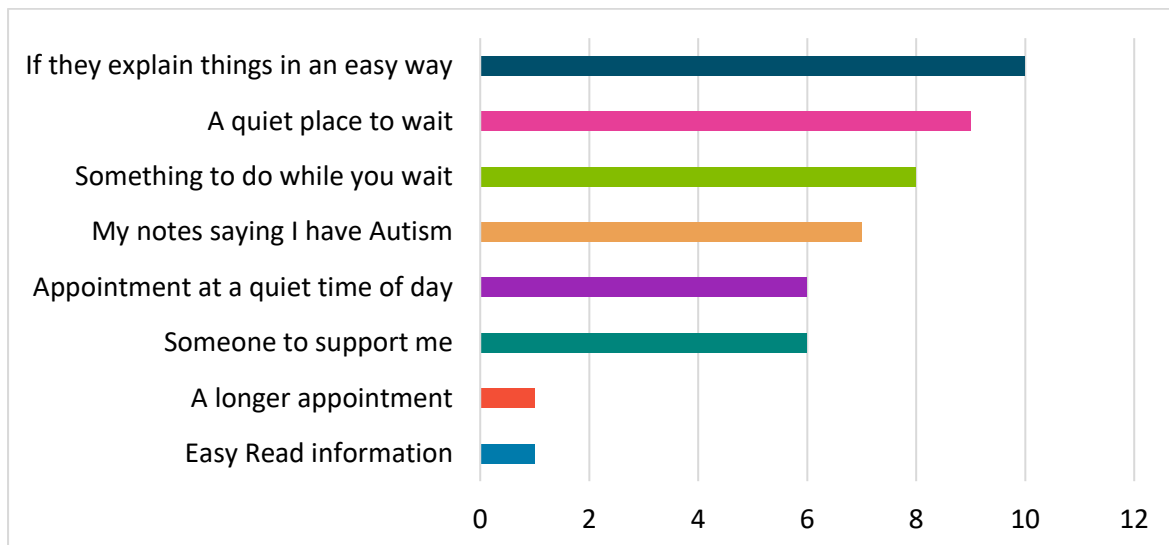
### 2.1 Going to the Doctors

Most of the children and young people told us that they found waiting at the Doctors difficult, because it can take a long time and they don't like waiting. They also said that they can find it difficult to explain what is wrong and understand the Doctor.

'I find it quite stressful in the waiting room'

'I get a bit anxious trying to explain what is wrong'

#### What would make it easier?



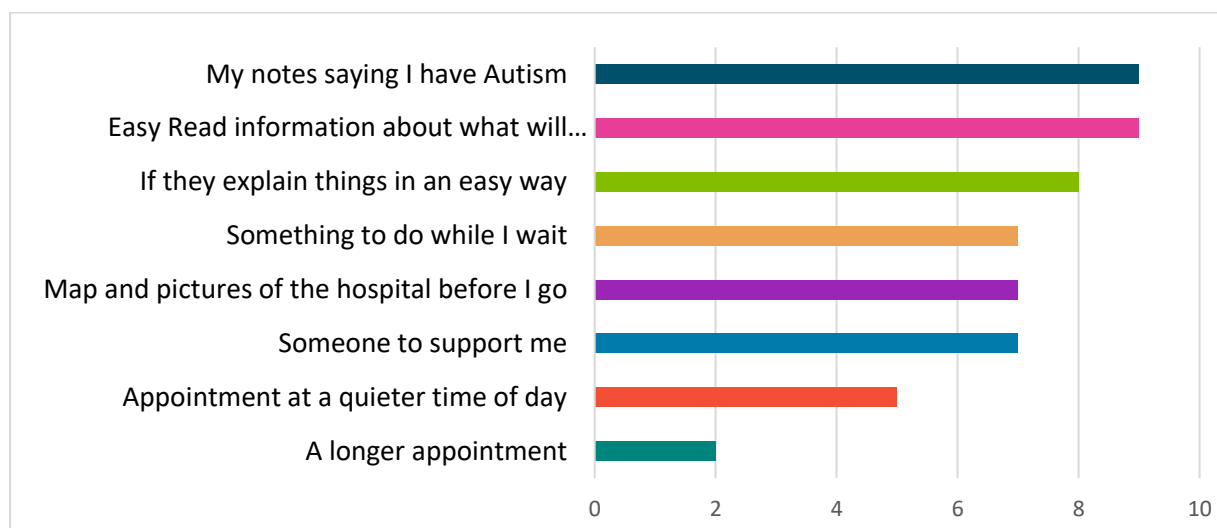
### 2.2 Going to the Hospital

Most of the children and young people said that they would feel anxious before an appointment at the hospital. Many also said they would find it difficult to get to the hospital and find the right department without support and that waiting would make them anxious.

'I would be scared'

'If I was on my own I would not cope'

## What would make it easier?



### **2.3 Support**

A number of children and young people said they had found going to a group for people with Autism helpful. Some also said they had had support at school, support to help with communication and support to find a job which was helpful. Responses to what other support would be helpful included support at school and employers who understand Autism.

## **3. Engagement and other feedback**

29 people with Autism Spectrum Conditions took part in engagement through group and individual discussions at ASPIE, NAS Companions Group and Bromsgrove District Housing Trust youth group.

The majority of the feedback given by groups and individuals we spoke to reiterated the feedback given in the surveys, about difficulties faced when going to the Doctors and the Hospital. Many of those who took part in group discussions felt that awareness of Autism was very important and that training for health professionals should include meeting and talking with people with Autism Spectrum Conditions.

Many of those who took part in group discussions told us how they valued attending the group, as an opportunity to go somewhere where they felt understood and to meet others with similar experiences.

Concerns were raised during group discussions about current waiting times for adult diagnosis, the experiences of those who had not received a diagnosis when they were younger and how this had impacted on their mental health, at work and in relationships. There were also examples given within the group of difficulties accessing mental health support and lack of understanding of Autism Spectrum Conditions amongst mental health services.

## Section C - Feedback from Carers of people with Autism Spectrum Conditions

We gathered feedback from parents and carers of people with Autism Spectrum Conditions about going to the Doctors, going to the Hospital, finding useful information, getting support for the person they care for and themselves and about the process of getting a diagnosis.

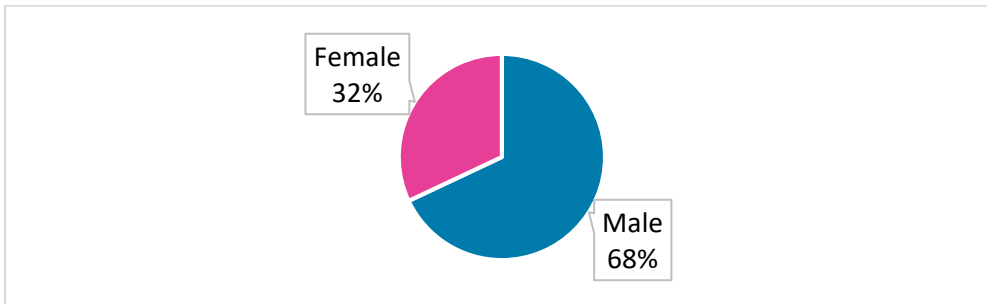
- 101 Carers completed our survey
- 40 Carers took part in group and individual discussions as part of our engagement.

### 4. Survey for Carers of people with Autism Spectrum Conditions

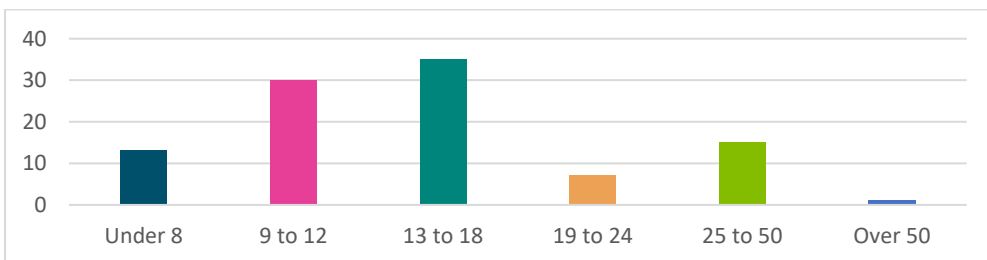
101 carers of people with Autism Spectrum Conditions completed our survey - 31 completed paper copies and 70 completed this online.

The majority (94%) of the carers were female and age between 25 and 50 (71%).

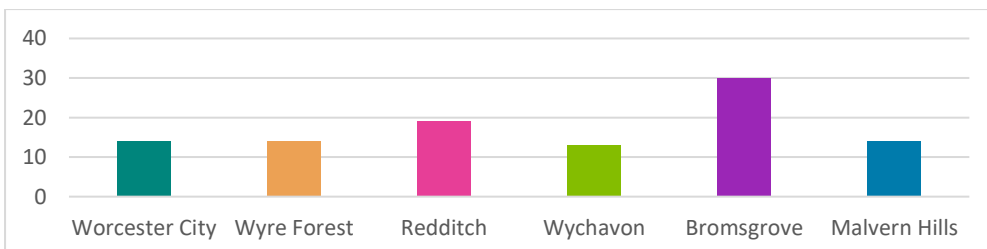
#### Gender of the person they care for:



#### Age of the person they care for:

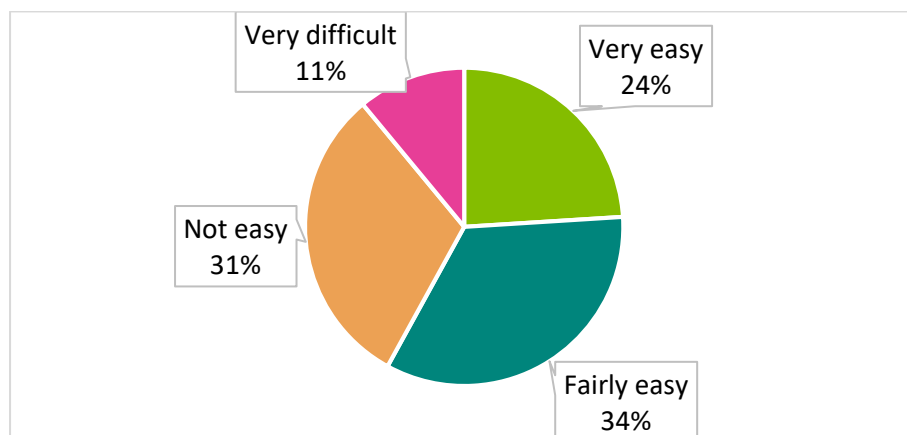


#### Where respondents live:



## Going to the Doctors

### 4.1. How easy do you find it to make an appointment at the Doctors for the person you care for?



#### **Additional Comments**

The reasons given for how easy people found it to book an appointment for the person they care for varied greatly. Many of the comments, both positive and negative, related to the availability of appointments and how easy they found it to use the particular system for booking appointments, such as use of a triage system. Particular issues raised included the ability to book appointments with a named GP and arranging appointments to enable the carer to provide support.

'I wish it was possible to make appointments in advance, rather than having to ring on the day for a phone call - it has to be made at a time when we are together, as he struggles to speak on the phone'

'I am trying to get consistency and a relationship between our child and the GP, this is impossible to implement'

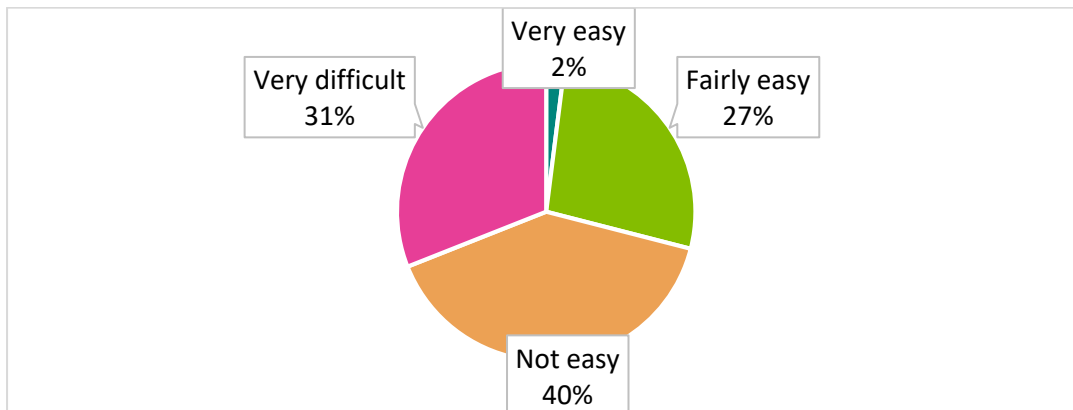
### 4.2. What would make it easier to make an appointment?

81% of carers said that they thought that it would be helpful to have something in their notes to say they have Autism, so that the receptionist can see this when making the appointment and make appropriate adjustments.

Some carers also commented that it is important for receptionists to have an understanding of Autism, so they can identify the need for flexibility with the booking system. For example, where possible: booking appointments in advance, having appointments with a named GP and arranging appointments when carer is able to provide support.



### 4.3. How easy does the person you care for find waiting to see a Doctor or Nurse?

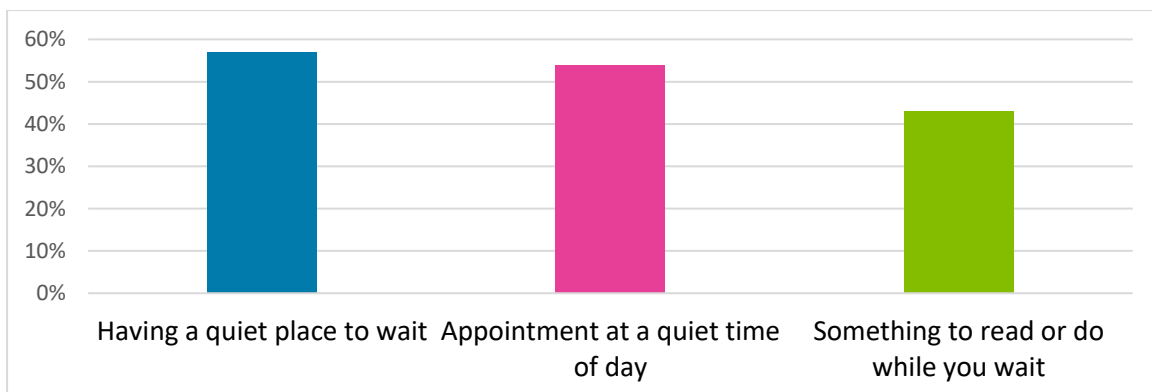


#### Additional Comments

Most carers told that the person they cared for found this difficult because they found waiting and / or sitting still very difficult. Sensory issues were also mentioned, such as the crowded and noisy environment. Other issues raised were related to the person's fears about hygiene or infection when sitting with others who are ill and the need for them to have something to fiddle with or do while they wait.

'People on the autistic spectrum crave routine and predictability. They are also highly anxious at all times. If they are told an appointment is at a certain time they cannot understand why they are not seen at that appointed time.'

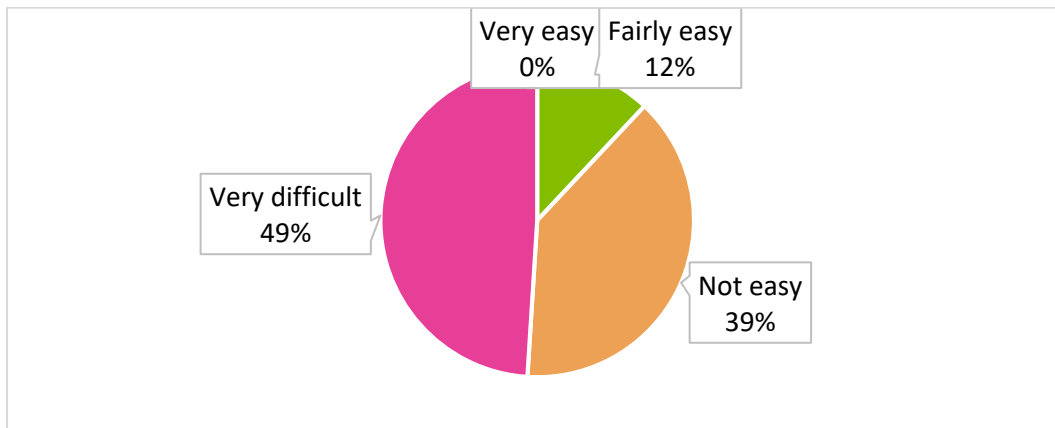
### 4.4. What would make waiting easier?



Additional comments suggested in addition to appointments running to time, that it would be helpful if they could be notified and / or updated about waiting times as this would help them to manage expectations and explain to the person the care for.

Suggestions about things to do while waiting included having something to fiddle with or interactive screens. Many carers said that they would bring an activity with them such as electronic games device or music with headphones.

#### 4.5. How easy do they find it to explain to the Doctor or Nurse about the reason for their visit?



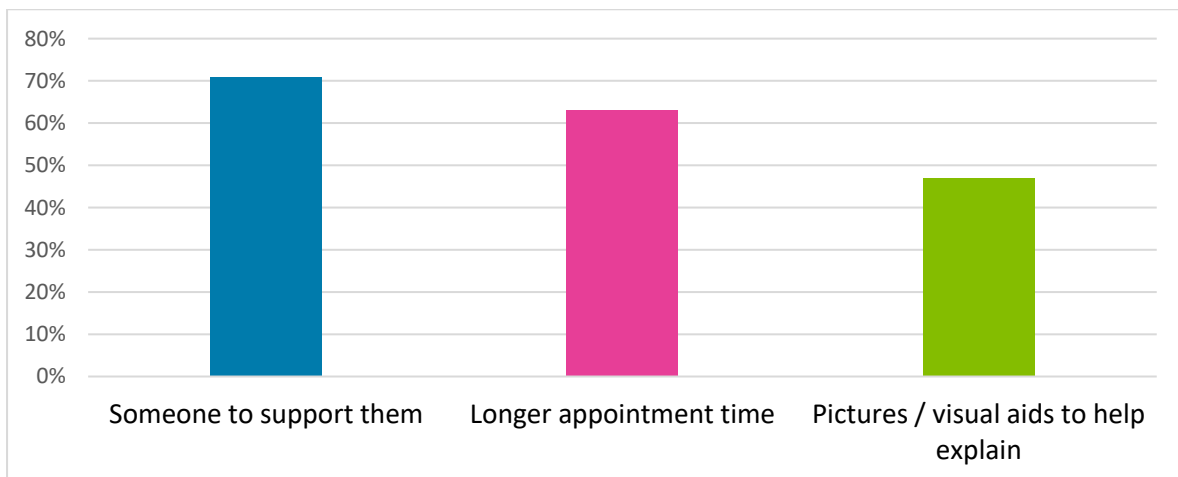
#### Additional Comments

Carers told us that this was due to difficulties in communication and explaining themselves, in some cases because they were non-verbal. Some said that this was also due to anxiety.

'He cannot easily express what his symptoms are, and would say something like 'I am not well', but will have to be asked specifically to explain why, and he can't always say if there is a pain, irritation, headache etc.'

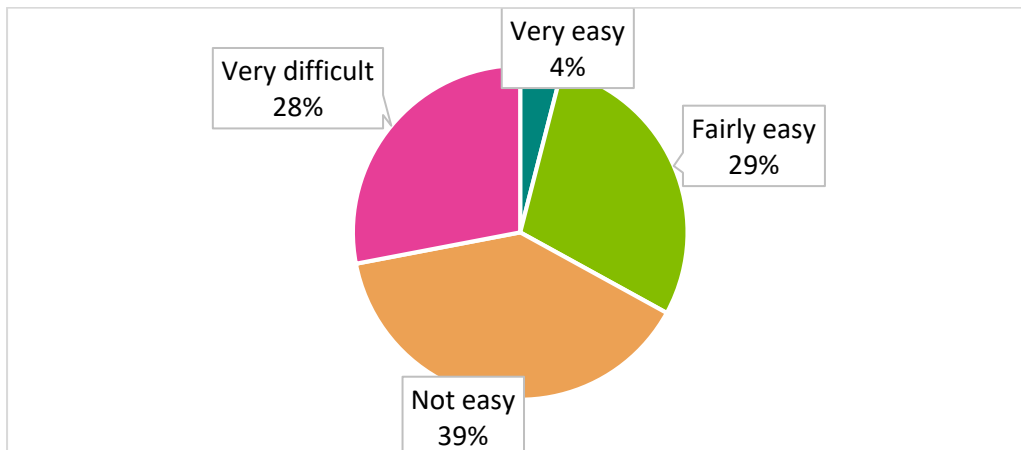
'If you have a person with order processing problems, understanding and then trying to answer the question can be very stressful.'

#### 4.6. What would make it easier to explain things to the Doctor or Nurse?



Additional comments suggested that some carers thought that being able to see the same Doctor or the Doctor taking time to make the person feel at ease, for example by asking about a special interest, would be helpful. Carers also said that the Doctor having an understanding of Autism is important.

#### 4.7. How easy do they find it to understand what they are told about treatment, medication or follow on care?



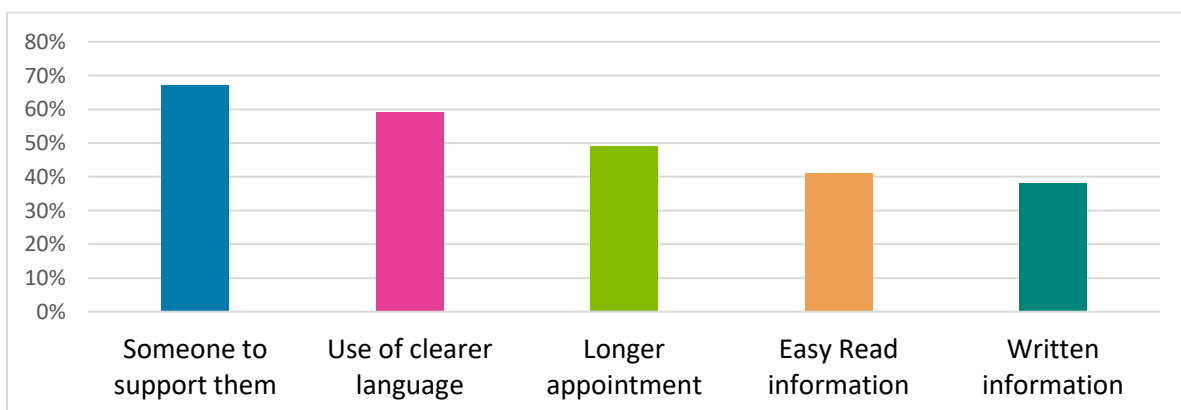
#### Additional Comments

Carers told us that this was mainly due to a difficulty understanding and processing verbal communication. They also said that the use of jargon made it more difficult and that communication needed to be simple and where possible written down. Some carers also told us that they would find it difficult to remember what they had been told or have a poor attention span to listen to the information being given.

‘The doctor, nurse and receptionist always use their own jargon. They often give too many instructions to follow, and they are given too quickly.’

‘Instructions need to be specific and broken down into manageable tasks. It takes longer for information to be processed.’

#### 4.8. What would help them to understand what they are being told?



Other suggestions included use of pictures and symbols and being able to see a Doctor that they know. Further comments about the language included not using figurative language and being aware that people with Autism prefer more clear and precise information as uncertainty and ‘grey areas’ can cause anxiety.

#### 4.9. Additional comments about going to the Doctors

The majority of additional comments made related to the importance of training and awareness of Autism Spectrum Conditions for GP practice staff, including medical staff and receptionists. Many suggested that it would be helpful to have a specialist or lead GP in each practice.

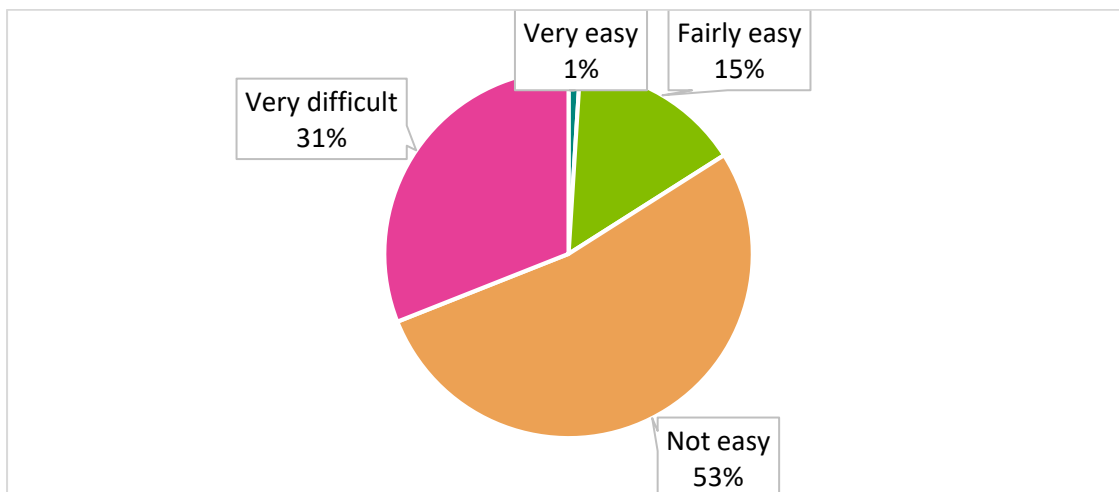
‘Why not have a GP at each practice that has a passion for the Spectrum and is the go to person.’

A number of carers also gave positive feedback about their GP practice.

‘We feel extremely fortunate that our surgery provides an excellent service: this includes both the reception team and the medical team.’

### Going to the Hospital

#### 4.10. How easy would the person you care for find it to prepare for an appointment at the hospital?



#### Additional Comments

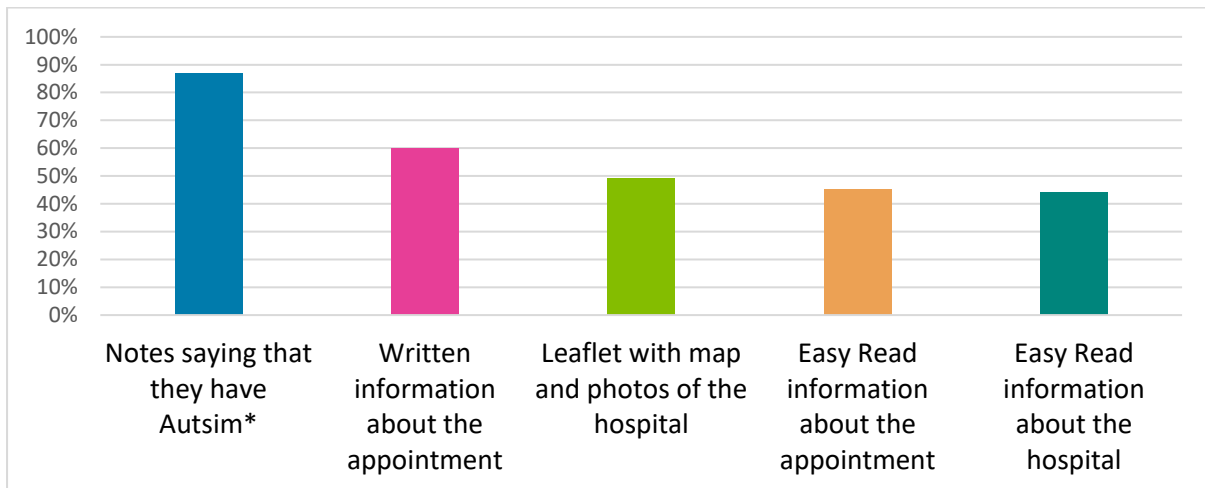
Carers told us this would be difficult due to anxiety and not knowing what to expect.

‘Anxiety goes through the roof’

‘Not being sure what is going to happen or going to an unusual place is distressing.’

‘Appointments always cause anxiety; we always discuss at length what the appointment might entail so there are no surprises. A picture of a waiting room etc would be helpful for people with Autism too.’

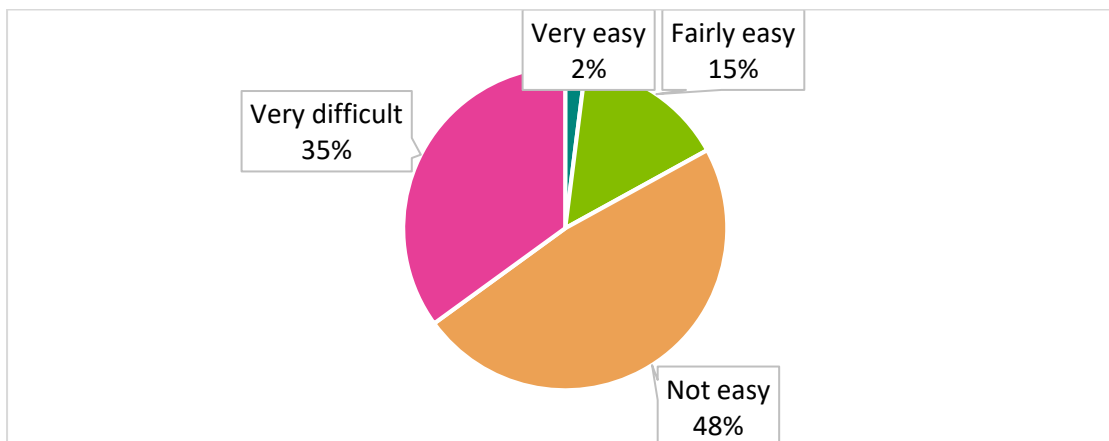
#### 4.11. What would help them to prepare for an appointment?



\*So that this can be taken into account when sending information and making adjustments for the appointment

Some carers also told us that they would use pictures or symbols to help them prepare for an appointment. One carer told us that a film about someone else having the same operation had been very helpful.

#### 4.12. How easy would the person you care for find waiting for an appointment at the hospital?



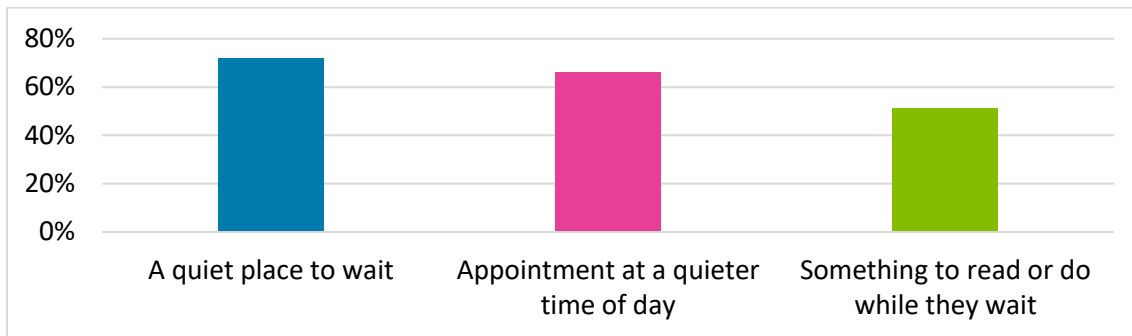
#### Additional Comments

Carers told us that this would be difficult due to difficulties waiting, especially if the appointment is delayed or it is unclear how long they may have to wait. Many also said that being in a crowded waiting room would be difficult due to noise and sensory overload and being in an unfamiliar environment.

‘Waiting especially in a crowded and noisy place for a long time is extremely stressful.’

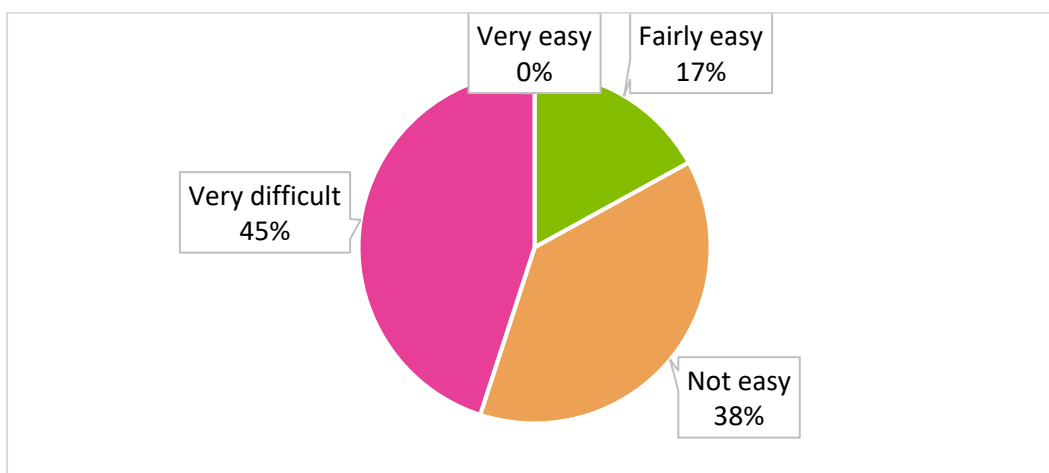
‘Noise, lighting, general sensory overload. Strange environment. New people. Unknown doctor.’

#### 4.13. What would make waiting easier?



Some carers also told us that being given information about how long they may have to wait when they arrive would be helpful. Suggestions for activities for people to do while they wait included having fiddle toys and a sensory room or space.

#### 4.14. How easy does the person you care for find it to explain things to the Doctor or Nurse?



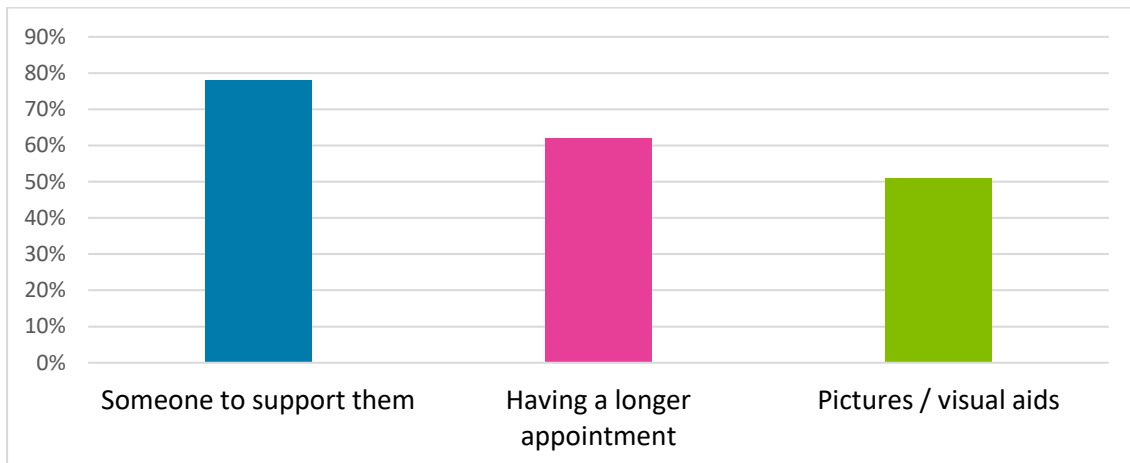
#### Additional Comments

The main reasons given by carers were communication difficulties and not being able to explain themselves. Others said that anxiety would be an issue and a lack of understanding about how much information and what information they should be giving to the Doctor.

‘Cannot find the words to explain themselves clearly.’

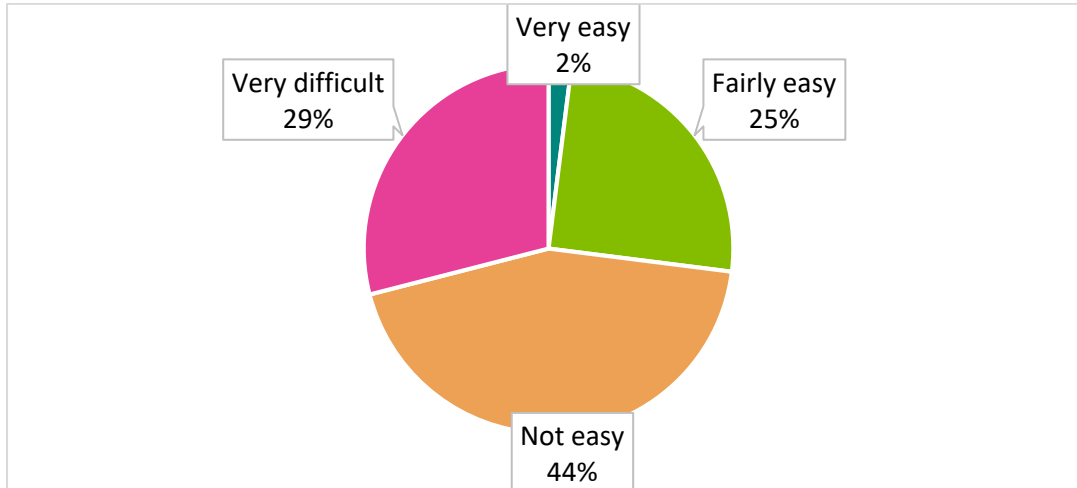
‘Not sure how to prioritise information, or how much detail is necessary to give initially and how much can wait for the doctor / nurse’s questions.’

#### 4.15. What would help them to explain things to a Doctor or Nurse?



Some carers said that the Doctor having an understanding of Autism and being patient would help. Other carers suggested understanding why as an adult someone may still want support at an appointment. A couple of carers mentioned that the person they cared for found it helpful to make some notes beforehand to help them to remember what to say at the appointment.

#### 4.16. How easy would they find it to understand what they are told about treatment, medication or follow on care?



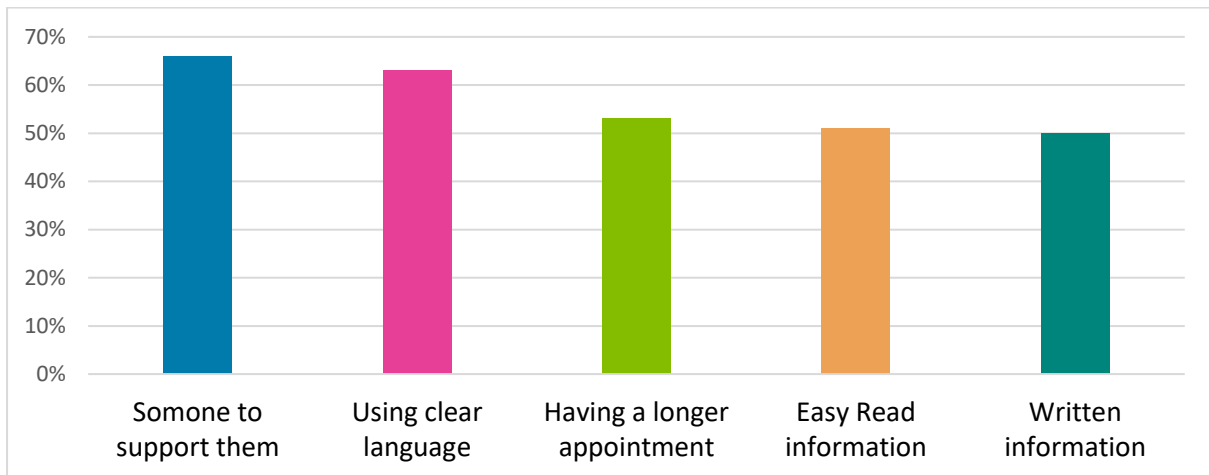
#### Additional Comments

Carers told us this was because they would find it difficult to understand the information and would need simple explanations, extra time, visual aids or written information.

‘A lot to take in in a pressured situation. Won’t ask the questions he needs until we are alone later.’

‘May not say anything at the time and doctors will assume they have understood.’

#### 4.17. What would help them to understand what they are being told?



A number of carers told us that the use of pictures and symbols would help as well as precise language.

‘No metaphors!!! Very precise and full description with clearly defined time scale.’

#### 4.18. Additional comments about going to the hospital

The majority of additional comments related to the need for staff to have an awareness and understanding of Autism Spectrum Conditions.

Other comments related to issues previously covered, such as the use of visual prompts and pictures, quieter areas to wait, understanding of anxiety and a flagging system to identify patients with Autism Spectrum Conditions. Another issue mentioned by a few carers, was anxiety caused by parking difficulties.

‘People not making quick judgements based on appearances.’

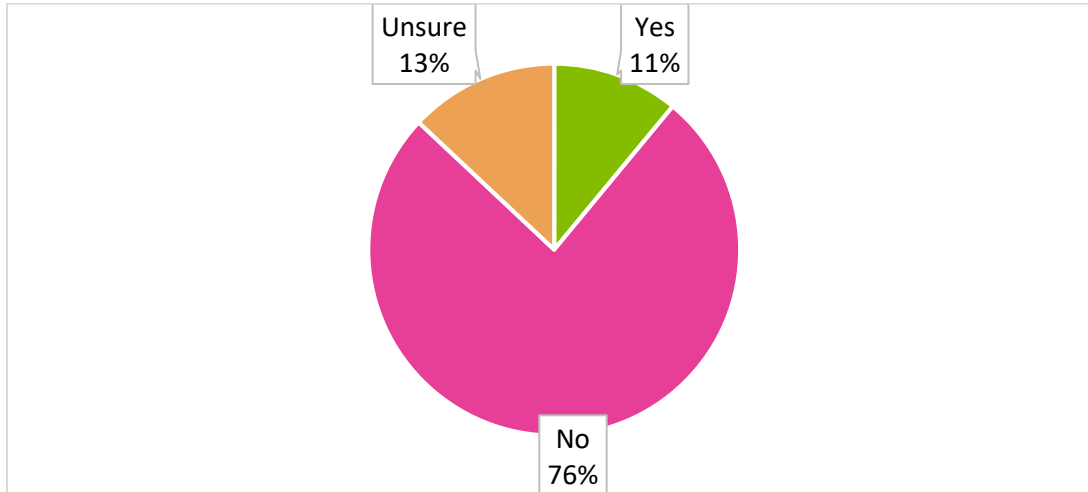
‘It would help if all hospital staff were trained in Autism awareness and for staff to remember that people on the autistic spectrum are wired differently, think differently and learn differently.’

‘Provide visual guides and explanations about procedures and visits. Also make sure that there is a bank of resources to keep children entertained to take their mind off the visit and alleviate anxiety.’



## Information about support and services

**4.19. Do you feel you have enough information about support and other services and groups available for people with an Autism Spectrum Condition and their carers?**



**4.20. What has been the most valuable?**

27 carers told us that support or social groups had been the most valuable information. Groups that were specifically mentioned were - Aspie, Autism West Midlands, Your Ideas, Rainbow Autism, Sky, What Makes You Different Makes You Beautiful and Little Stars.

Other responses given by more than one carer included - Paediatrician, online / Facebook group, information about social activities, school, and other parents.

Other responses were - family, friends, self-advocacy group, Portage service, diagnosis and Child and Adolescent Mental Health Service (CAMHS).

12 carers made negative comments in response to this question, stating that they had not received any information, that there is not much information available or that they had not received any useful information.

**4.21. What other information would you find useful?**

The highest response was information about support available. 30 carers said that they would like information about support including: support groups for people with Autism Spectrum Conditions, family and siblings, and support via helpline, specialist website or a dedicated Facebook page.

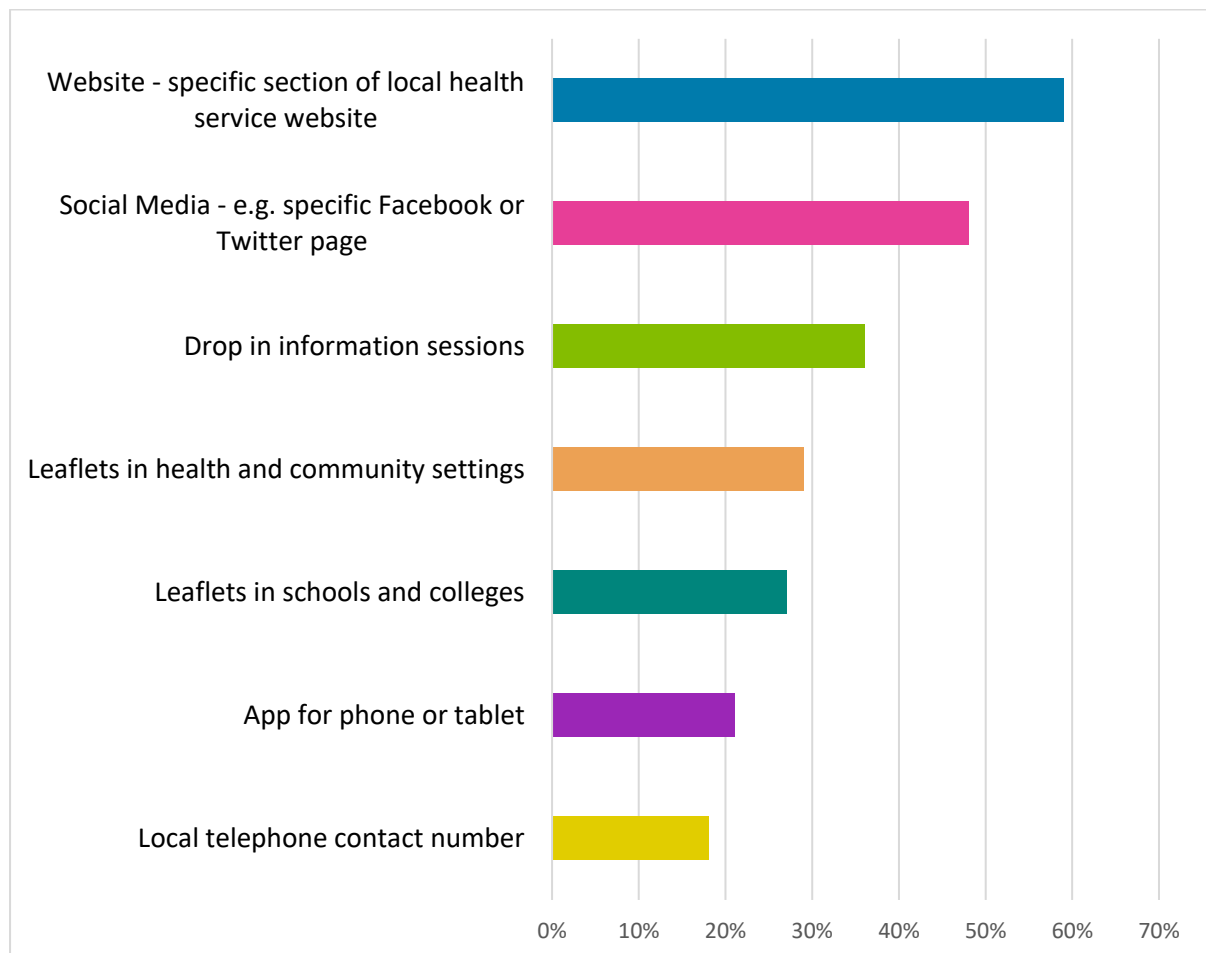
Other responses given by more than one carer included: information about specialists, especially in relation to mental health and available therapies; employment support; information about social events and activities to do in the

holidays and at weekends; a single point of contact for local information and relevant books and DVDs.

Other responses included information about sensory issues, overcoming social barriers, playgroups and general understanding of Autism.

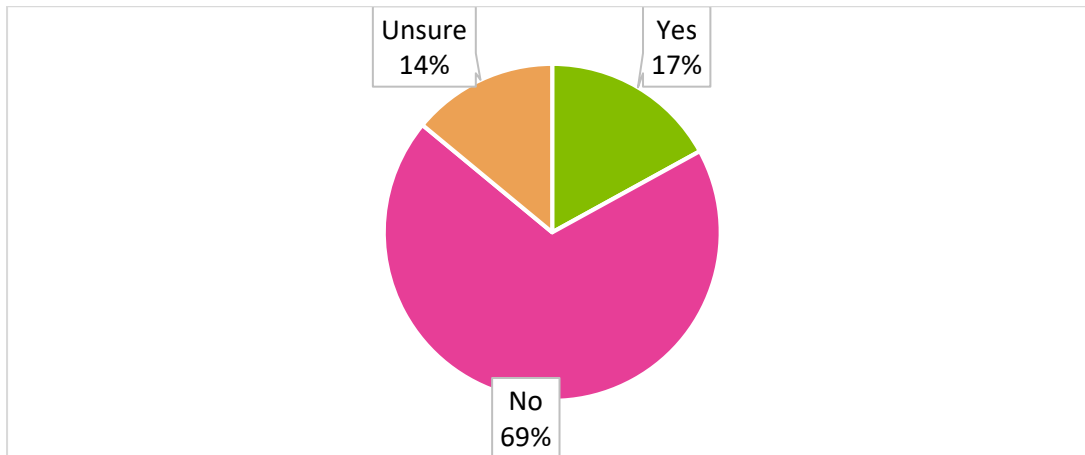
‘An informed single point of contact who could provide a reliable up-to-date list of services and activities explaining what they do, where they do it, who they do it for and how to contact them, preferably accompanied by Easy Read information.’

#### 4.22. Which of these would you find / have you found the most useful ways to access information about support and other services for people with an Autism Spectrum Condition?



## Support for people with Autism Spectrum Conditions and their carers

4.23. Overall, do you feel the person you care for receives the support that they need related to their Autism Spectrum Condition?



4.24. What support has been the most valuable?

15 carers told us that support at school, by teachers or from the School SENCO had been the most valuable.

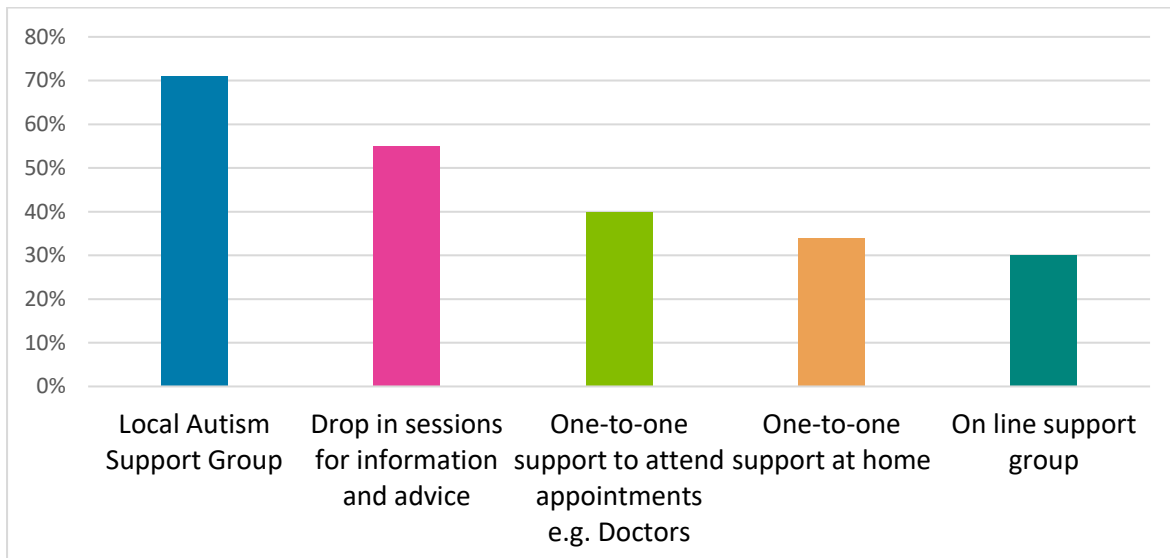
13 carers said that support from a support group, social group or charity had been most valuable, including: Aspie, Autism West Midlands, Your Ideas, Worcestershire Parent and Carer Community and What Makes You Different Makes You Beautiful. Carers told us that in addition to providing them with opportunities to socialise and gain peer support, this had helped them to develop their understanding of Autism.

Other responses given by more than one carer were - CAMHS, receiving direct payments for respite care, Paediatrician, GP, receiving early support when child at nursery and having a support worker.

Other responses given were: help getting work; private speech and language therapy; Portage service; Snoezelen; the Family Psychologist Service; support from Mentor Link; Autism and Me workshop for children by Autism West Midlands; and information sessions for parents previously run at Perdiswell by professionals giving understanding of Autism and suggestions for support.

12 of the responses to this question stated that either: they had not received any support; that any support received had not been appropriate as not Autism specific; or that support that had previously been available was not any more, either due to funding or transition to adult services.

#### 4.25. What other support would they find useful?



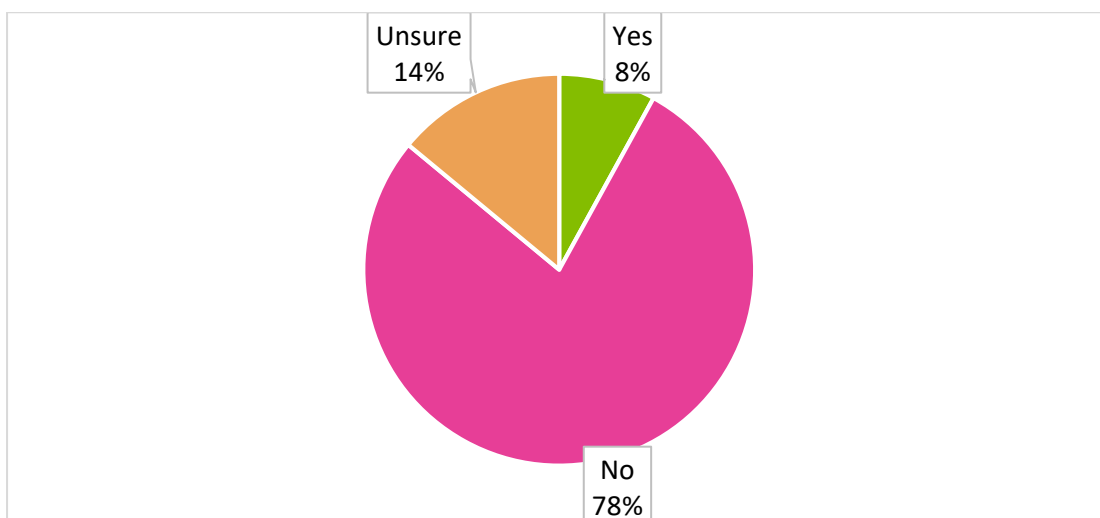
Other main areas carers felt that support was needed were -

- Support at school and planning for future education and training
- Life skills, developing independence and dealing with issues such as mental health and emotional wellbeing.
- Developing social skills and accessing social opportunities
- Employment

Other types of support included mentoring and a buddy system.

Further comments about Autism support groups included having groups that are more local, groups specific to Asperger Syndrome and groups for girls.

#### 4.26 As a Carer, do you feel you receive the support you need?



#### **4.27 What support has been most valuable?**

The most popular responses were support groups and clubs, other support received through voluntary organisations and talking to other parents, including on line such as Facebook.

Support from teachers was also valued by a number of carers, as well as support received from other professionals including: CAMHS, Adult Social Care Carer's Assessment, Paediatrician, GP, Family Support Worker, Social Worker and Worcestershire Association of Carers.

#### **4.28 What other support would you find useful?**

The majority of responses from carers said that they would find it useful to have access to family support, information and guidance via organised parent / carer groups or drop in sessions.

Many carers said that having access to mental health support and social care for the person they care for would be the most useful support for them.

Other support that carers would find useful were -

- Advice on transition, adult services and employment
- Advice on supporting with day-to-day tasks and life skills
- Support worker to help child access activities outside of school
- Updates from professionals involved, such as school / advocacy support

A few of the carers told us that they would benefit from one-to-one emotional support or mental health support. Some also said that support that enabled them time to themselves or to manage better financially would also be helpful.

### **Diagnosis**

30 carers told us that the person they care for had received a diagnosis in the last 3 years.

- 21 children had received a diagnosis via the Umbrella Pathway
- 7 adults had received a diagnosis from the Family Psychologist Service

2 had paid to have a diagnosis privately due to waiting times

## **4.29 Umbrella Pathway**

### **Satisfaction with time taken for diagnosis -**

The majority of the carers rated the time taken as either poor or very poor. Many commented that the process as a whole, including referral to the pathway had taken many years and some felt there was a reluctance to refer to the pathway in the first place. A few commented that they had been forgotten during the process or had to chase up progress made.

### **Information and support to understand diagnosis -**

Three carers rated this as good and five as ok. The remaining 12 rated it as poor or very poor. The majority of additional comments stated that they had not received any information, while a few said they had been given a leaflet or a letter.

## **4.30 Family Psychologist Service**

Feedback about the waiting time for a diagnosis was mainly rated as poor or very poor. Information and support to understand diagnosis was generally rated as good or ok. Comments showed that the one-to-one sessions following diagnosis were valued, although some felt that the number of sessions was too limited and that further sessions would be useful.

## **Additional Feedback**

### **4.31 Do you have any other feedback about health and care services for people with Autism Spectrum Conditions and their Carers?**

15 carers made additional comments about the lack availability of support, need for additional services, lack of funding for services or the need for better planning and joint working between services.

10 carers raised concerns about mental health services. This included the lack of mental health support available, the lack of understanding within mental health services of Autism and people with Autism Spectrum Conditions being excluded from receiving mental health support, by CAMHS in particular. Some also commented about the need for mental health support for parents and carers, due to the difficulties supporting someone with Autism Spectrum Conditions experiencing mental health difficulties.

Other issues raised included the need for: a greater understanding of Autism Spectrum Conditions, both generally and within services; better access to information and advice; quicker diagnosis and support for parents.

## 5. Engagement and other feedback from Carers

40 Carers took part in group and one-to-one discussions as part of our engagement, which included visiting a number of support groups.

Feedback at these groups reflected feedback given via the survey about difficulties people with Autism Spectrum Conditions experience when going to the Doctors and the Hospital; and accessing information and support.

Issues that were specifically raised as concerns by parents and carers of children with Autism Spectrum Conditions were: difficulties and delays with diagnosis process; accessing appropriate support at school and getting the school to recognise the needs of children with Autism; accessing emotional wellbeing and mental health support for their children.

Issues that were specifically raised by parents and carers of adults with Autism Spectrum Conditions were: concerns about their lack of employment and / or social activity and the impact of this on their mental health and wellbeing; lack of services for adults with Autism Spectrum Condition and mental health support; the impact of not receiving a diagnosis in some cases as a child and therefore the individual having a limited acceptance, understanding and awareness.

Many carers spoke about the impact on their own mental health of caring for someone with Autism and how this was at times a real struggle. Many valued the opportunity to attend a support group and talk to others who shared similar experiences.

## Section D

### Feedback from Health Services about Autism Spectrum Conditions

We requested feedback about the levels of awareness and training of Autism Spectrum Conditions amongst staff and any adjustments they make to support patients with Autism Spectrum Conditions from -

- GP Practices
- Worcestershire Acute Trust
- Worcestershire Health and Care Trust
- Care UK
- West Midlands Ambulance Service

#### 6. GP Practice Questionnaires

All 65 GP Practices in Worcestershire were sent a questionnaire in May 2017 requesting feedback about awareness of Autism Spectrum Conditions and any specific adjustments made within their practices. We also wanted to find out about awareness of an information pack for GPs - 'Autism: A Guide for GPs and Professionals in Worcestershire' developed and distributed by the Autism Strategic Partnership Board. A copy of the guide was sent to practices with the request.

17 practices responded to this initial request. A further request was sent to practices in November 2017. In total 30 GP Practices responded to our request.

##### **6.1. Were you previously aware of Autism: A Guide for GPs and Professionals in Worcestershire?**

Of the 30 practices who sent a response only 9 responded that they had previously received the guide. Although two suggest that they were confirming they had received the guide from Healthwatch Worcestershire as part of our earlier request, rather than the initial distribution. Additional comments, made by several of those who said they had not received the guide, suggested that it may have been missed due to the volume of information received by practices.

##### **6.2. How has the guide been cascaded and distributed throughout your practice?**

15 practices told us that they had distributed the guide to staff in the practice either by email, their own intranet network, through discussion at staff meetings and in one case by adding it to their accessible resource box for learning disabilities.



### 6.3. How has this had an impact on how staff support patients with Autism Spectrum Conditions?

Most responses to this question suggested it was too early to say as they had only just distributed it, following our communication. However, comments suggested they felt it was a valuable resource and would provide an increased awareness:

‘The guide provided useful information especially in the contact list at the back, we added some of these to our website’

‘It has been a useful reminder on a number of issues relating to autism (e.g. about autism friendly conversations)’

One practice gave examples of adjustments made for patients as a result of receiving the guide.

### 6.4. Have you received any information from other sources about Autism Spectrum Conditions? If so, where from?

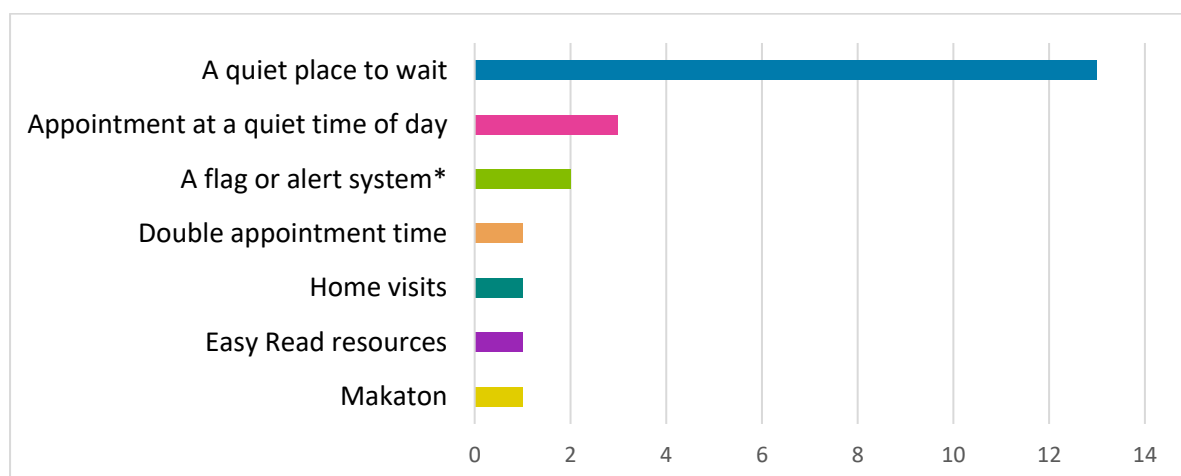
6 practices told us they had received information from other sources, which included:

- National Awareness Week
- NAS website page [www.autism.org.uk/gp](http://www.autism.org.uk/gp)
- Working with a local care home and the Psychologist who works with their residents
- Via the Learning Disability Link Nurse

Receiving information about the Umbrella Pathway and more general Autism information was also mentioned.

### 6.5. Can you give any examples of how your service has made reasonable adjustments for patients with Autism Spectrum Conditions?

Of the 22 practices who responded to this question, 16 gave examples of adjustments they make for patients with Autism Spectrum Conditions.



\*so they are aware if they have Autism

In addition, one practice has a dedicated learning disability receptionist who contacts patients to make sure they have the appropriate information in the appropriate format. Another practice said they are currently working on signage within the practice to make this clearer

Of the practices that did not give examples, some said they did not make any specific adjustments or had not done so yet. Two said they would make adjustments based on individual needs.

One practice stated that ‘this is a stigma on a patient and its inappropriate.’

#### **6.6. Do you feel staff within your service have enough information about how to signpost adults and children who may require a diagnosis or support around Autism Spectrum Conditions?**

- 12 practices - Yes
- 7 practices - No
- 3 practices - More would be helpful

Four additional comments expressed concerns about the local provision for diagnosis and waiting times. One of these also commented about the limited support available for adults with Autism Spectrum Conditions.

One practice suggested ‘a one sheet page of contact details of local NHS and voluntary providers’.

One practice felt that they had developed a good understanding of Autism due to the close links with a residential care home and their residents with Autism who are patients at the practice.

#### **7. Please give any further information about training or specialism in Autism Spectrum Conditions undertaken by any of your staff**

16 practices responded to this question.

Two practices felt that the close links they had with residential services for people with an Autism Spectrum Conditions in their area had helped them to develop an understating of Autism and provide appropriate support for patients.

‘We co-produced a photo staff guide for the home to use ahead of appointments or visits from GP’.

One practice told us about the use of a flagging system:

‘As these service users are flagged on the clinical system, we are able to monitor their use of our services and we try to adapt to make it less stressful. All staff have an awareness and are trained in these areas’

Three practices said that their staff had received training from the Learning Disability Nurse.

One practice said that in addition they provided regular training for staff about dealing with vulnerable and anxious patients. Another practice told us that they had accessed online training.

One practice told us that they had a member of staff who took a lead in Autism Spectrum Conditions:

‘Our advanced nurse practitioner has a specialist interest and other clinicians can seek her advice and patients can be directed to her.’

10 of those that responded said they had received no training about Autism Spectrum Conditions.

### **In summary**

The responses to the questionnaire for GP practices shows examples of adjustments that are being made by GP practices for patients with Autism and the use of systems such as having a flag on patient notes. It shows the benefits practices have found of working closely with local care providers to develop their understanding of Autism and support patients. It has also highlighted resources that they have found helpful, such as the guide for GPs and professionals, online resources and a member of staff with a particular expertise in this area.

However, the response rate and the feedback from practices suggests a variation in the awareness of Autism Spectrum Conditions amongst practices in Worcestershire. It suggests that there are no specific training requirements for GP practice staff and that many have not undertaken any training. It also suggests that many practices do not currently make any adjustments to support patients with Autism Spectrum Conditions and there is not a requirement for them to undertake this.

## **7. Worcestershire Acute Hospital Trust Response**

We requested a response to our questionnaire about Autism awareness and adjustments made from departments within the Worcestershire Acute Hospital Trust. We received 11 completed questionnaires.

We asked about the information, training or resources that staff had used to access information about Autism Spectrum Conditions.

### **7.1 Autism Awareness and Training**

It appears it is not currently mandatory for staff across the Acute Trust to undertake any training or awareness of Autism Spectrum Conditions.

Only about half of the respondents to our questionnaire felt that any staff in their departments had received any training or information about Autism. Two respondents said that they had received training from the Learning Disability Liaison team. The others who said they had an awareness or training said this was due to their personal experiences or training in a previous role working for another organisation. In one case awareness training had been provided to staff to help them to provide support to a member of staff.

### **7.2 Examples of adjustments made for patients with Autism Spectrum Conditions**

Examples were given about trying to reduce waiting times for patients where possible, offering a quiet place to wait or giving appointments at a quieter time of day. Many who responded said that although they didn't currently offer these, they felt it was something they could do in the future. Although one response said that it may be difficult at times to be able to offer a quiet place to wait.

One example given was trying to use simple language and explain the sequence of events. Another department has been trying to get different visual appointment letters produced.

### **7.3 What additional information, training and resources would be helpful?**

All of the respondents said that training about Autism Spectrum Conditions would be helpful. Many said that it would be useful to have specific training about Autism in addition to current training given on Learning Disabilities. Some felt that this should be part of Trust induction or as a mandatory refresher. Awareness sessions for volunteers was also suggested.

Some of the responses also said that more resources such as information to give to patients, for example, about tests and procedures would be helpful.

The importance of having an understanding of patients' needs in advanced was raised, both by increasing awareness of Hospital Passports and receiving information as part of a referral.

## **8. Worcestershire Health and Care Trust**

We requested a response to our questionnaire about Autism awareness and adjustments made from departments within the Worcestershire Health and Care Trust. We received 9 completed questionnaires, including: four from departments within Adult Mental Health and Learning Disabilities, one from Children, Young People and Families, three from Specialist Primary Care and one on behalf of Community Services.

We asked about the information, training or resources that staff had used to access information about Autism Spectrum Conditions.

### **8.1 Autism Awareness and Training**

Responses showed that there is not a mandatory requirement for all staff across the Trust to undertake Autism Awareness Training. There is not currently any specific training offered by the Trust about Autism. Previously some training about Autism had been delivered within the Trust by a Psychologist who has now left the Trust.

The levels of awareness and training completed varied depending on the departments and areas of speciality. Responses from teams within the Adult Mental Health and Children, Young People and Families told us that for some of the roles, having an understanding of Autism is core to their role and would have been covered as part of staff training.

Staff within the Learning Disabilities team are encouraged to attend the one-day Autism Awareness Training delivered by Worcestershire County Council. This is now included as part of their induction training. Feedback suggests that this has been useful, but that more in depth training would be helpful.

Other teams within Mental Health and Learning Disabilities gave examples of awareness including: organising in house training and updates by a specialist nurse, having an Autism champion who provides the team with updates and attending relevant external events. A number of examples were also given about online resources being used, such as the NAS website and E-learning courses on Autism.

## **8.2 Examples of adjustments made for patients with Autism Spectrum Conditions**

The specialist teams were able to give a number of examples about how they adapt their service to meet the needs of people with Autism Spectrum Conditions. This included: initial visits being arranged for a familiar environment, using specialised software to provide visual support, use of social stories, Easy Read documents, adjusting times of visits and support from Learning Disabilities Community Nurses to help prepare people prior to medical procedures.

Responses from the Community Services and Specialist Primary Care suggested that some teams were aware of how to access Easy Read information and that they would try to make adjustments to environment and communication where possible. But that in some cases opportunity to do this may be limited, e.g. providing a quiet place to wait.

## **8.3 What additional information, training and resources would be helpful?**

Responses suggest that access to further training and information about Autism Spectrum Conditions would be beneficial, especially within more general services, where respondents felt there was not such a good understanding.

Some felt that it would be helpful to have information about supporting people with Autism in their specific service and feedback and experiences from people with Autism, for example Dentist and Sexual Health services.

The idea of having official Autism Champions, both for each Service Delivery Unit and within departments was suggested.

An additional comment also suggested that previously a Consultant Clinical Psychologist had taken a lead on work around Autism, both at a strategic level and providing support for people with Autism and their families and that now they had left, this had left a gap within the Trust.

## **9. Care UK**

Care UK provide NHS 111 service and Out of Hours GP service in Worcestershire. We requested feedback from them about levels of awareness of Autism and any adjustments their services had made.

They were not aware of any specific training that is provided or available to staff currently. They did say that this is something they felt is needed and they would like to look into. They felt this was especially important due to the nature of the services, they are dealing with many patients that they have no prior knowledge of. They would be grateful for any further information and resources.

Some staff had received a talk from the mother of a patient with Autism who had experienced difficulties when accessing their service. They try to make a 'special note' on patients' notes when they are aware that they have Autism. They also told us they would offer a quiet place to wait where possible.

## 10. West Midlands Ambulance Service

We requested feedback from West Midlands Ambulance Service about the availability of Autism training or awareness for staff and adjustments made for patients with Autism.

They told us that although there was no mandatory requirement for Paramedic staff to complete training on Autism, a number of resources are available for staff Continuing Professional Development. They provide a link to an awareness film created by Staffordshire Council and call takers have an on-line training and awareness of Autism Spectrum Conditions.

Staff have access to the Health Education England e-Learning for Health website, which contains many e-learning resources. Some of these relate specifically to Autism.

- Autistic Spectrum Disorders
- Supporting Autism Spectrum Disorder
- Introduction to Autism Spectrum Disorder
- Autism Spectrum Matters
- Autism and Related Problems

They are unable to provide numbers of how many staff have completed the online training or accessed the resources or give any specific examples of how adjustments are made for patients with Autism Spectrum Conditions.

## Section 5

### Conclusions and Recommendations

The following recommendations are made based on the findings of our work on Autism Spectrum Conditions, in relation to the priorities within the Worcestershire All Age Autism Strategy.

#### i. Diagnosis, Information and Support

*Priority 1: We will have a clear pathway for diagnosis and support for children, young people and autism spectrum conditions.*

*Priority 8: We will promote the use of support groups in local communities and ensure they can access information about services that are available*

#### Diagnosis Pathways

Feedback suggests that in some cases, children, young people and adults have experienced long waits for diagnosis. Many felt that they did not receive adequate information about the process for diagnosis and adequate information to understand the diagnosis or what support would be available following diagnosis.

A review of the Umbrella Pathway has recently been carried out, by Worcestershire County Council, which included gathering feedback from parents and producing revised information. Similar work has been done to look at developing and distributing the information available to GP practices and individuals about the pathway for adult diagnosis.

#### Recommendations:

- Commissioners to continue to work with providers to monitor waiting times for diagnosis via the Umbrella Pathway and Adult Diagnosis Service and where possible identify opportunities to increase capacity to reduce waiting times.
- Consider how monitoring will be carried out to ensure that revised information about referral and diagnosis pathways and support available is passed on to individuals, carers and relevant health professionals e.g. GP practices.
- Ensure that people with Autism Spectrum Conditions and carers are involved in giving feedback about their experiences of referral and diagnosis pathways, information received and future development.



## Accessing Information

Our findings suggest that people with Autism Spectrum Conditions and their carers did not feel they had been provided with enough information about support and services available and were unsure where to find this information.

### **Recommendations:**

- Ensure that comprehensive and up to date information is available about the statutory and voluntary services and support available for people with Autism Spectrum Conditions and their carers.
- Consider use of a specific website or section of website to provide information about services and support.
- Consider use of social media e.g. specific Facebook and / or Twitter pages to promote information about services and support and where to find further information.
- Consider if any of the following methods could also be used to promote information about services and support -
  - Drop in information sessions
  - Leaflets in health and community settings
  - Leaflets in schools and colleges
  - App for phones and tablets
  - Local telephone contact number
- Consider if further information can be made available about -
  - Developing understanding of Autism Spectrum Conditions and strategies for support, in particular around sensory issues and developing social and communication skills
  - Support and advice for partners, families and siblings
  - Mental health support and other available therapies
  - Gaining employment and employment support
  - Social activities and events

## **Support**

Our findings also suggest that on the whole people with Autism Spectrum Conditions and their carers do not feel that they currently receive the level of support that they need in relation to their Autism Spectrum Condition or their caring role. In particular a need for appropriate mental health support was identified.

### **Recommendations:**

- Consider how to increase provision and access to Local Autism support groups for people with Autism Spectrum Conditions and carers across all areas of Worcestershire.
  
- Consider if there is scope to establish or increase provision and access for people with Autism Spectrum Conditions to
  - Drop in sessions for support and advice
  - One-to-one support with day to day tasks
  - Online support groups
  - One-to-one support with attending appointments e.g. GP practices, Hospitals
  - Support in education and planning for future education and training
  - Employment support
  - Support to develop social skills and access social opportunities
  - A mentoring or buddy system.
  
- Consider if there is scope to establish or increase provision and access for Carers of people with Autism Spectrum Conditions to
  - Drop in sessions for support and advice
  - Online support groups
  - Advice about transition, adult services, employment and supporting with day to day tasks and life skills.

## ii. Understanding and awareness of Autism Spectrum Conditions

*Priority 2: We will identify gaps in knowledge and understanding and make sure that all organisations can access high quality awareness raising and training*

Our findings show that there is variation in the awareness and provision for training across health services in Worcestershire. Although some staff, in particular those whose roles have a learning disability or mental health focus, have received training, there does not appear to be a mandatory expectation that staff will undergo training across universal services.

Some health services have identified useful sources of information and benefitted from individuals' experience and specialist knowledge. This has enabled them to provide appropriate support and adjustments to patients. Others felt that there is a need to raise awareness amongst staff and welcomed further training and information.

Feedback from people with Autism Spectrum Conditions and their carers suggests the importance of all staff within services having an awareness and the positive impact this has made to individuals and their care.

### Recommendations:

- Ensure all health care providers in Worcestershire have an understanding and demonstrate a commitment to the vision of the All Age Autism Strategy.
- Review and adapt *Autism: A Guide for GPs and Professionals in Worcestershire* to include feedback from people with Autism Spectrum Conditions and carers and the recommendations reported in this report - *Healthwatch Worcestershire Autism Spectrum Conditions Report March 2018*.
- Following review and adaptation of *Autism: A Guide for GPs and Professionals in Worcestershire*, reissue to all GP practices in Worcestershire, to ensure they are aware of feedback and recommendations made in this report.
- Consider distribution of *Autism: A Guide for GPs and Professionals in Worcestershire* to other health services in Worcestershire, including Worcestershire Acute Hospital Trust, Worcestershire Health and Care Trust, Care UK and West Midlands Ambulance Service.
- Identify and promote training and awareness opportunities to GP practices, Worcestershire Acute Hospital Trust and Worcestershire Health and Care Trust.

- Consider how to encourage and gain commitment from GP practices, Worcestershire Acute Hospital Trust and Worcestershire Health and Care Trust to provide Autism Awareness training for staff.
- Consider identifying champions within GP practices and departments within Worcestershire Acute Hospital Trust and Worcestershire Health and Care Trust, with existing knowledge or willingness to undertake training to provide a point of contact for other staff when supporting patients with Autism Spectrum Conditions and their carers.

### iii. Access to health services

*Priority 5: We will make sure that children, young people and adults with autism spectrum conditions have access to all universal and health and social care services.*

#### Going to the Doctors

Responses to the surveys for people with Autism Spectrum Conditions and their carers suggest that people with Autism Spectrum Conditions experience difficulties when going to the Doctors with making appointments, waiting to see the Doctor and communication during appointments. In particular they find it difficult to explain to the Doctor or nurse about the reason for their visit.

Responses to our GP practice questionnaire showed that some practices are already making adjustments to support patients with Autism Spectrum Conditions, which could be implemented in other practices.

#### **Recommendations**

GP practices should consider:

- Ensuring all staff, including reception staff, have an updated knowledge of Autism Spectrum Conditions via access to training and appropriate information and resources.
- In particular, that staff have an understanding of the importance of using clear language, avoiding the use of jargon and figurative language and allowing time to process information and check understanding.
- Using a flagging system to enable staff to see that patients have a diagnosis of Autism so appropriate adjustments can be made.

- How to enable patients with Autism Spectrum Conditions to have appropriate support to attend appointments where possible. For example, booking appointments at a time a carer is available.
- Offering appointments at a quieter time of day.
- Offering longer appointment times.
- Offering a quiet place to wait.
- Providing patients with information about the expected waiting time for their appointment.
- Providing activities for a variety of age groups in the waiting area, if possible to include fiddle toys and sensory items.
- Providing patients with written and / or Easy Read information about visiting the practice and diagnosis, treatment and follow on care required.

### **Going to the Hospital**

Responses suggest that people with Autism Spectrum Conditions have difficulty when going to the hospital with remembering and getting to appointments, waiting for their appointment and communicating during appointments, in particular explaining themselves to the Doctor or Nurse.

### **Recommendations:**

The Worcestershire Acute Hospital Trust and Worcestershire Health and Care Trust should consider -

- Ensuring all staff, including reception staff, have an updated knowledge of Autism Spectrum Conditions, via access to training and appropriate information and resources.
- In particular, that staff have an understanding of the importance of using clear language, avoiding the use of jargon and figurative language and allowing time to process information and check understanding.
- Flagging system to enable staff to see that patients have a diagnosis of Autism so appropriate adjustments can be made.
- How to enable patients with Autism Spectrum Conditions to have appropriate support to attend appointments where possible, for example, booking appointments at a time a carer is available.
- If reminders, such as a text message can be sent to patients prior to their appointment.
- Sending written and Easy Read information to patients in advance about the Hospital, the purpose of the visit and what will happen at the appointment.

- Offering appointments at a quieter time of day.
- Offering longer appointment times.
- Offering a quiet place to wait.
- Providing patients with information about the expected waiting time for their appointment.
- Providing activities for a variety of age groups in the waiting area, if possible to include fiddle toys and sensory items.
- Providing patients with written and / or Easy Read information about visiting the hospital and diagnosis, treatment, procedures and follow on care required.
- Providing visual resources to help aid communication during appointments.

### **Access to Mental Health Services**

- Consider reviewing if there is currently adequate access to mental health support for people with Autism Spectrum Conditions and their Carers.