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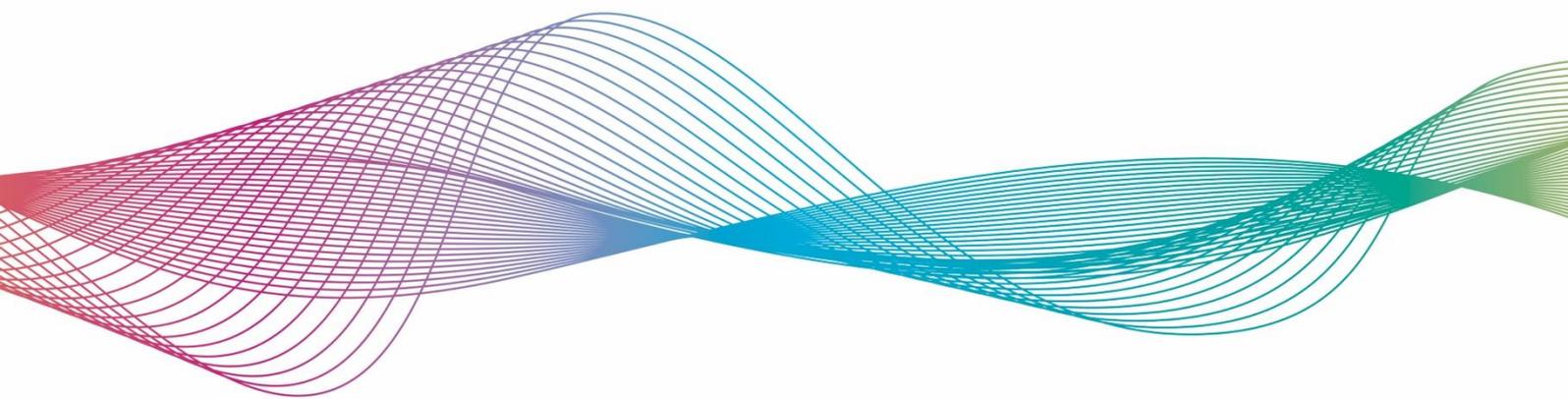


Midlands and Lancashire
Commissioning Support Unit

Autism Spectrum Disorder (ASD) Services

Report of findings

August 2019



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1 Background and Introduction

This report of findings presents the feedback from the Autism Spectrum Condition (ASD) engagement survey between 15 May and 31 July 2019.

1.1 Introduction

The current contract for Autism Spectrum Condition (ASC) services in southern Staffordshire is due to end on 30 September 2019. To comply with the law around NHS contracts, the local CCGs must award a new contract to provide the service and invite potential providers to bid.

Cannock Chase, East Staffordshire, South East Staffordshire and Seisdon Peninsula and Stafford and Surrounds CCGs asked patients to complete a survey exploring their experiences of Autism services. The evidence from this survey will help shape the future of this service.

The online survey was live from Wednesday 15th May 2019 until Wednesday 31st July 2019. There was a total of 136 responses to the survey.

2 Communications and engagement

The CCGs engaged with parents, carers and families about the appropriate method of engagement to undertake. To try to reach as many families as possible, it was agreed to use a combination of an online survey that could be shared virtually through channels such as social media groups and hardcopies that could be shared face to face.

The questionnaire was developed with input from parents, carers, families and staff and shared across a range of channels including the CCG websites, social media, patient forums, service user support groups and the local media.

The CCGs engaged with the community and voluntary sector, including existing service user support groups, to run face-to-face engagement sessions following the same format as the online survey to ensure the feedback being collected was comparable. Face to face engagement sessions were also held with children and young people who use the existing service, although these were tailored to meet the needs of those involved and the feedback collated in a separate report.

The following face-to-face engagement events were held across the four CCG areas:

Date	Time of day	Location	Target audience
Thursday 16 May	AM	Rugeley	All
Friday 17 May	AM	Stafford	All
Wednesday 22 May	PM	Stafford	All
Thursday 23 May	PM	Burntwood	All
Thursday 30 May	PM	Burntwood	Children
Thursday 6 June	AM	Stafford	Children
Monday 17 June	AM	Perton	All
Thursday 20 June	PM	Tamworth	All
Thursday 27 June	AM	Burton	All
Saturday 13 July	PM	Uttoxeter	All

A range of communication materials were produced to encourage feedback from parents, carers and their families. They included:

- **Survey:** The survey was originally intended to run from 14 May to 17 June 2019 but was then extended until 31 July 2019.
- **Two press releases:** One at the start of the engagement period on 20 May 2019 and the second on 25 June to inform stakeholders of the extended closing date
- **Social media posts:** The consultation was promoted across the CCGs' Facebook and Twitter profiles
- **Web content:** The consultation was promoted on each of the CCGs' websites.

3 Engagement survey

3.1 Respondent profiling

Survey respondents were asked to provide the location of their GP – findings are presented in table 1. Most responses were from respondents whose GP locality is Stafford (29%), followed by Cannock (15%), whilst 20% of respondents were from other nearby areas, the most common being Stone and Uttoxeter.

Table 1. Overall responses by GP locality. Base: 136

GP Locality	Number	%
Stafford	40	29%
Cannock	21	15%
Burton	12	9%
Lichfield	11	8%
Rugeley	9	7%
Tamworth	10	7%
Stone	8	6%
Uttoxeter	6	4%
Burntwood	6	4%
Perton	3	2%
Codsall	3	2%
Cheslyn Hay	2	1%
Seisdon	1	1%
Brewood	2	1%
Penkridge	2	1%
Norton Canes	1	1%
Featherstone	1	1%
Walsall Wood	1	1%
Birmingham	1	1%

3.2 Survey Findings

This section presents the feedback from the engagement survey. This section is structured as follows:

- Reporting and analysis notes
- Diagnosis
- Autism support
- Referral process
- Assessment process
- Key workers
- Crisis care
- Interventions
- Future services
- Communications with future services
- Other considerations

3.2.1 Reporting and analysis notes

The consultation survey used a combination of 'open text' questions, for respondents to make written comments and 'closed' questions where respondents 'ticked' a list of provided answers.

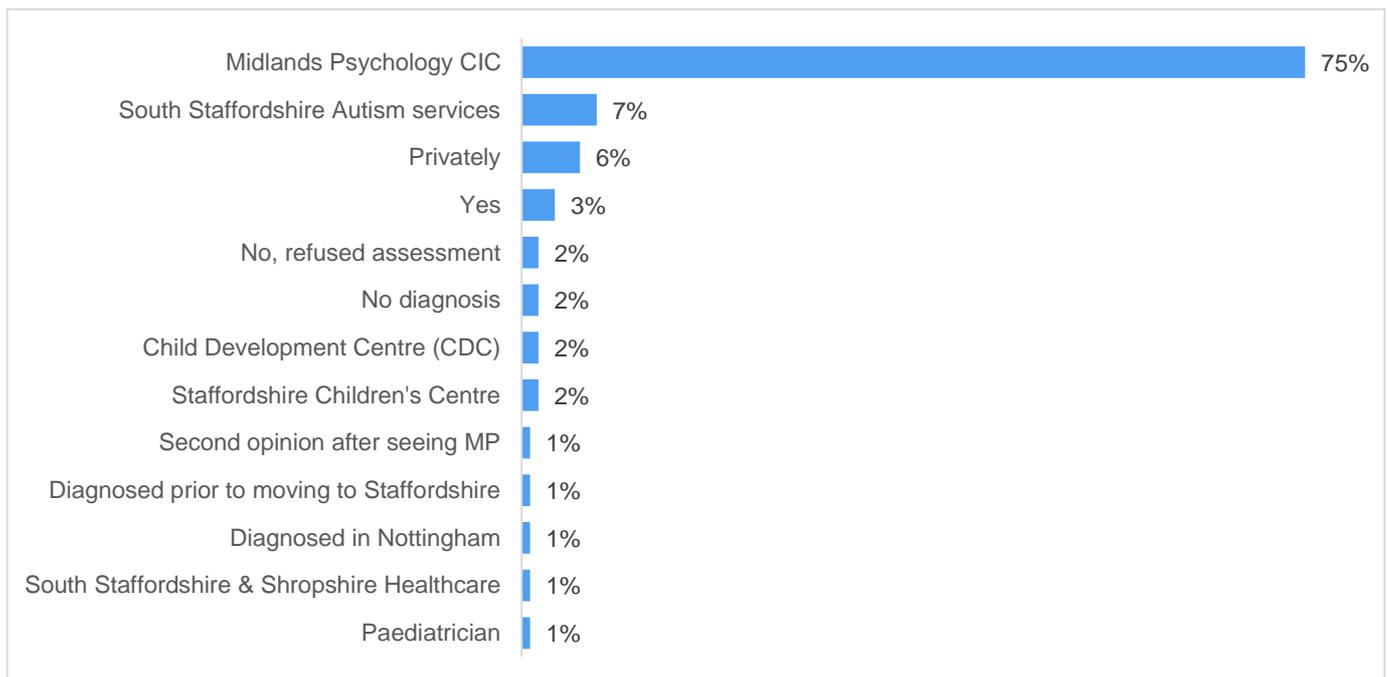
For the open questions, a random sample of responses from each question was read and the key themes (codes) mentioned by respondents were identified. This was undertaken for every open question. Some codes were replicable across more than one question, while others were specific to one or two questions. This means that every comment was coded because the list of themes was not predetermined, but instead emerged from the responses received.

For survey responses, results are shown by CCG area.

3.2.2 Diagnosis

Survey respondents were asked how their child was diagnosed. Figure 1 shows that most children were diagnosed through Midlands Psychology CIC (94 / 75%).

Figure 1. Q2. Was your child diagnosed privately or through South Staffordshire Autism Services (Midlands Psychology CIC)? Base 125



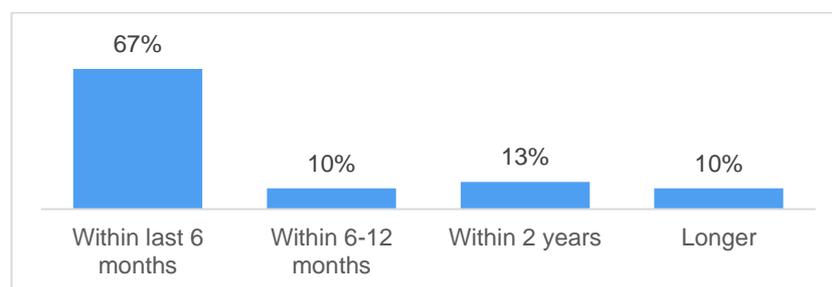
The top two responses in each CCG area are:

- **Cannock Chase:**
 - Midlands Psychology CIC (21 / 70%)
 - South Staffordshire Autism services (5 / 17%)
- **Stafford and Surrounds:**
 - Midlands Psychology CIC (37 / 84%)
 - Privately (2 / 5%)
 - No, refused assessment (2 / 5%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Midlands Psychology CIC (25 / 76%)
 - Yes (3 / 9%)
- **East Staffordshire:**
 - Midlands Psychology CIC (9 / 60%)
 - South Staffordshire Autism services (2 / 13%)
 - Privately (2 / 13%)

3.2.3 Autism support

Respondents were asked when their child last requested support from their current autism service. Figure 2 shows that most respondents last requested support from autism related services within the last six months (87 / 67%). A small group (13 / 10%) had not received treatment within two years. The majority of respondents therefore have recent experience of receiving support.

Figure 2. Q3. When did you or your child last request support from the current autism services? Base 130



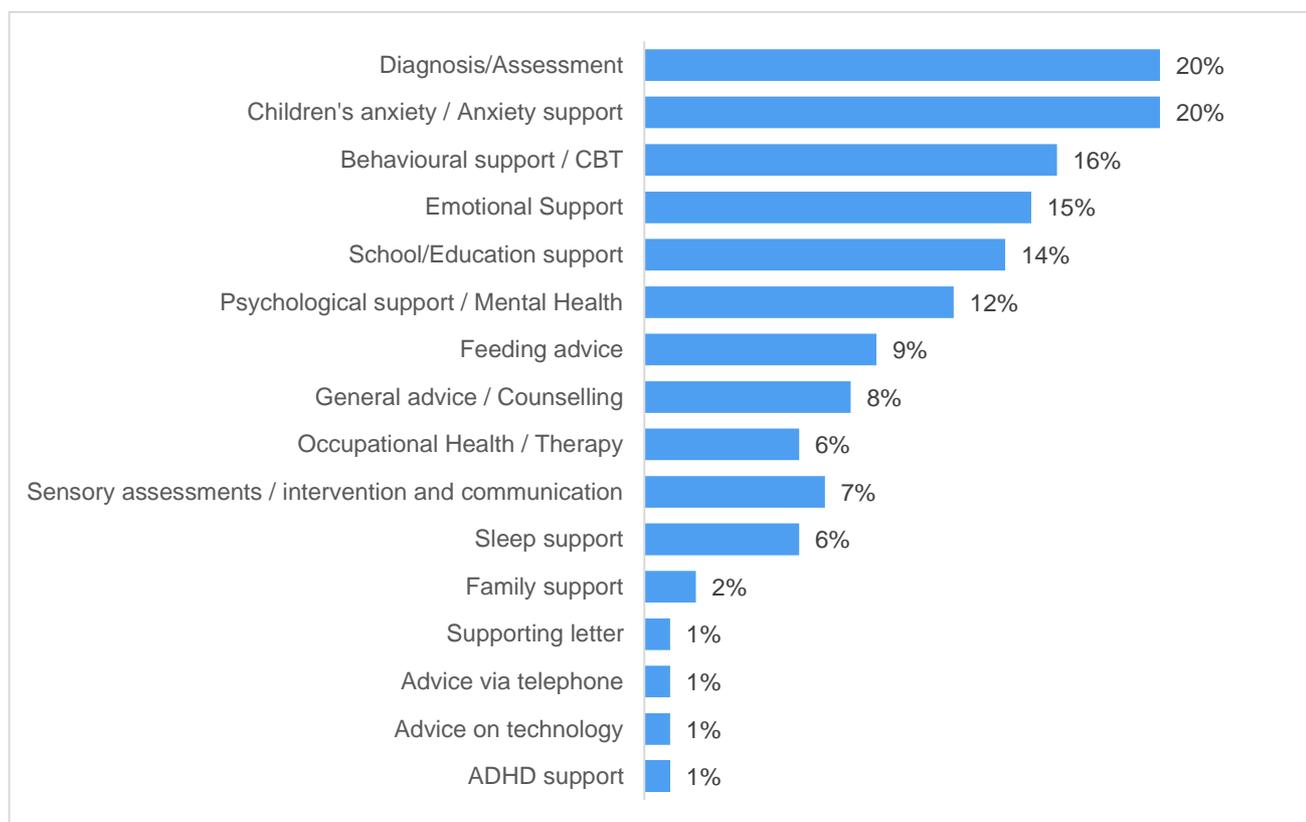
The majority of those stating they waited longer than two years commented they had to wait at least four years for a diagnosis (5 / 50%).

The top two responses in each CCG area are:

- **Cannock Chase:**
 - Within last 6 months (20 / 67%)
 - Within 6-12 months (4 / 13%)
 - Within 2 years (4 / 13%)
- **Stafford and Surrounds:**
 - Within last 6 months (33 / 72%)
 - Within 2 years (6 / 13%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Within last 6 months (23 / 74%)
 - Within 2 years (4 / 13%)
- **East Staffordshire:**
 - Within last 6 months (8 / 44%)
 - Longer (6 / 33%)

Respondents were then asked to explain the type of support they requested. Figure 3 shows 25 (20%) requested support for childrens anxiety or anxiety support and 24 (20%) respondents requested support with diagnosis or assessment. Behavioural, emotional, school, and psychological support were also regularly requested.

Figure 3. Q4 What type of support was requested? Base: 123



The top two responses in each CCG area are:

- **Cannock Chase:**
 - Diagnosis/Assessments (8 / 28%)
 - Children's anxiety / Anxiety support (8 / 28%)
 - Sensory assessments / intervention and communication (4 / 14%)
 - Behavioural support / CBT (4 / 14%)
 - School/Education support (4 / 14%)
- **Stafford and Surrounds:**
 - Children's anxiety / Anxiety support (14 / 30%)
 - Behavioural support / CBT (11 / 23%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Emotional support (7 / 23%)
 - School/Education support (6 / 20%)
- **East Staffordshire:**
 - Psychological support / Mental Health (4 / 33%)
 - School/Education support (3 / 25%)

Exemplar quotes

Respondents quotations below provide further detail on the comments raised by respondents around the type of support they requested and why.

Diagnosis / assessment

*“Assessment for and diagnosis of Autism Spectrum Condition and referral to Autism Outreach Team”
[Cannock GP locality]*

“Specialist Autism Psychologist support and advice on current issues, plus a letter following assessment for the EHC plan review (which the LA rejected as it was not a report format) so an assessment report” [Burntwood GP locality]

“Full assessment and help afterwards when things have been hard.” [Stafford GP locality]

Children's anxiety / anxiety support

“Support with sleep and anxiety, sensory processing disorder assessment. Support for us as parents. Further understanding of autism and how we can help my child.” [Stone GP locality]

“Formalise diagnosis and ask questions about his anxiety around his diagnosis” [Rugeley GP locality]

“Anxiety and emotional support - Support with transition to High School Diagnosis :- further diagnosis as still have other concerns” [Stafford GP locality]

Behavioural support / CBT

“Support for feeding and behaviour management” [Rugeley GP locality]

“Sensory and behaviour including anger and emotions.” [Stafford GP locality]

“Advice on a second opinion and I am still waiting for this from December” [Cannock GP locality]

*“Anger management, understanding autism, and just requested transition to adulthood”
[Tamworth GP locality]*

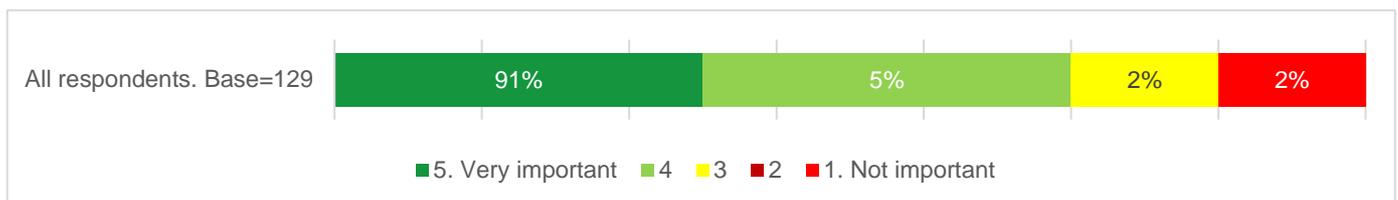
“School support, social groups: Liberty/Blast, NHS hospital admissions, Pause, CAMHS, home school support (Ausums), SEND - EHCP advice. Cannot access West Midlands Psychology because our GP is not Staffs, but access AUSUMS.” [Walsall Wood GP locality]

“Anxiety around schoolwork - lacks confidence and gets worked up, especially during lead up to exams - threatens suicide. Struggles with everyday life” [Lichfield GP locality]

3.2.4 Referral Process

Respondents were asked to indicate how important it is for them to receive a confirmation referral to the services. Figure 4 shows that the majority of respondents (117 / 91%) consider confirmation of a referral being received as very important, whilst only a very low proportion (3 / 2%) stated it was not important.

Figure 4. Q5 When thinking about the referral process for a future service, how important is it for you to receive confirmation that the referral has been received by the service?

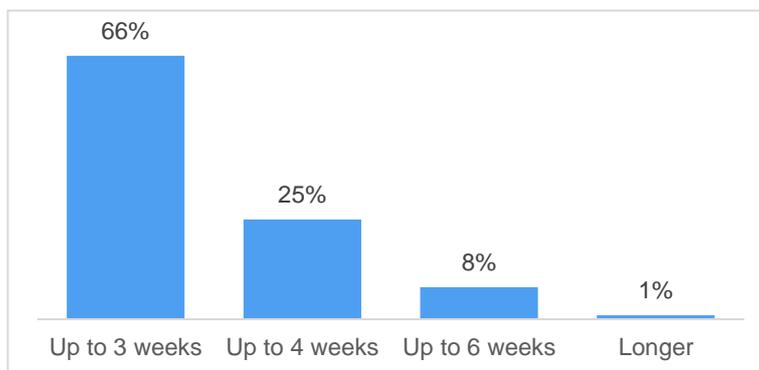


The proportion stating that it is important (rating of 4 or 5) in each CCG area are:

- **Cannock Chase:** 29 (95%)
- **Stafford and Surrounds:** 43 (96%)
- **South East Staffordshire and Seisdon Peninsula:** 31 (97%)
- **East Staffordshire:** 18 (100%)

Respondents were asked what they consider to be a timely response from a future service to receive a confirmation that the referral has been received. Figure 5 shows that the majority of respondents (89 / 66%) consider a period of up to three weeks to be a timely response from a future referral service, whilst only a small proportion (10 / 8%) considered a period of up to six weeks or more as an appropriate timeframe.

Figure 5. Q6 What would you consider to be a timely response from a future service to receive confirmation that your referral has been received? Base: 134

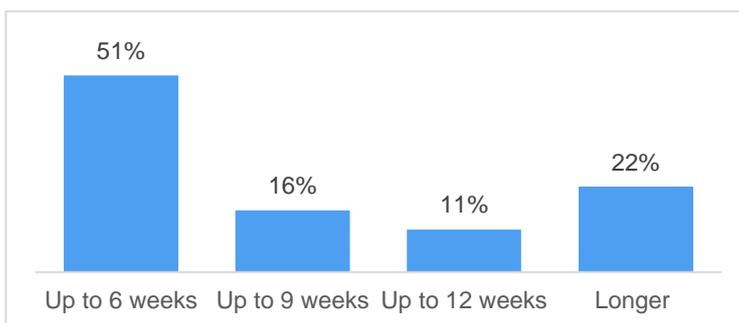


The top two responses in each CCG area are:

- **Cannock Chase:**
 - Up to 3 weeks (20 / 65%)
 - Up to 4 weeks (7 / 23%)
- **Stafford and Surrounds:**
 - Up to 3 weeks (34 / 72%)
 - Up to 4 weeks (8 / 17%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Up to 3 weeks (25 / 76%)
 - Up to 4 weeks (7 / 21%)
- **East Staffordshire:**
 - Up to 4 weeks (10 / 56%)
 - Up to 3 weeks (7 / 39%)

Respondents were asked how long they had to wait for their referral date after being notified it has been accepted. Figure 6 shows around 62 (51%) of respondents have waited up to six weeks for confirmation of their referral, whilst 27 (22%) had to wait longer than 12 weeks.

Figure 6. Q7 To shape the capacity requirements of the future service, how long did you wait from the date of your referral to receiving notification that it has been accepted or declined? Base: 122



Of those stating they had to wait more than 12 weeks, 18 (49%) commented they had to chase the referral themselves or no confirmation had been received, whilst 3 (8%) respondents said they had to wait between four to six months and 4 (11%) had to wait one to two years.

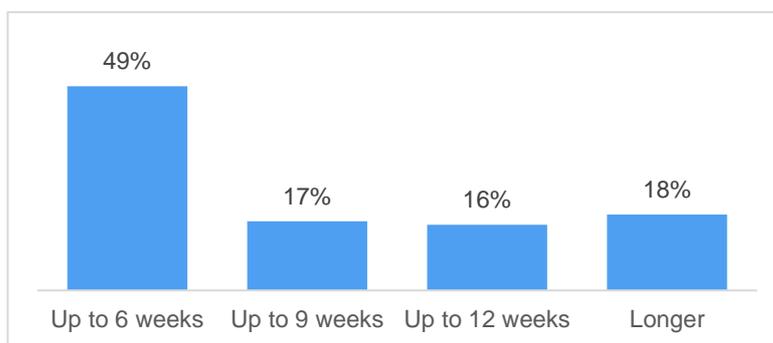
The top two responses in each CCG area are:

- **Cannock Chase:**
 - Up to 6 weeks (17 / 61%)
 - Up to 9 weeks (6 / 21%)

- **Stafford and Surrounds:**
 - Up to 6 weeks (20 / 47%)
 - Longer (11 / 26%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Up to 6 weeks (18 / 56%)
 - Longer (6 / 19%)
- **East Staffordshire:**
 - Longer (7 / 44%)
 - Up to 6 weeks (6 / 38%)

Respondents were asked how long they waited from the date of their initial referral being sent to receiving an appointment. Figure 7 shows 59 (49%) respondents waited up to six weeks from the date their initial referral was sent to receiving an appointment. 22 (18%) respondents stated they waited more than 12 weeks.

Figure 7. Q8. Once your referral has been received by the service, a clinical screening takes place based on the details within the referral letter. To shape the capacity requirements of the future services, how long did you wait from the date your initial referral was sent to receiving an appointment? Base: 120



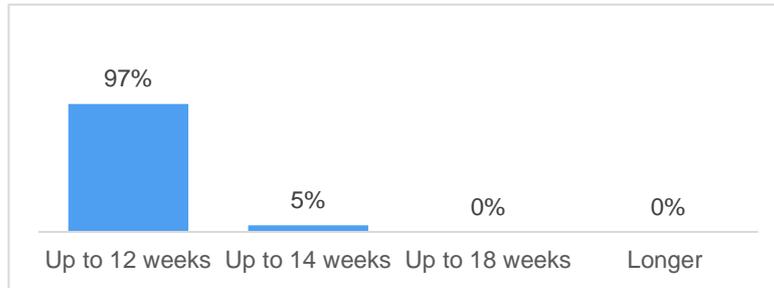
Of those waiting longer than 12 weeks, 6 (19%) commented they had to chase the appointment, 10 (31%) respondents said they had to wait between four and seven months. 6 (19%) respondents stated they did not receive an appointment, or an appointment was not offered.

The top two responses in each CCG area are:

- **Cannock Chase:**
 - Up to 6 weeks (15 / 50%)
 - Up to 12 weeks (7 / 23%)
- **Stafford and Surrounds:**
 - Up to 6 weeks (21 / 51%)
 - Longer (10 / 24%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Up to 6 weeks (12 / 40%)
 - Longer (7 / 23%)
- **East Staffordshire:**
 - Up to 6 weeks (9 / 56%)
 - Up to 9 weeks (4 / 25%)

Respondents were asked how long they felt was a reasonable timeframe to be seen after a referral has been accepted. Figure 8 shows 125 (97%) respondents thought up to 12 weeks was a reasonable timeframe to be seen by a future service once a referral has been accepted.

Figure 8. Q9 What do you feel is a reasonable timeframe to be seen by a future service once a referral has been accepted?
Base: 119



The top two responses in each CCG area are:

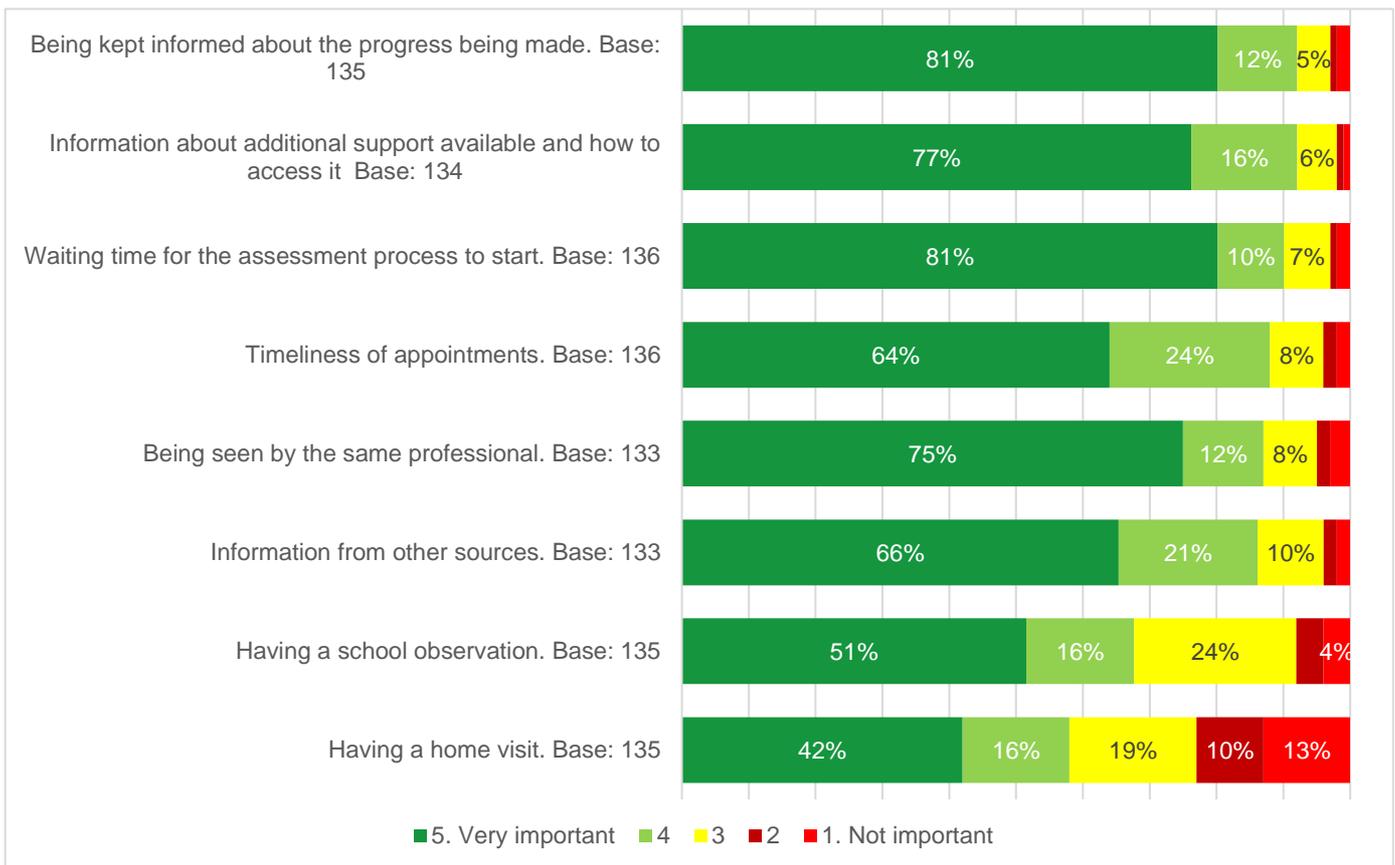
- **Cannock Chase:**
 - Up to 12 weeks (27 / 93%)
 - Up to 14 weeks (2 / 7%)
- **Stafford and Surrounds:**
 - Up to 12 weeks (45 / 100%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Up to 12 weeks (31 / 94%)
 - Up to 14 weeks (2 / 6%)
- **East Staffordshire:**
 - Up to 12 weeks (18 / 100%)

3.2.5 Assessment process

Respondents were asked to score out of 5, where 5 is very important and 1 is very unimportant, a range of factors which are part of the assessment process. Figure 9 shows how important different components of the assessment process are to respondents.

- Most respondents felt waiting times for the assessment process to start, timeliness of appointments, being kept informed, being seen by the same professional, information about additional support available and how to assess it were all very important.
- However, having a home visit or school observation were less important.

Figure 9. Q10 Once you have been accepted by the service, please score the importance of the following factors in regards to the assessment process of a future service.



The top two most important (those selecting 4 and 5 in the rating) factors in each CCG area are:

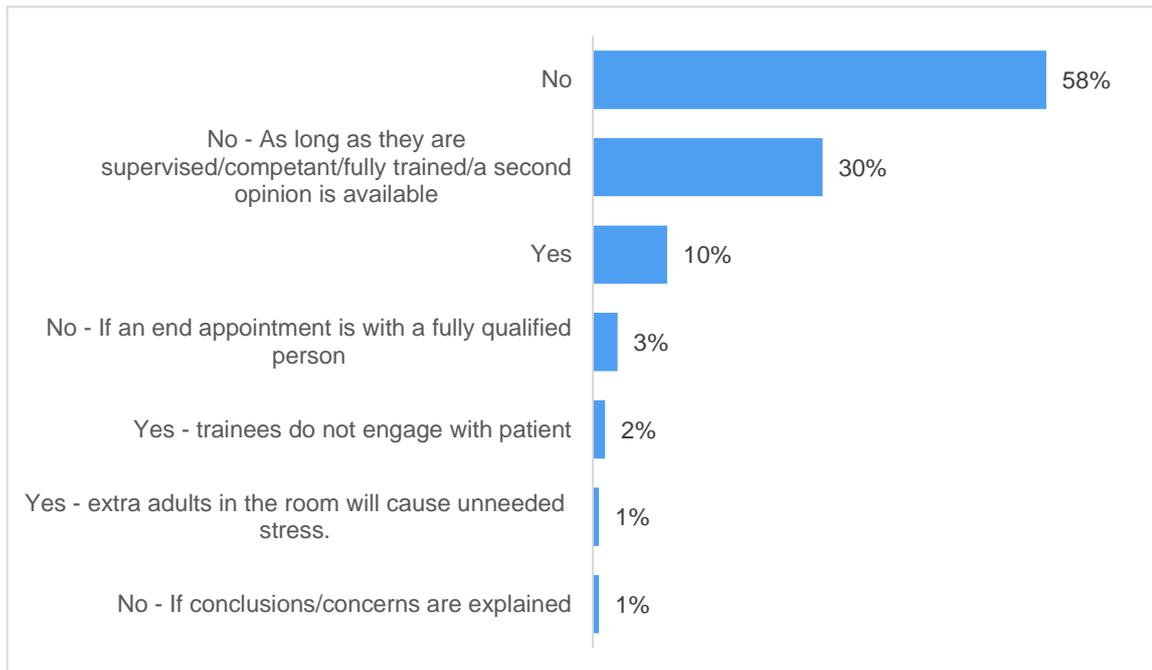
- **Cannock Chase:**
 - Information about additional support available and how to access it (this could include courses, support groups etc) (29 / 94%)
 - Being kept informed about the progress being made (28 / 90%)
- **Stafford and Surrounds:**
 - Being kept informed about the progress being made (44 / 92%)
 - Waiting time for the assessment process to start (43 / 90%)
 - Information about additional support available and how to access it (this could include courses, support groups etc) (43 / 90%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Timeliness of appointments (33 / 100%)
 - Waiting time for the assessment process to start (32 / 97%)
 - Being kept informed about the progress being made (32 / 97%)
 - Information about additional support available and how to access it (this could include courses, support groups etc) (32 / 97%)

- **East Staffordshire:**

- Timeliness of appointments (18 / 100%)
- Being kept informed about the progress being made (18 / 100%)
- Information about additional support available and how to access it (this could include courses, support groups etc) (17 / 95%)

Respondents were asked if they have any concerns about a trainee being involved in their care in a future service model. Figure 10 shows 73 (58%) respondents do not have concerns about a trainee being involved in their care as part of future service, whilst 37 (30%) commented they don't have concerns as long as trainees are fully supervised, competent, trained and a second opinion is available.

Figure 10. Q11a Do you have any concerns about a trainee being involved in your care as part of a future service? Base 125



The top two responses in each CCG area are:

- **Cannock Chase:**

- No (21 / 70%)
- No - As long as they are supervised/competent/fully trained/a second opinion is available (8 / 27%)

- **Stafford and Surrounds:**

- No (23 / 50%)
- No - As long as they are supervised/competent/fully trained/a second opinion is available (14 / 30%)

- **South East Staffordshire and Seisdon Peninsula:**

- No (19 / 61%)
- No - As long as they are supervised/competent/fully trained/a second opinion is available (9 / 29%)

- **East Staffordshire:**

- No (6 / 43%)
- No - As long as they are supervised/competent/fully trained/a second opinion is available (6 / 43%)

Exemplar quotes

Respondents quotations below provide further detail on the comments raised by respondents around trainees being involved in delivery of care.

No - As long as they are supervised/competent/fully trained/a second opinion is available

“No, as long as any conclusions/concerns are explained and there is a chance for parental evidence be taken into account and discussed before any definitive conclusions regarding diagnosis etc are made.” [Brewood GP locality]

“Not if they are mentored and not involved in decision making and child is happy to have more than one person in the room.” Stafford GP locality]

“I have no concern about a trainee being involved as long as they receive regular supervision in place and feedback from patient/carer is reviewed.” [Stafford GP locality]

“I don't have any concerns about trainees being involved. People have to learn, and we need people in this area with expertise. Supervision during the learning process and mentoring is key though.” [Uttoxeter GP locality]

“No as long as fully supported by a qualified person” [Burton GP locality]

Other verbatims

“Yes - I had a trainee with my son and they didn't know enough - she sent my son into a meltdown” [Stafford GP locality]

“Yes, as I am not confident they will be overseen adequately as my experience has shown” [Stone GP locality]

“Yes, as my son has social anxiety and needs to know who he will be seeing before the appointment, any extra adults in the room causes him unneeded stress. He would have to have an established relationship with the supervising professional before a trainee being introduced.” [Stafford GP locality]

“Yes, having experienced a trainee psychologist work with my child. They seemed to be sticking rigidly to a scripted programme with no flexibility to deviate and really engage him in convention.” [Stone GP locality]

Respondents were asked what would reassure them about a trainee being involved in their care as part of a future service. Figure 11 shows 57 (56%) respondents would be reassured by a trainee having regular contact with a supervisor, whilst 20 (19%) respondents felt that no reassurance would be required. Respondents also commented other ways of reassuring patients would be; trainees explaining their roles, or being monitored or checked, knowing their area of expertise, or meeting with trainees before agreeing their involvement.

Figure 11. Q11b What would help to reassure you about a trainee being involved in your care as part of a future service? Base 102



The top two responses in each CCG area are:

- **Cannock Chase:**
 - Regular contact with supervisor (14 / 56%)
 - No / nothing / N/A (5 / 20%)
- **Stafford and Surrounds:**
 - Regular contact with supervisor (17 / 47%)

- Explaining their role (8 / 22%)
- No / nothing / N/A (8 / 22%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Regular contact with supervisor (18 / 72%)
 - Monitoring/observing/interim checks (4 / 16%)
- **East Staffordshire:**
 - Regular contact with supervisor (8 / 50%)
 - Explaining their role (4 / 25%)
 - No / nothing / N/A (4 / 25%)

Exemplar quotes

Respondents quotations below provide further detail on the comments raised by respondents around what would reassure them if a trainee were involved in delivering their care.

Regular contact with supervisor

“That they were never on their own providing care, or assessment, I would want someone qualified there as well.” [Cannock GP locality]

“Any decisions made are reviewed by the senior clinician and discussed with us before they are finalised” [Rugeley GP locality]

“That their work was over seen by an experienced professional who is a qualified autism specialist” [Burntwood GP locality]

“Knowing what their area of expertise is, why they are currently training, access to supervisor, regular contact with supervisor to check how things are going.” [Stafford GP locality]

Other verbatims

“That the trainer has some knowledge and previous experience of the area of concern.” [Stafford GP locality]

“Being asked if the parents are happy with a trainee being involved, giving them the option to ask questions.” [Burton GP locality]

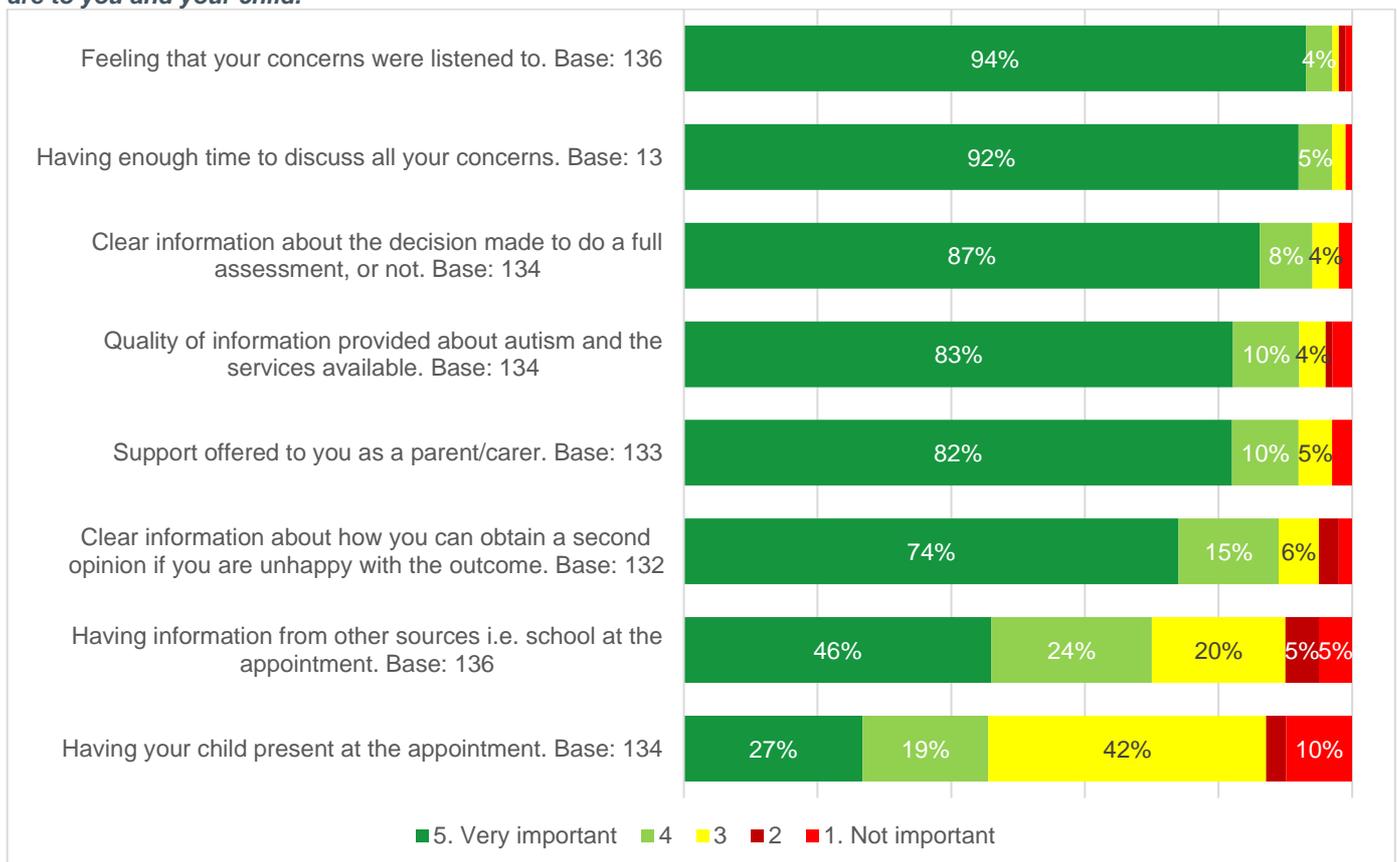
“Nothing. A trainee sent in with no supervision to ‘support’ a child who wants to commit suicide is appalling and unethical.” [Stone GP locality]

“Wouldn't mind a trainee. Need to explain who they are / what they are there for.” [Stafford GP locality]

Respondents were asked the importance of a range of factors to them during their first appointment with a future service. Figure 12 shows how important different components of the first appointment with a future service are to respondents.

- Most respondents felt having enough time to discuss concerns, feeling listened to, having clear and quality information, access to second opinions and support offered to parents/carers were very important.
- Having the child present at the appointment was considered less important.

Figure 12. Q12 During a first appointment with a future service, please score the following in terms of how important they are to you and your child.



The top two most important (those selecting 4 and 5 in the rating) factors in each CCG area are:

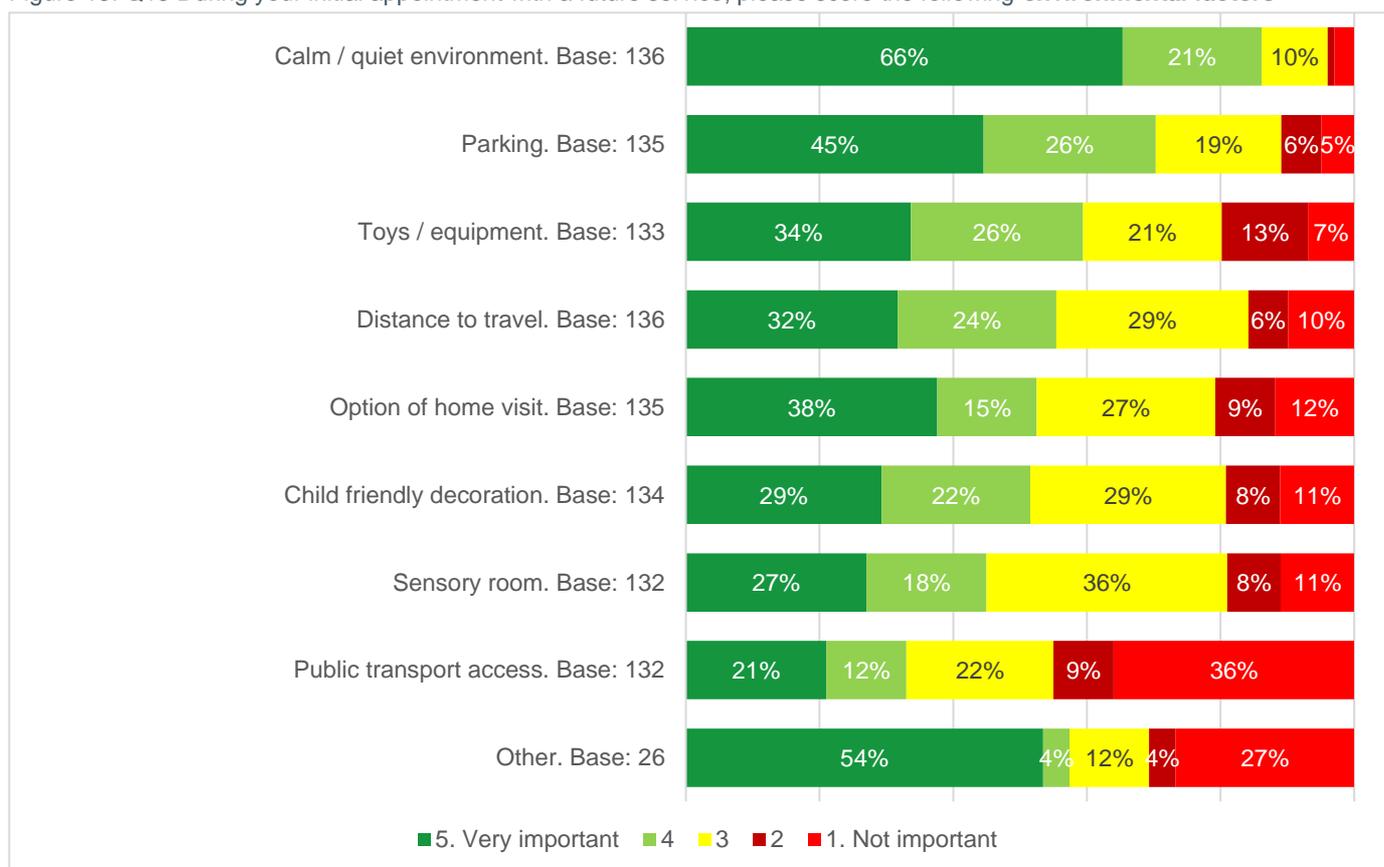
- **Cannock Chase:**
 - Having enough time to discuss all your concerns (31 / 97%)
 - Feeling that your concerns were listened to (31 / 97%)
 - Clear information about how you can obtain a second opinion if you are unhappy with the outcome (28 / 93%)
 - Support offered to you as a parent/carers (28 / 93%)
- **Stafford and Surrounds:**

- Feeling that your concerns were listened to (47 / 98%)
- Clear information about the decision made to do a full assessment, or not. (47 / 98%)
- Quality of information provided about autism and the services available (46 / 96%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Having enough time to discuss all your concerns (33 / 100%)
 - Feeling that your concerns were listened to (33 / 100%)
 - Clear information about the decision made to do a full assessment, or not. (33 / 100%)
 - Quality of information provided about autism and the services available (33 / 100%)
 - Support offered to you as a parent/carer (29 / 91%)
- **East Staffordshire:**
 - Support offered to you as a parent/carer (17 / 94%)
 - Clear information about how you can obtain a second opinion if you are unhappy with the outcome (15 / 83%)

Respondents were asked what environmental factors are important during their initial appointment with a future service. Figure 13 shows how important a range of environmental factors were to respondents at their first appointment with their future service.

- More than half of respondents stated having a calm and quiet environment, parking, toys/equipment, distance to travel, options of home visits and child friendly decoration are important.
- Sensory room and access to public transport are considered less important.

Figure 13. Q13 During your initial appointment with a future service, please score the following *environmental factors*



Other important factors mentioned by respondents are:

- For appointments to not take place in a hospital / clinical setting (7 / 37%)
- Access to local services as travelling long distances can cause anxiety (4 / 21%)
- Assessments that are adapted to children (3 / 16%)

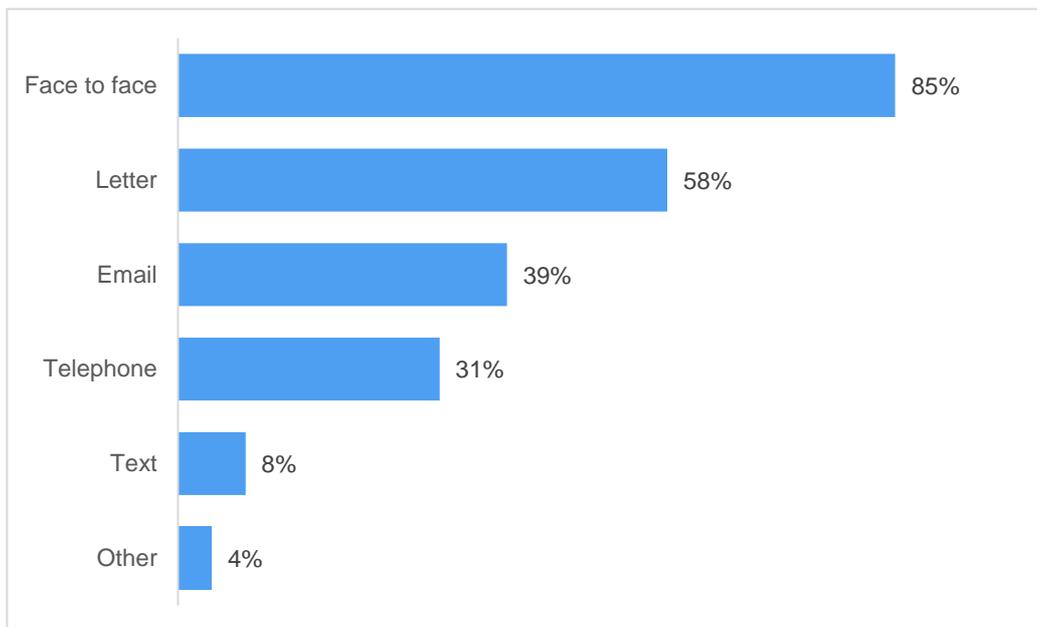
- Friendly staff (3 / 16%)

The top two most important (those selecting 4 and 5 in the rating) factors in each CCG area are:

- **Cannock Chase:**
 - Calm/quiet environment (29 / 91%)
 - Parking (21 / 68%)
- **Stafford and Surrounds:**
 - Calm/quiet environment (42 / 88%)
 - Parking (31 / 65%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Calm/quiet environment (27 / 82%)
 - Parking (24 / 73%)
- **East Staffordshire:**
 - Parking (17 / 95%)
 - Child friendly decoration (14 / 78%)
 - Toys/equipment (14 / 78%)

Respondents were asked how they would prefer to be informed about their diagnosis as part of a future service. Figure 14 shows 116 (85%) respondents would prefer to be informed about a diagnosis through face to face interaction, whilst only 11 (8%) stated they would prefer text.

Figure 14. Q14 How would you prefer to be informed about a diagnosis as part of a future service? Base 136



Of those selecting other, 5 (63%) respondents also stated having a written diagnosis which could be shared with their children’s school would be preferable, whilst 2 (25%) respondents stated whichever method is quickest.

The top two responses in each CCG area are:

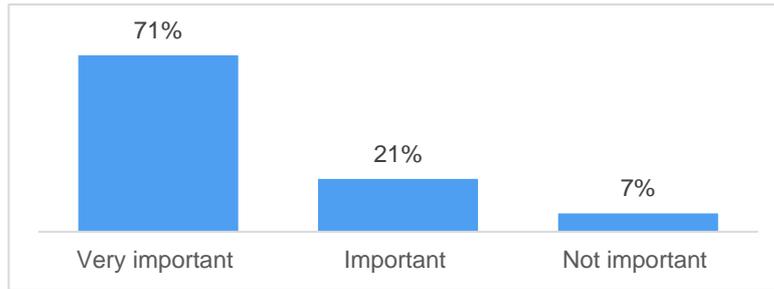
- **Cannock Chase:**
 - Face to face (24 / 75%)
 - Letter (18 / 56%)
- **Stafford and Surrounds:**
 - Face to face (44 / 90%)
 - Letter (26 / 53%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Face to face (30 / 91%)

- Letter (23 / 70%)
- **East Staffordshire:**
 - Face to face (14 / 78%)
 - Letter (13 / 72%)

3.2.6 Key Workers

Respondents were asked how important it is to be assigned a key worker following diagnosis as part of a future service. Figure 15 shows 97 (71%) respondents believe it is very important for patients to be assigned a key worker following diagnosis as part of future services.

Figure 15. Q15 How important is it to be assigned a key worker following diagnosis as part of a future service, a key workers role is to offer individual support and be a permanent point of contact within the service? Base 136

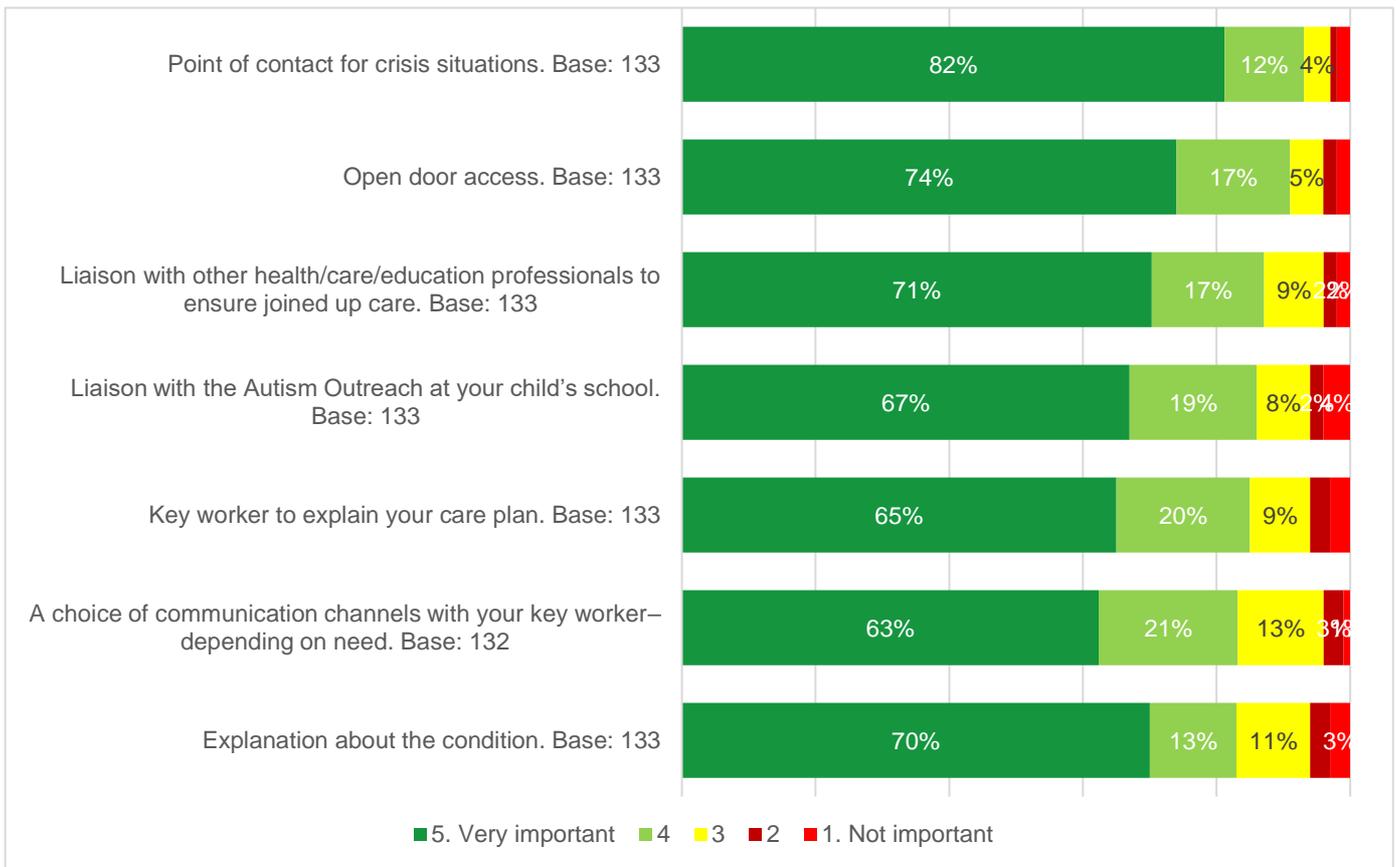


The proportion stating an assigned key worker is very important in each CCG area are:

- **Cannock Chase:** 18 / 56%
- **Stafford and Surrounds:** 34 / 17%
- **South East Staffordshire and Seisdon Peninsula:** 27 / 82%
- **East Staffordshire:** 14 / 78%

Respondents were asked what support they would need from a key worker as part of a future service. Figure 16 shows all support services provided by a key worker are important to the majority of respondents.

Figure 16. Q16 What support would you need from a key worker as part of a future service? Please score the following factors in terms of importance

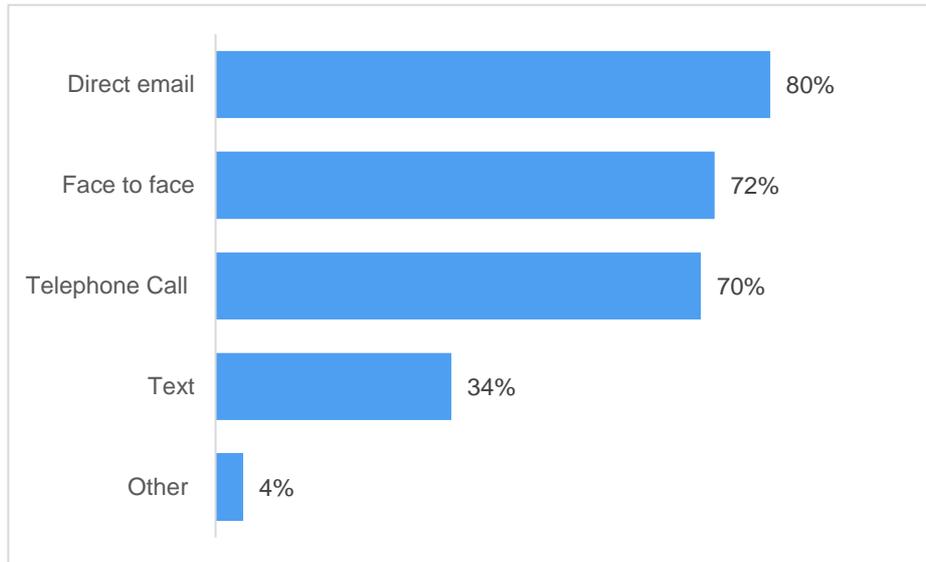


The top two most important (those selecting 4 and 5 in the rating) factors in each CCG area are:

- **Cannock Chase:**
 - Point of contact for crisis situations (28 / 93%)
 - Open Door access (28 / 93%)
 - A choice of communication channels with your key worker— depending on need (27 / 90%)
- **Stafford and Surrounds:**
 - Point of contact for crisis situations (45 / 94%)
 - Open Door access (44 / 92%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Point of contact for crisis situations (31 / 97%)
 - Liaison with other health/care/education professionals to ensure joined up care (30 / 94%)
- **East Staffordshire:**
 - Open Door access (18 / 100%)
 - Point of contact for crisis situations (17 / 95%)

Respondents were asked how they would prefer to access their key worker as part of a future service. Figure 17 shows 109 (80%) respondents would prefer to access their key worker via email, whilst 98 (72%) would like face to face and 95 (70%) telephone access.

Figure 17. Q17 How would you prefer to access your key worker as part of a future service? Base 136



Of those selecting other, 2 (33%) commented whatever method is needed at the time, whilst 1 (17%) stated video calling.

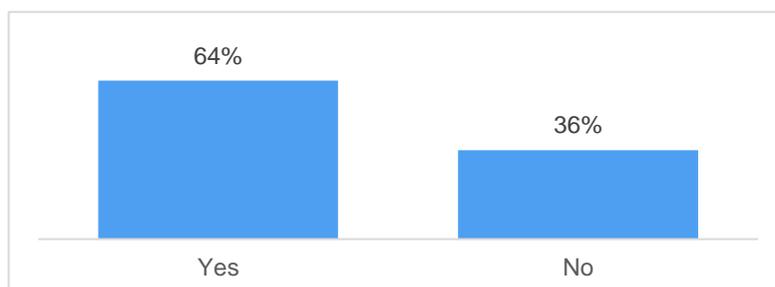
The top two responses in each CCG area are:

- **Cannock Chase:**
 - Direct email (26 / 81%)
 - Telephone call (22 / 69%)
- **Stafford and Surrounds:**
 - Face to face (37 / 77%)
 - Direct email (36 / 75%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Direct email (31 / 94%)
 - Face to face (26 / 79%)
- **East Staffordshire:**
 - Direct email (14 / 78%)
 - Telephone call (13 / 72%)

3.2.7 Crisis Care

Respondents were asked if their child has been in crisis and if they felt they needed additional support. Figure 18 shows 87 (64%) respondents felt they needed additional support from Autism services whilst their child was in crisis.

Figure 18. Q18 Has your child been in crisis where you felt you needed additional support from Autism Services? Base 135

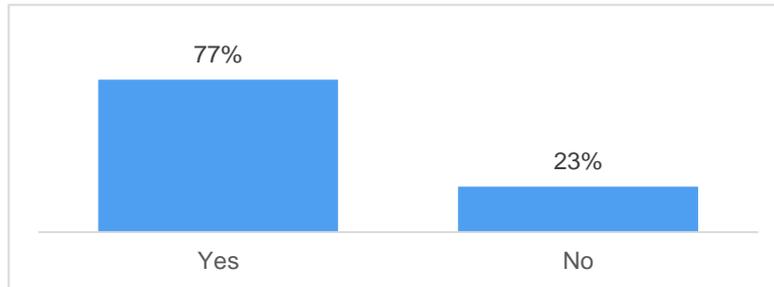


The proportion stating yes in each CCG area are:

- **Cannock Chase:** 16 / 52%
- **Stafford and Surrounds:** 38 / 78%
- **South East Staffordshire and Seisdon Peninsula:** 14 / 42%
- **East Staffordshire:** 14 / 82%

Respondents were asked if they felt there was anywhere they could safely take their child for crisis support. Figure 19 shows 88 (77%) respondents felt there was somewhere they could take their child safely in the event of a crisis.

Figure 19. Q19 Did you feel there was anywhere you could safely take your child for crisis support? Base 113

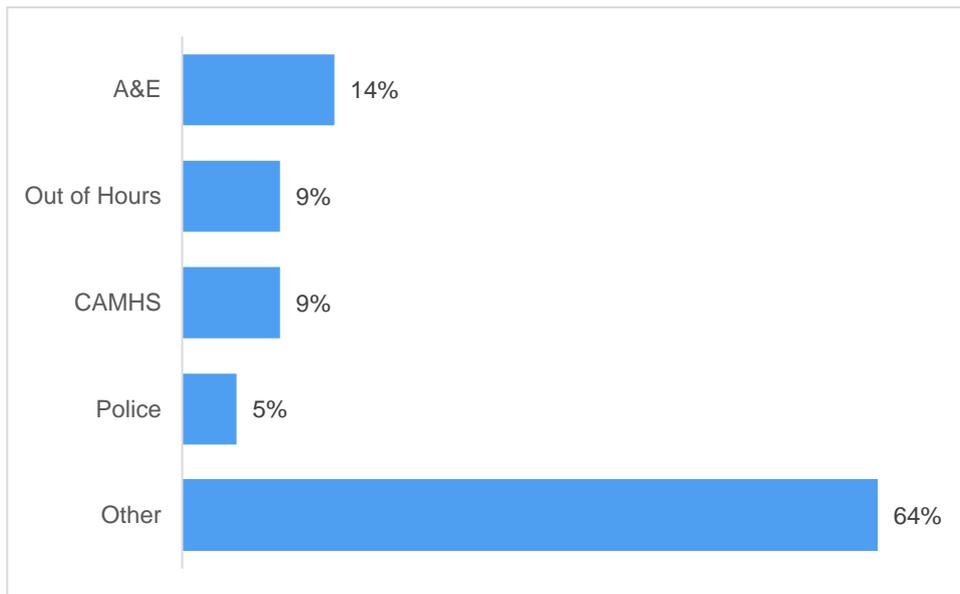


The proportion stating yes in each CCG area are:

- **Cannock Chase:** 5 / 21%
- **Stafford and Surrounds:** 11 / 23%
- **South East Staffordshire and Seisdon Peninsula:** 5 / 22%
- **East Staffordshire:** 5 / 33%

Respondents were asked where they took their child in the event of a crisis. Figure 20 shows which services respondents took their child to for crisis support.

Figure 20. Q19a In the event of the crisis where did you take your child? Base 22



Of those selecting other;

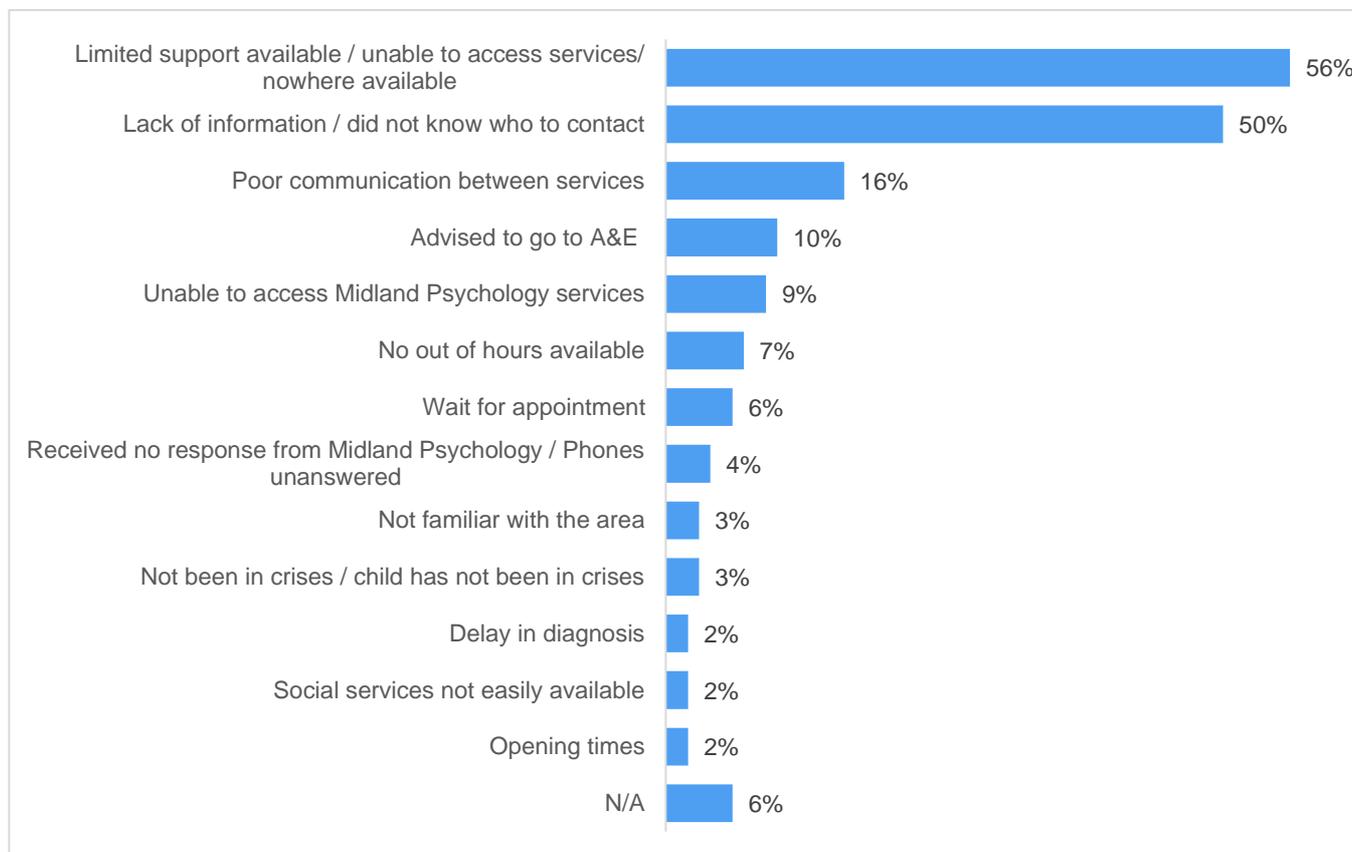
- 9 (82%) commented they took their child to Midlands Psychology
- 1 (9%) commented they took their child to their GP
- 1 (9%) commented they sought support from friends

The top two responses in each CCG area are:

- **Cannock Chase:**
 - Other (4 / 100%)
- **Stafford and Surrounds:**
 - Other (5 / 56%)
 - A&E (2 / 22%)
 - Out of Hours (2 / 22%)
- **South East Staffordshire and Seisdon Peninsula:**
 - CAMHS (2 / 50%)
 - Other (2 / 50%)
- **East Staffordshire:**
 - Other (3 / 60%)
 - A&E (1 / 20%)
 - Police (1 / 20%)

Respondents were asked why they had not taken their child for crisis support. Figure 21 shows the reasons why respondents did not take their child for crisis support. 38 (56%) respondents stated there was limited support available and they were unable to access the services, and 34 (50%) respondents stated they didn't know who to contact.

Figure 21. Q19b If you have not taken your child for crisis support what are the reasons? Base 68



The top two responses in each CCG area are:

- **Cannock Chase:**
 - Lack of information / did not know who to contact (8 / 53%)
 - Limited support available / unable to access services/ nowhere available (7 / 47%)
- **Stafford and Surrounds:**
 - Limited support available / unable to access services/ nowhere available (15 / 52%)
 - Lack of information / did not know who to contact (8 / 53%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Limited support available / unable to access services/ nowhere available (8 / 73%)
 - Lack of information / did not know who to contact (8 / 73%)
- **East Staffordshire:**
 - Limited support available / unable to access services/ nowhere available (7 / 70%)
 - Lack of information / did not know who to contact (5 / 50%)

Exemplar quotes

Respondents quotations below provide further detail on the comments raised by respondents around why they have not taken their child to crisis support.

Limited support available / unable to access services / nowhere available

"I kept being told that SSAS was not an emergency service, and I would have to wait for an appointment to see if he needed seeing by a psychologist. We were just left with nothing and only option was to phone an ambulance when he got really bad. We were just left." [Cannock GP locality]

"Crisis often happens outside of normal working hours which can in itself cause additional stress as not knowing what to do when faced with it. Not having anyone to contact also increases anxiety."
[Stafford GP locality]

"When we called for help in a crisis it took over 8 months to get an appointment."
[Cannock GP locality]

"Having had a poor professional service from MPS and having to pay private, no help was given from the NHS, even though the private diagnosis was done by an NHS credited service."
[Burton GP locality]

"Didn't know where to turn to - had been previously told occupational therapy support would be available for crisis but no long-term solutions. Therapies recommended for small children aren't practical as children grow." [Tamworth GP locality]

"Rang first support and they were useless, so I was told to ring an ambulance or the police. There is no crisis support team available." [Burton GP locality]

Lack of information / did not know who to contact

"I didn't know where to go but used telephone advice to get through the crisis. I received telephone advice from a psychologist who specialised in autism to get over the phone advice before an appt could be arranged" [Burntwood GP locality]

“There wasn’t anywhere that I knew of to take them. I have had to deal with it myself.”
[Cannock GP locality]

“I speak to the school but not sure of the alternative options” [Stafford GP locality]

“There is nowhere and no one to call out of hours. Advised to go A&E if things get that bad. This is not a practical solution for our children” [Stone GP locality]

Other verbatims

“Rang first support and they were useless, so I was told to ring an ambulance or the police. There is no crisis support team available.” [Burton GP locality]

“It took so long for my daughter to be diagnosed she was self-harming we had to deal with that ourselves. Midlands and cams need to work together more” [Stafford GP locality]

“Midlands Psychology and CAMHS do not work together so we are still not getting the help we need even after Crisis point” [Uttoxeter GP locality]

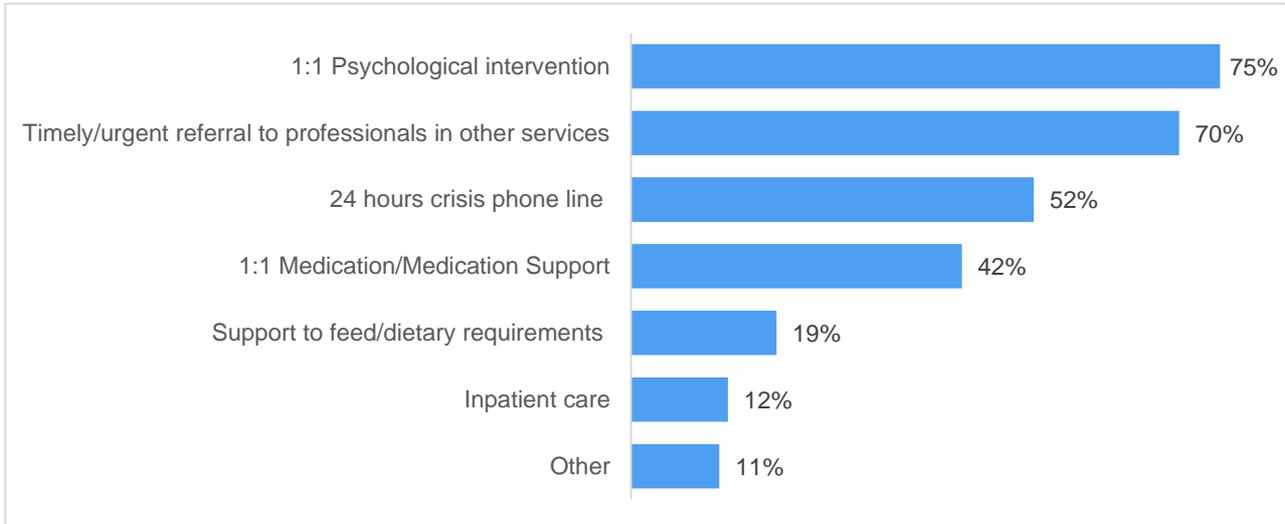
“My child is currently suffering with severe anger and behaviour issues due to complex global sensory processing disorder and we needed support for this.” [Stafford GP locality]

“School thought he was spoilt - CAMHS thought he was ok I knew he was depressed and finally a specialist helped me to help him.” [Stafford GP locality]

“No one answered the door at MP or answered their phone. Next time reception answered the door and told me I wasn’t allowed in without an appointment” [Stafford GP locality]

Respondents were asked, if their child has been in crisis care, which of the following interventions were needed to support their child. Figure 22 shows 73 (75%) respondents felt they needed 1:1 psychological intervention and 68 (70%) respondents felt they needed a timely, urgent referral to professionals in other services whilst their child was in crisis.

Figure 22. Q20 If your child has been in crisis which of the following interventions do you feel were needed to support you and your child during this period? Base 97



Of those stating other, the following interventions were mentioned:

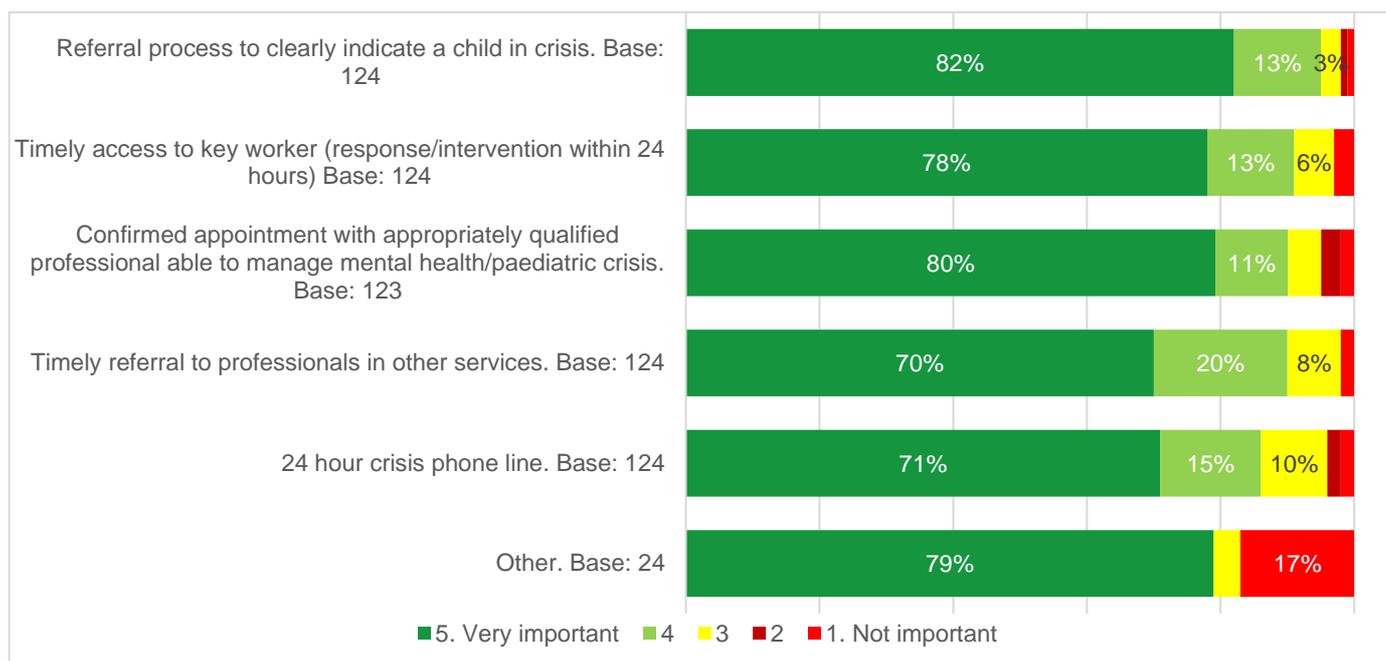
- Strategies to deal with different type of autism
- Sensory support
- Local system knowledge when registering with GP

The top two responses in each CCG area are:

- **Cannock Chase:**
 - 1:1 Psychological intervention (13 / 72%)
 - Timely/urgent referral to professionals in other services (13 / 72%)
- **Stafford and Surrounds:**
 - 1:1 Psychological intervention (31 / 78%)
 - Timely/urgent referral to professionals in other services (26 / 65%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Timely/urgent referral to professionals in other services (14 / 74%)
 - 1:1 Psychological intervention (13 / 68%)
- **East Staffordshire:**
 - 1:1 Psychological intervention (12 / 80%)
 - Timely/urgent referral to professionals in other services (11 / 73%)

Respondents were asked what support they would require during a crisis. Figure 23 shows all the proposed forms of support would be important to respondents during a crisis.

Figure 23. Q21 What support would you need during a crisis? Please score the following factors in terms of importance.



Other support mechanisms stated by respondents include: the support required is dependent on what the crisis is (3 / 43%), somewhere other than A&E (1 / 14%) and mental health support (1 / 14%).

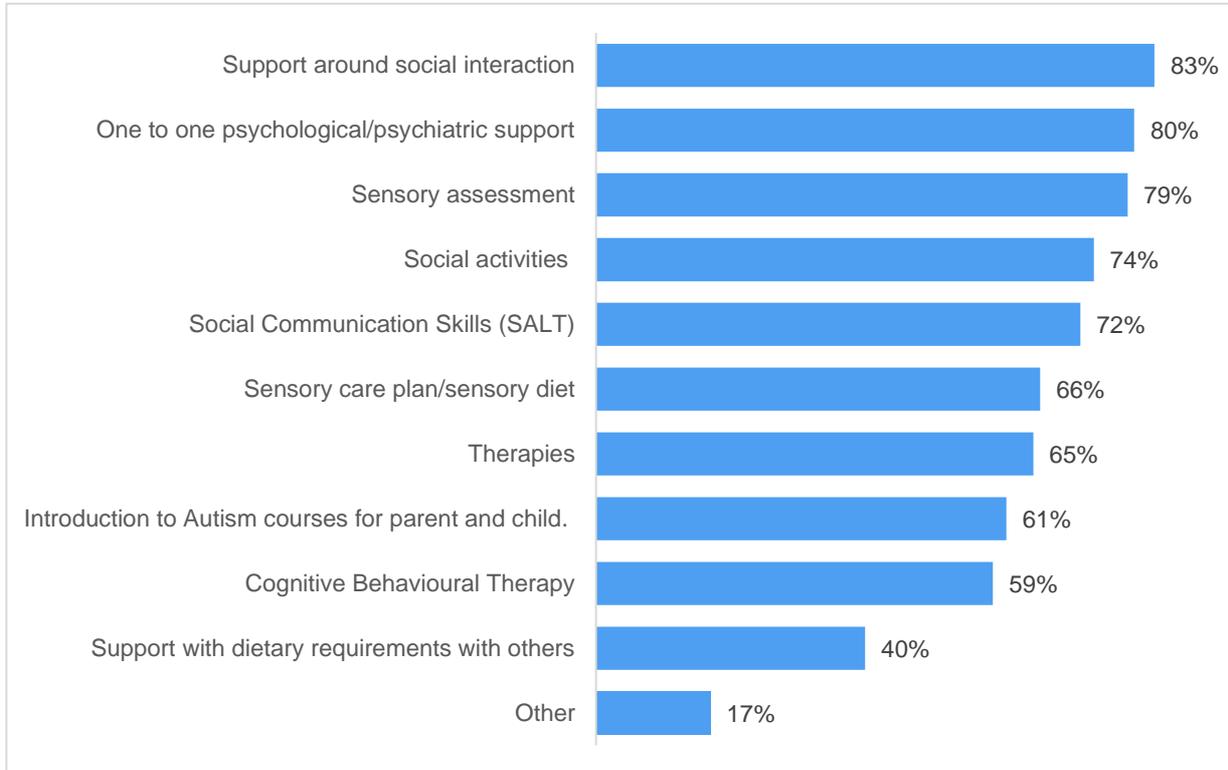
The top two most important (those selecting 4 and 5 in the rating) factors in each CCG area are:

- **Cannock Chase:**
 - Timely access to key worker (response/intervention within 24 hours) (27 / 96%)
 - Referral process to clearly indicate a child in crisis (27 / 93%)
 - Confirmed appointment with appropriately qualified professional able to manage mental health/paediatric crisis (26 / 93%)
- **Stafford and Surrounds:**
 - Referral process to clearly indicate a child in crisis (42 / 96%)
 - Timely access to key worker (response/intervention within 24 hours) (41 / 91%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Timely referral to professionals in other services (27 / 96%)
 - Referral process to clearly indicate a child in crisis (27 / 96%)
 - Timely access to key worker (response/intervention within 24 hours) (26 / 93%)
 - Confirmed appointment with appropriately qualified professional able to manage mental health/paediatric crisis (27 / 93%)
- **East Staffordshire:**
 - Referral process to clearly indicate a child in crisis (17 / 95%)
 - Timely referral to professionals in other services (17 / 94%)
 - Confirmed appointment with appropriately qualified professional able to manage mental health/paediatric crisis (16 / 94%)

3.2.8 Interventions

Respondents were asked which interventions (from a list) did they think would provide support to their child to live well with autism. Figure 24 shows the main interventions respondents would like to support their child are; support around social interactions (109 / 83%), one to one psychological/ psychiatric support (106 / 80%) and sensory assessments (104 / 79%).

Figure 24. Q22 Which of the following interventions do you feel would support your child to live well with autism from a future service? Base 132



Of those selecting other;

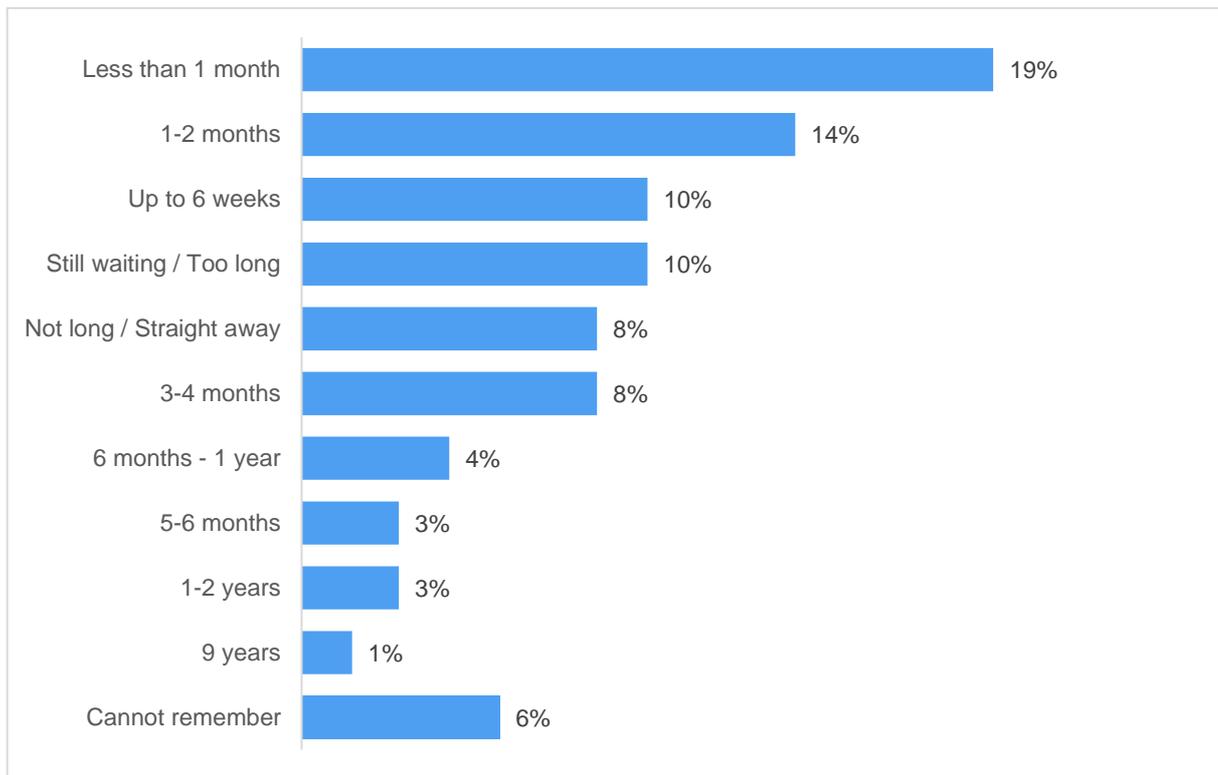
- 6 (26%) respondents commented family support
- 3 (13%) respondents commented school support
- 2 (4%) respondents commented emotional support for the child, behavioural workshops, access to more social activities and puberty support for children

The top two responses in each CCG area are:

- **Cannock Chase:**
 - Support around social interaction (25 / 86%)
 - Sensory assessment (22 / 76%)
- **Stafford and Surrounds:**
 - One to one psychological/psychiatric support (41 / 87%)
 - Sensory assessment (38 / 81%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Support around social interaction (29 / 88%)
 - Sensory assessment (28 / 85%)
- **East Staffordshire:**
 - One to one psychological/psychiatric support (15 / 83%)
 - Support around social interaction (15 / 83%)
 - Social activities (14 / 78%)

Respondents were asked how long they had to wait if they'd requested an intervention from autism services. Figure 25 shows how long respondents waited for an intervention from autism services. 7 (19%) respondents waited less than one month.

Figure 25. Q23 If you have requested an intervention from autism services, how long did you wait? Base 73



The top two responses in each CCG area are:

- **Cannock Chase:**
 - N/A (3 / 21%)
 - 3-4 months (2 / 14%)
 - 1-2 months (2 / 14%)
 - Less than 1 month (2 / 14%)
 - Not long / Straight away (2 / 14%)
 - Cannot remember (2 / 14%)
- **Stafford and Surrounds:**
 - Less than 1 month (8 / 29%)
 - N/A (6 / 21%)
- **South East Staffordshire and Seisdon Peninsula:**
 - 1-2 months (3 / 17%)
 - Less than 1 month (3 / 17%)
 - Not long / Straight away (3 / 17%)
 - Still waiting / Too long (2 / 11%)
 - Cannot remember (2 / 11%)
 - N/A (2 / 11%)
- **East Staffordshire:**
 - 1-2 months (3 / 30%)
 - Up to 6 weeks (2 / 20%)

Exemplar quotes

Respondents quotations below provide further detail on the comments raised by respondents around how long they had to wait for an intervention after requesting autism services.

“Ages, and then only got it because I went ballistic, and my kid ended up really ill before we got anything” [Cannock GP locality]

“Still waiting 12 months later for emotional support for my child with severe learning difficulties but told only for my child to attend a workshop which would be impossible” [Lichfield GP locality]

*“Not long but that was because Mid Psych were in group just before the procurement process started.”
[Uttoxeter GP locality]*

“Midlands Psychology contacted me following a crisis email by telephone to offer advice and support. Following that I had an appointment after 3 weeks. They were brilliant” [Stafford GP locality]

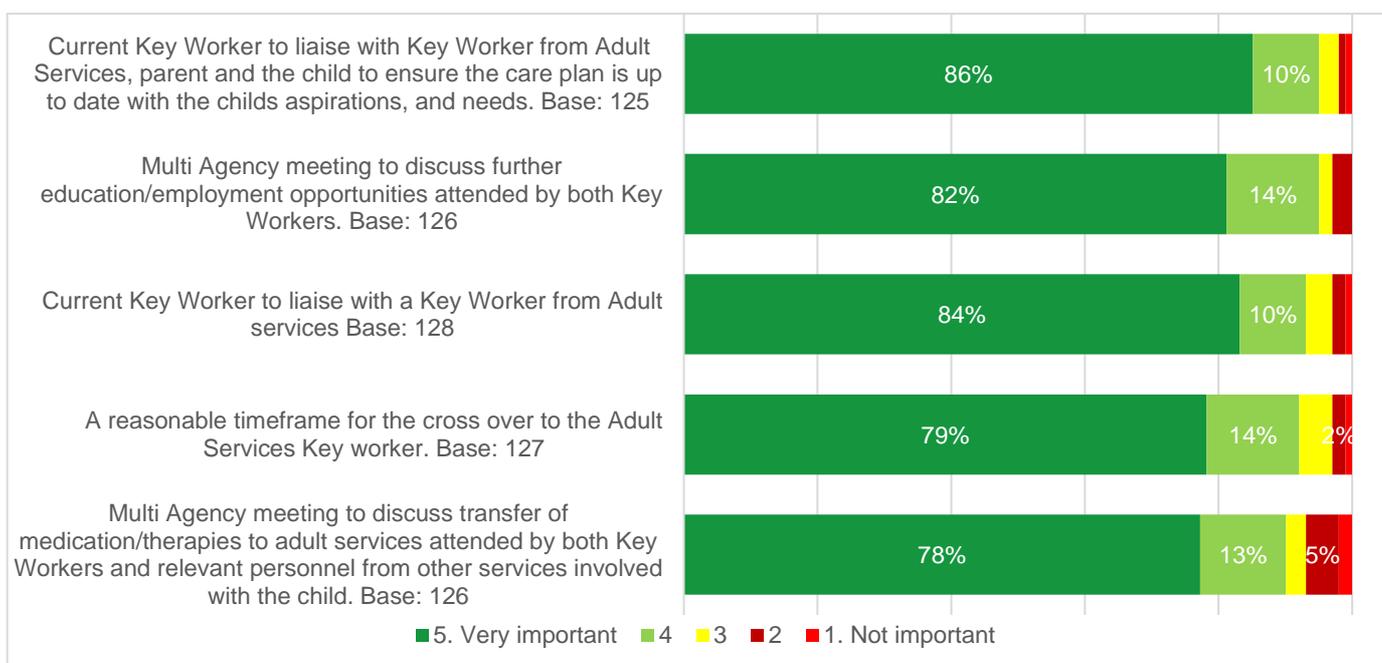
*“Requested Cognitive Behaviour Therapy last April and still waiting - had appointments in the summer but his anxiety isn't apparent then as he's not at school and away from the triggers”
[Lichfield GP locality]*

“We received confirmation that our request for support around feeding was accepted within 2 weeks. We attended a course that was great as we were able to speak to other parents that understood our concerns. We can't fault the service we have received with Midlands Psychology; they have been first class.” [Rugeley GP locality]

3.2.9 Future services

Respondents were asked what support would help to make the transition process easier as part of a future service. Figure 26 shows respondents' ratings of the importance of factors to make the transition process easier as part of a future service. Respondents viewed all of the factors as important, with 120 (96%) of respondents rating 'Current Key Worker to liaise with Key Worker from Adult Services, parent and the child to ensure the care plan is up to date with the child's aspirations, and needs' as very important or important. 114 (96%) respondents also rated 'Multi Agency meeting to discuss further education/employment opportunities attended by both Key Workers' as very important or important.

Figure 26. Q24 What support would help to make the transition process easier as part of a future service? Please score the following factors in terms of importance.



The top two most important (those selecting 4 and 5 in the rating) factors in each CCG area are:

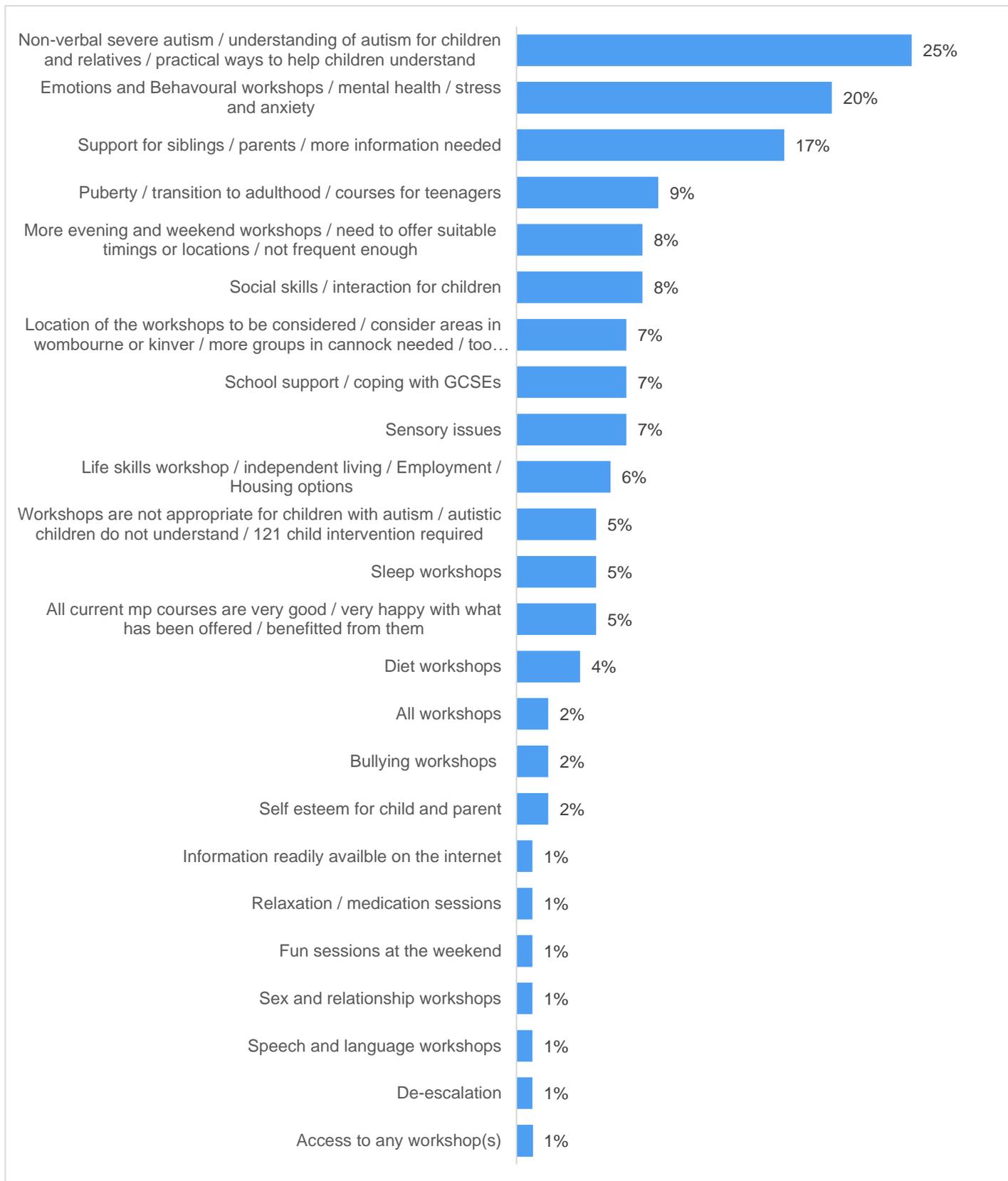
- **Cannock Chase:**
 - A reasonable timeframe for the cross over to the Adult Services Key worker. (30 / 97%)
 - Current Key Worker to liaise with a Key Worker from Adult services (29 / 94%)
- **Stafford and Surrounds:**
 - Current Key Worker to liaise with a Key Worker from Adult services (43 / 96%)
 - Current Key Worker to liaise with Key Worker from Adult Services, parent and the child to ensure the care plan is up to date with the child's aspirations, and needs. (43 / 96%)
 - Multi Agency meeting to discuss transfer of medication/therapies to adult services attended by both Key Workers and relevant personnel from other services involved with the child. (43 / 96%)
 - Multi Agency meeting to discuss further education/employment opportunities attended by both Key Workers (43 / 96%)
 - A reasonable timeframe for the cross over to the Adult Services Key worker. (41 / 91%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Current Key Worker to liaise with Key Worker from Adult Services, parent and the child to ensure the care plan is up to date with the child's aspirations, and needs. (30 / 100%)
 - Multi Agency meeting to discuss further education/employment opportunities attended by both Key Workers (29 / 100%)
 - Multi Agency meeting to discuss transfer of medication/therapies to adult services attended by both Key Workers and relevant personnel from other services involved with the child. (29 / 97%)

- **East Staffordshire:**

- Multi Agency meeting to discuss further education/employment opportunities attended by both Key Workers (17 / 100%)
- Multi Agency meeting to discuss transfer of medication/therapies to adult services attended by both Key Workers and relevant personnel from other services involved with the child. (15 / 88%)

Respondents were asked what workshops they would find helpful for their children. Figure 27 shows the workshops respondents would find helpful. Key themes were 'non-verbal severe autism' (25 / 25%) and emotional and behavioural workshops (20 / 20%).

Figure 27. Q25 What workshops would you find helpful for you and your child? Base 101



The top two responses in each CCG area are:

- **Cannock Chase:**
 - Non-verbal severe autism / understanding of autism for children and relatives / practical ways to help children understand (6 / 24%)
 - Emotions and Behavioural workshops / mental health / stress and anxiety (5 / 20%)
- **Stafford and Surrounds:**
 - Emotions and Behavioural workshops / mental health / stress and anxiety (9 / 27%)
 - Non-verbal severe autism / understanding of autism for children and relatives / practical ways to help children understand (8 / 24%)
 - Support for siblings / parents / more information needed (8 / 24%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Non-verbal severe autism / understanding of autism for children and relatives / practical ways to help children understand (6 / 24%)
 - Emotions and Behavioural workshops / mental health / stress and anxiety (4 / 16%)
- **East Staffordshire:**
 - Non-verbal severe autism / understanding of autism for children and relatives / practical ways to help children understand (4 / 27%)
 - More evening and weekend workshops / need to offer suitable timings or locations / not frequent enough (4 / 27%)
 - Support for siblings / parents / more information needed (3 / 20%)
 - School support / coping with GCSEs (3 / 20%)

Exemplar quotes

Respondents quotations below provide further detail on the comments raised by respondents around how type of workshops they think would be helpful for their children.

Non-verbal severe autism / understanding of autism for children and relatives / practical ways to help children understand

“Parents - coping strategies and understand the condition. Child - explain their differences relating to autism and coping strategies, life skills and communication. 18-25s geared towards age group - job skills, career advice, life skills, access to education.” [Cannock GP locality]

“I have been to a lot of courses provided by Midlands Psychology and they have been a fantastic source of information. Introduction to Autism I feel is important. Introduction to Emotions was also brilliant. My daughter also attended a girl’s group which was amazing for her.” [Stafford GP locality]

“We moved here from Nottingham and there was nothing like this service up there. We have done Intro to autism and this was brilliant. We learnt such a lot about our son and how to help him. He has done the emotions group and that really helped him. We are going to do the social skills. We have done the sleep group as well.” [Cannock GP locality]

“Introduction to autism was very good and everyone should do it. I took my parents because they didn’t understand at first. My son did I am me and emotions. I have attended the OT workshop and challenging behaviour workshop. The groups are really helpful. Parents have to learn how to help their child because this is for life.” [Lichfield GP locality]

Emotions and Behavioural workshops / mental health / stress and anxiety

“Child needing support to talk about feelings, wishes and gain a better understanding of their condition.” [Stafford GP locality]

“Anxiety child support groups - child friendly Eating disorders School support” [Stafford GP locality]

“Behaviour, diet, keeping focused, communication, support.” [Stafford GP locality]

Other verbatims

“For the child: what autism is, strategies for dealing with emotions, social situation training, decoding friendships and relationships, bullying - what it looks like and what to do if you are bullied, puberty” [Burntwood GP locality]

“Support for parents to get the best out of my child e.g. am I doing things right, how can I help him? Training for teachers and schools so they understand.” [Burton GP locality]

“Workshops that take into account that many children on the spectrum are not in school and are waiting a SEN placement. I have been unable to attend any of the workshops due to the time that they are taking place” [Perton GP locality]

“Information needs to be tailored for children Drop-in sessions would be useful to talk to a range of professionals depending on your specific needs” [Lichfield GP locality]

“Social groups/ advocacy groups - how to navigate Employment/ housing options Helping parents/ family to understand!” [Cannock GP locality]

“Needs to be a lot more when children are over 18 and transferring to adult services - there is nothing for them and this is when they need the most support with further education and employment and just being able to survive in the world. There needs to be a lot more joined up work with the schools so they understand the condition and how to support the parents rather than labelling the child as naughty and suspending them every time they have an episode.” [Burton GP locality]

“Practical ways to help children understand their autism and meet with children who also have autism Relaxation/meditation sessions for children to help them manage stress” [Rugeley GP locality]

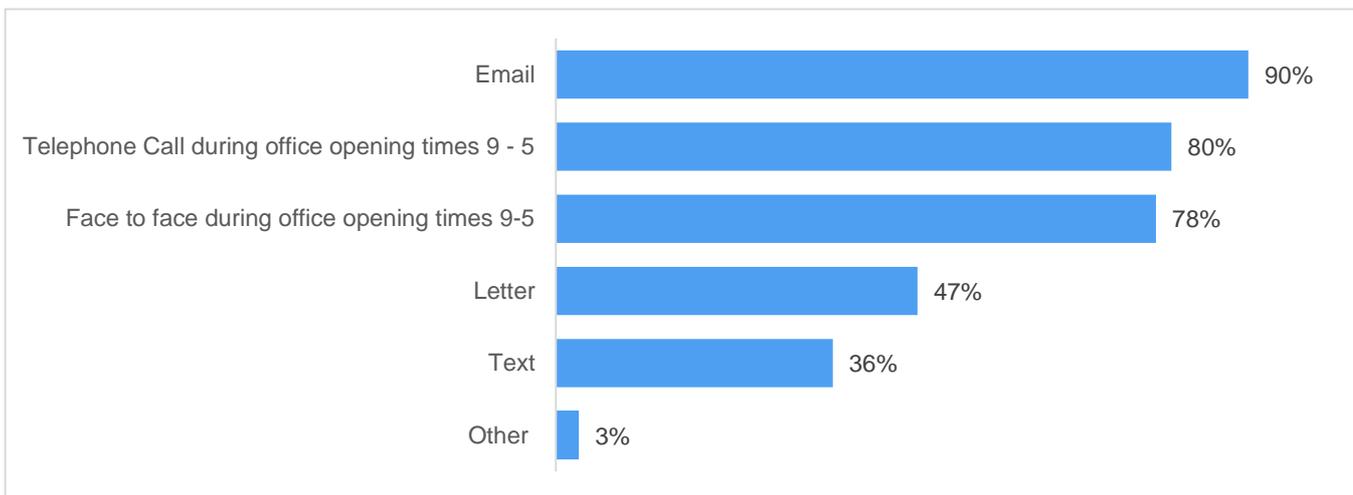
“A younger sibling course, my daughter is 6 and finds it hard to understand her brother's autism. Also, sessions to be made available out of school hours to avoid meltdowns over routine change.” [Cannock GP locality]

“Child to understand sensory processing disorder, child to understand social situations from kindness, being laughed AT and with, being bullied, when body language is mean,” [Stone GP locality]

3.2.10 Communications with future services

Figure 28 shows how respondents would prefer to communicate with a future service. Respondents could select more than one option, with email (123 / 90%) being the most selected choice. Two respondents who selected other indicated that they would prefer communication via an online forum.

Figure 28. Q26 How would you prefer to communicate with a future service? Base 134

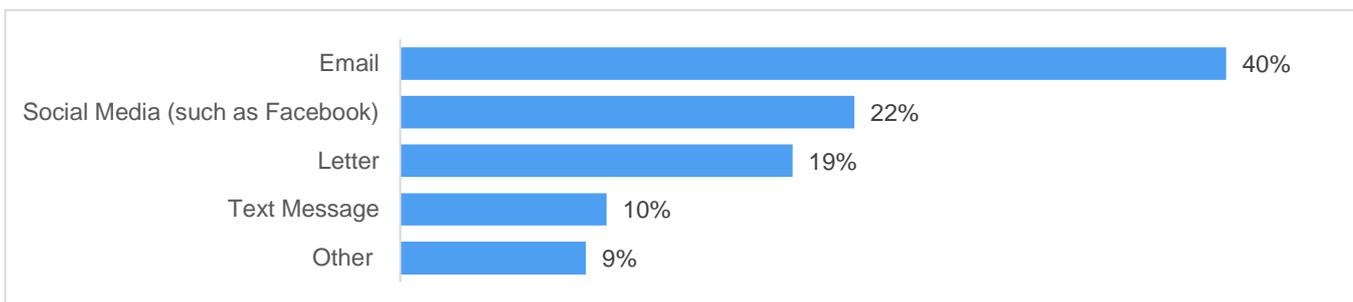


The top two responses in each CCG area are:

- **Cannock Chase:**
 - Email (28 / 88%)
 - Face to face during office opening times 9-5 (22 / 69%)
- **Stafford and Surrounds:**
 - Email (42 / 86%)
 - Telephone call during office opening times 9 - 5 (40 / 82%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Email (33 / 100%)
 - Face to face during office opening times 9-5 (32 / 97%)
- **East Staffordshire:**
 - Email (16 / 89%)
 - Telephone call during office opening times 9 - 5 (14 / 78%)

Respondents were asked how they would like to receive information about a future service, other events and courses. Figure 29 shows how respondents would prefer to receive information about a future service and other events and courses. Again, email (53 / 40%) was the most popular choice. Another method highlighted by respondents was leaflets (1 / 3%)

Figure 29. Q27 How would you prefer to receive information about a future service and/or other events/courses? Base 134



The top two responses in each CCG area are:

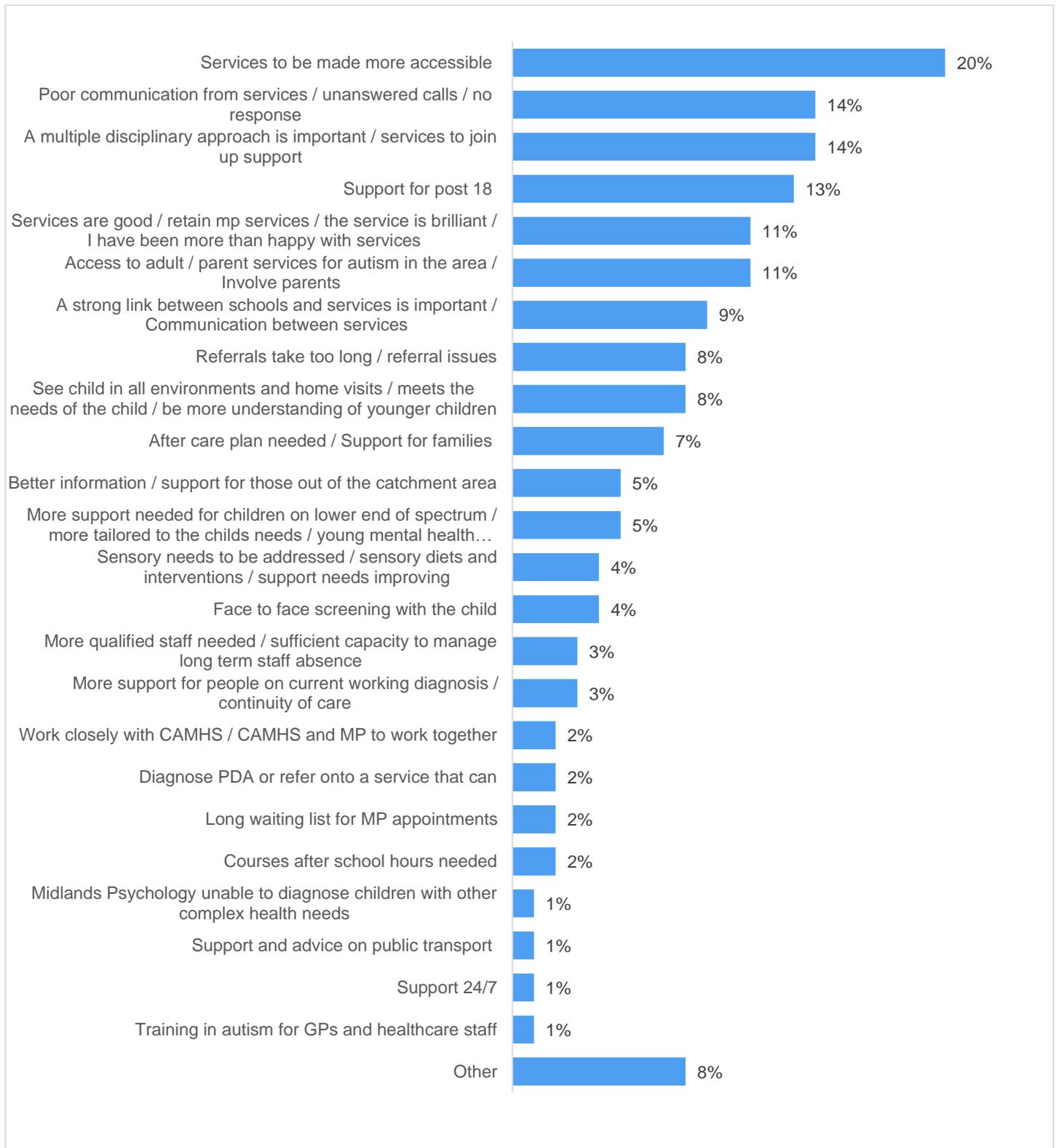
- **Cannock Chase:**
 - Email (19 / 59%)
 - Social Media (such as Facebook) (6 / 19%)
- **Stafford and Surrounds:**
 - Email (17 / 36%)
 - Social Media (such as Facebook) (11 / 23%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Letter (10 / 30%)

- Social Media (such as Facebook) (9 / 27%)
- Email (9 / 27%)
- **East Staffordshire:**
 - Email (8 / 44%)
 - Social Media (such as Facebook) (3 / 17%)
 - Letter (3 / 17%)
 - Other (please specify in box below) (3 / 17%)

3.2.11 Other considerations

Figure 30 shows the other considerations raised by respondents. Key considerations raised were the need for services to be more accessible (20 / 20%); poor communication from services (14 / 14%) and the need for a multi-discipline approach (14 / 14%).

Figure 30. Q28 What else do you feel we should take into consideration? Base: 100



The top two responses in each CCG area are:

- **Cannock Chase:**
 - A strong link between schools and services is important / Communication between services (4 / 17%)
 - A multiple disciplinary approach is important / services to join up support (4 / 17%)
 - Other (4 / 17%)
 - See child in all environments and home visits / meets the needs of the child / be more understanding of younger children (3 / 13%)
 - Services are good / retain mp services / the service is brilliant / I have been more than happy with services (3 / 13%)
- **Stafford and Surrounds:**
 - Services to be made more accessible (10 / 27%)
 - Poor communication from services / unanswered calls / no response (6 / 16%)
- **South East Staffordshire and Seisdon Peninsula:**
 - Support for post 18 (7 / 33%)
 - Services to be made more accessible (5 / 24%)
- **East Staffordshire:**
 - Access to adult / parent services for autism in the area / Involve parents (4 / 27%)
 - A multiple disciplinary approach is important / services to join up support (4 / 27%)
 - Support for post 18 (3 / 20%)
 - Services to be made more accessible (3 / 20%)
 - A strong link between schools and services is important / Communication between services (3 / 20%)
 - Referrals take too long / referral issues (3 / 20%)
 - Poor communication from services / unanswered calls / no response (3 / 20%)

Exemplar quotes

Respondents quotations below provide further detail on the comments raised by respondents about what else should be taken into consideration.

Services to be made more accessible

“Took so long to get diagnosis. Went on early bird course and people who were running it said they would give working diagnosis. Was not told about groups at the time and had to discover for ourselves. Need somewhere to call when in crisis. What support will be available for adult services as my son is 18. Nothing out there for him - he still has same needs at 19 as he does at 18 where do we go for help? Law says should provide services up to 25 so why isn't Staffordshire?”

[Burton GP locality]

“Hard to get through on the phone. Don't always have messages answered. Would like appointments to be more frequent. Need to prioritise calls and answering the phone and offering more phone access.” [Stafford GP locality]

“More access, more appointments so I have a chance of accessing the service. More than once a month. Weekly appointments would be great.” [Brewood GP locality]

“If Midland Psychology go you are putting children at risk. Mental and physical health will be damaged. To bring in a new service will be a backward step as requires familiarity.” [Stafford GP locality]

“Would really like some intervention/ support to help with school. Have SENCO at appointments. Schools need to understand autism and be educated. Forrest school and gardening activities. See a lot of signs for 'dyslexic friendly school' don't see any for autism friendly. Teacher training days for autism.” [Rugeley GP locality]

Poor communication from services / unanswered calls / no response

“I do not think MPS offer a professional service for asd. I had letters with incorrect information and other patients' information on several occasions, was treated with contempt when I complained, plus many more issues” [Burton GP locality]

“the service needs to be expanded the waiting lists for appointments is ridiculous, once you get your diagnosis it appears to be every man for themselves because unless you need to contact midlands psychology you do not hear anything from anyone.” [Stafford GP locality]

To reply to emails and confirm receipt of referrals” [Codsall GP locality]

Door lock. Not listened t at first Don't feel supported passed about from different services door shut don't know where to go Soon as got diagnosis everyone disappeared - speech therapist said not involved, educational psychologist not involved anymore.” [Uttoxeter GP locality]

A multiple disciplinary approach is important / services to join up

“Passes about between Local Support Team, paediatrics and school nurse Poor communication between the services” [Stafford GP locality]

“Diagnosis letter is too generic and not specific to the child More training needed for educational services - give less weight to teacher's opinion Being bounced around different services - damaged my own mental health and left child without support for 20 months Referrals need to be done better - standard questionnaire” [Stafford GP locality]

*“Services need to be able to offer ‘joined up’ support, between learning disabilities/medication.”
[Cannock GP locality]*

“There needs to be more/improved integration between all agencies Policy (local) needs to be less ambiguous and open to personal (head) interpretation. Need to apply and work with schools to apply flexibility in a person-centred way based on need. A blanket approach to discipline in school does not work for children with SEN. I am concerned about the procurement process and the large mental health provider in staffs are better places to write their bid. What support is midlands Psych receiving from commissioners in writing their bid. Midland partnership Trust is absolutely not the place for this service.” [Cannock GP locality]

Other verbatims

“There’s is nowhere in staffs that offer sensory intervention and sensory diets. Sensory support really lacks and needs improving.” [Stafford GP locality]

“We have had excellent support from Midlands psychology. It has been a lifeline. Speaking to others that understand and you don't need to explain. Ausums has helped all of us understand more and how to access further support and service.” [Stone GP locality]

“The service has been wonderful to me and my family. From the moment I had assessment to my interventions with my little one. Staff from the admin team to the Clinician i have made me feel listened to and guided when sometimes I have felt a little lost.” [Stafford GP locality]

“Please just provide a service that keeps our kids healthy and safe, I don’t want to end up in A & E, just to get some basic meds. I don’t want to have to email, phone, sit in the building to get anyone to provide basic support. It’s about time Staffordshire provided something decent.” [Cannock GP locality]

“You need more staff and to make these kids feel like they matter instead of them being a second thought” [Cannock GP locality]

“My child has been recently diagnosed so I am quite new to this, I feel that the group courses need to be more tailored to the child, my son will not do groups. There needs to be more in other areas everything is Staff” [Lichfield GP locality]

“Going into schools, educate them on autism - make sure all teachers are well informed. Promote groups more. Work with nurseries and pre-schools as well. Putting groups on at accessible times i.e. school hours. Accessible by public transport. Forrest school and gardening. Huge emphasis on schools. Make sure all people who have dealings with autistic children have a basic level of autism training. Supported living.” [Rugeley GP locality]

4 Summary and conclusion

4.1.1 Diagnosis

- 94 (75%) survey respondents stated their child was diagnosed through Midlands Psychology CIC.

4.1.2 Autism Support

- Most respondents (87 / 67%) last requested support from autism related services within the last six months.
- 117 (90%) respondents had received treatment within 2 years.
- 25 (20%) had requested support for children's anxiety or anxiety support and 24 (205%) requested support with diagnosis or assessment.
- Behavioural, emotional, school and psychological support were also regularly requested.

4.1.3 Referral Process

- 117 (91%) respondents considered the confirmation of a referral being received as very important.
- 89 (66%) indicated that a period of up to three weeks would be a timely response to receive confirmation.
- 62 (51%) respondents have waited up to six weeks for a referral date while 27 (22%) had to wait longer than 12 weeks.
- 18 (49%) of those stating they had to wait more than 12 weeks for a referral date commented they had to chase the referral themselves or no confirmation had been received.
- 59 (49%) respondents waited up to six weeks from the date their initial referral was sent to receiving an appointment. 22 (18%) respondents stated they waited more than 12 weeks.
- 125 (97%) respondents thought up to 12 weeks was a reasonable timeframe to be seen by a future service once a referral has been accepted.

4.1.4 Assessment Process

- Most respondents felt waiting times for the assessment process to start, timeliness of appointments, being kept informed, being seen by the same professional, information about additional support available and how to access it were all very important.
- 73 (58%) respondents do not have concerns about a trainee being involved in their care as part of future service, while 37 (30%) commented they don't have concerns as long as trainees are fully supervised, competent, trained or a second opinion is available.
- When asked what factors were important during their first appointment with a future service, most respondents felt having enough time to discuss concerns, feeling listened to, having clear and quality information, access to second opinions, support offered to parents/carers and a calm environment were very important. Having the child present at the appointment was considered less important.
- 116 (85%) of respondents stated they would prefer to be informed about a diagnosis face to face.

4.1.5 Key workers

- 97 (71%) respondents believe it is very important for patients to be assigned a key worker following diagnosis as part of future services.
- All the options given for support from key workers were important to most respondents, the most popular being a point of contact for crisis situations.
- Most respondents indicated they would prefer access to a key worker via direct email, face to face interaction or by telephone.

4.1.6 Crisis Care

- 88 (77%) respondents felt there was not anywhere they could safely take their child in the event of a crisis but 87 (64%) felt they needed additional support from Autism services at this time.
- A range of services were selected by respondents for where they take their child during a crisis, the most popular being Midlands Psychology.
- Of those who had not taken their child for crisis support, 38 (56%) stated there was limited support available or they had been unable to access the service.
- 73 (75%) respondents needed one to one psychological intervention during a crisis period while 68 (70%) felt they needed a timely referral to professionals in other services.
- All the proposed forms of support were deemed very important by the majority of respondents during a crisis. This included the referral process to clearly indicate a child in crisis and a confirmed appointment with an appropriately qualified professional.

4.1.7 Interventions

- The main interventions respondents would like to support their child are; support around social interactions (109 / 83%), one to one psychological/ psychiatric support (106 / 80%) and sensory assessments (104 / 79%).
- The waiting time after requesting an intervention from autism services varied greatly, with 39 (53%) stating they had to wait up to six months.

4.1.8 Future Services

- Respondents viewed all of the factors to make the transition process easier as part of a future service as important, with over 90% of respondents stating they are important or very important.
- Respondents indicated workshops on non-verbal severe autism (25 / 25%) and emotional and behavioural workshops (20 / 20%) would be helpful.

4.1.9 Communications with future services

- Email (123 / 90%), telephone (109 / 80%) and face to face interactions (106 / 78%) were the most popular methods of communicating with a future service.
- The most popular method for hearing about future services, events and courses was email (53 / 40%).

4.1.10 Other Considerations

- Other key considerations raised were the need for services to be more accessible (20 / 20%), poor communication from services (14 / 14%) and the need for a multi-discipline approach (14 / 14%).