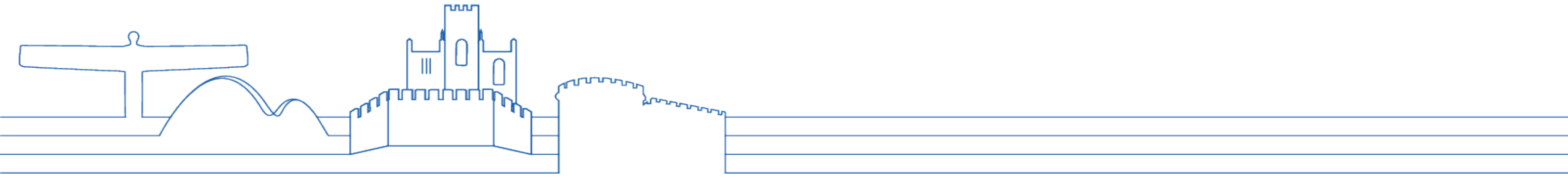
NHS
North East and
North Cumbria

Co-designing pre-assessment and post-diagnostic autism support services in Tees Valley

Stakeholder views to inform the scope of the services



This report was produced by Involve North East on behalf of the NHS North East and North Cumbria Integrated Care Board.

We are an independent organisation who specialises in involvement and engagement. We work with integrity, ensuring people's voices influence the design of services they receive.

We have vast experience and expertise in gathering the views and opinions of patients, carers and the general public in relation to health services. For example:

- service evaluations
- changes to care pathways
- locating new services

We employ quantitative and qualitative data collection techniques including:

- Questionnaires – paper-based and online
- Participatory appraisals
- Drop-in events
- Face-to-face and telephone interviews
- Focus groups
- Informal group discussions

For more information about the services we can provide please contact AJ White on 0191 226 3450 or email aj@involvene.org.uk. Visit our website at: www.involvene.org.uk

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Introduction

- NHS North East and North Cumbria Integrated Care Board (NENC ICB) in Tees Valley is looking to commission two new services which intend to support people waiting for an autism assessment, and autistic people, post-diagnosis.
- There are approximately 5000 autistic people living in Tees Valley and a further 1400 people awaiting an autism assessment. Around 80.0% will receive a diagnosis of autism at their assessment however the average waiting time for an assessment is around 555 days.
- While measures to reduce waiting times are being explored elsewhere, support is needed for people while they are waiting for their assessment.
- Furthermore, there is currently no post-diagnosis support in place once individuals receive a diagnosis.
- Therefore, they would like to offer support where needed, to people awaiting an assessment and to those who have received a diagnosis, so that they can access the services and support that they need.

Scope of services

- Pre-assessment service
    - There are no guidelines around what this type of service should cover although education around how autism might impact individuals would be outside the scope of the service.
- Post-diagnostic service
    - National Institute for Clinical excellence (NICE) make several recommendations for supporting young autistic adults and it is expected that these would form core functions of a post-diagnostic service:
        - Training and awareness raising for professionals.
        - Up-to-date, accessible information.
        - Parent/carer training and education programmes (individual and group)
        - Training and education programmes for young people (individual and group).
        - Information, advice and guidance.
        - Good transition planning and processes that are young person led.
        - Family support.
    - In addition to the above, the service will aim to improve the support offered to autistic people so that they receive the right support and advice to help meet their individual needs, and ensure they are able to achieve the best outcomes possible. It is expected that the service would provide:
        - An online/face-to-face educational programme.
        - Access to a support worker who could help with e.g. decision making, acting as an advocate, education, (further education/universities) employment, personal needs, family support or navigation between support services.
        - Access to peer support networks.
- Previous insights
    - During 2022 engagement work was conducted by Tees Valley Clinical Commissioning Group with 13 autistic young people aged 16 to 25 years old, to understand what support was available to their age group and what additional support they wanted. They provided a range of ideas:

Support service ideas	No. of respondents
Support around mental health e.g. anxiety, low mood	6
Support going to school/college/university	5
Support with daily life tasks	4
Access to peer group activities	3
Coping strategies	3
Provision of information about autism and what it means	3
Support to take part in hobbies/interests	3
Sharing diagnosis and what this means with schools/family	2
Support around furthering careers e.g. work experience, careers advice	2
Access to an occupational therapist (OT)	1
Budgeting	1
Greater awareness of autism from teachers	1
One-to-one support	1
Support around benefits	1
Support around health and wellbeing	1
Support around socialising	1

No. of respondents: 13
Respondents could give more than one answer

Researchers also highlighted a number of comments the young people made about support, with the majority highlighting a lack of support within education settings. Others commented on the peer support available and support at diagnosis.

> “Higher education is incredibly difficult with ASD [autism spectrum disorder]. Little to no support.”
>
> “If I had had the right support I wouldn't have crashed and burned at uni.”
>
> “Did attend DC [Daisy Chain] but at 17 don’t really want to hang around with 12 year olds - too young for adults’ group.”
>
> “Once I got my diagnosis no professionals did a follow-up call or gave me any support and still don’t now.”

Engagement activity

- In addition to the insights gathered in 2022, commissioners wanted the new services to be co-designed with potential service users to ensure that they meet the current needs of the people they are hoping to support. Involve North East was asked to engage with stakeholders to find out:
    - What people would want from a service while waiting for an autism assessment including:
        - The type of support.
        - The format of the support.
        - Travelling for support.
        - Accessing a travelling hub.

        - Current support accessed.
    - What autistic people would want from a post-diagnostic service including:
        - The type of support.
        - The format of the support.
        - Other reasonable adjustments.
        - Travelling for support.
        - Accessing a travelling hub.
        - Current support accessed.
        - Type of support needed whilst waiting for an assessment.
        - Type of support needed at time of diagnosis.
    - What carers/family members of autistic people would want from a post-diagnostic service including:
        - The type of support provided for autistic people.
        - Current support accessed.
        - Satisfaction with support available.
        - The type of support they would like.
        - The format of the support.
        - Travelling for support.
        - Accessing a travelling hub.

- Two surveys were used to gather feedback from:
    - Those waiting for an autism assessment.
    - Autistic people, post-diagnosis.
    - They were available online and in other formats upon request.
    - They were open between 15th May and 14th July 2024.
    - They were promoted across a range of channels:
        - X and Facebook, including posting in relevant community Facebook groups.
        - Local voluntary, community and social enterprise organisations with the request to cascade the information.
        - NHS organisations including Tees, Esk and Wear Valley NHS Trust who promoted it to relevant staff and patients and NENC ICB who promoted it to their involvement mailing list and displayed it on their website.
    - Sixty-nine people who are currently awaiting an autism assessment shared their views. Eleven of this group lived outside of Tees Valley; their responses have been summarised separately (see Appendix 4). See Appendix 1 for a profile of respondents.
    - Thirty-four autistic people shared their views. Three of this group lived outside Tees Valley; their responses have been summarised separately (see Appendix 4). See Appendix 2 for a profile of respondents.
        - Thirty carers/family members of autistic people shared their views. Of this group two lived outside of Tees Valley; their responses have been summarised separately (see Appendix 4). See Appendix 3 for a profile of respondents.

- In order to illicit a greater depth of information than that provided by the survey, the opportunity to take part in a focus group or provide an individual response was promoted across the channels identified above. Those responding to the survey were also invited to take part. Thirteen self-selecting people took part.
    - Pre-assessment:
        - Online focus group – 4 people (plus 1 individual who contributed via individual feedback).

- Post-diagnosis:
    - Face-to-face focus group – 4 people.
    - Post-diagnosis online group – 2 people.
    - Interview with carers/family members – 1 individual
    - Written feedback – 2 individuals.

The following is a summary of the findings broken down by:

- Survey responses.
- Focus groups/individual feedback findings.

Survey findings – people awaiting an autism assessment

This section summarises the findings of:

- 58 respondents who live in Tees Valley.
    - 28 responded themselves.
    - 30 responded on behalf of someone awaiting an assessment.

Please note that not all respondents answered every question.

Feedback from respondents living outside Tees Valley can be found in Appendix 4.

Key themes

Current support accessed

- Nearly two-thirds of respondents (63.6%) are currently accessing information and support outside of the NHS whilst waiting for their autism assessment. They are most likely to visit charity websites (77.1%), conduct general online searches (68.6%), look on NHS websites (65.7%) or look to social media and related platforms such as YouTube or Facebook (62.9%).

Service requirements

- There was strong support for all listed suggestions but in particular information about coping strategies (100.0% of respondents strongly agreed or agreed), available autism services (94.8%), how autism may affect them (93.1%) and support and information about autism for family members (91.4%). There was less support for advice around education (27.6%) and dealing with loneliness or isolation (54.4%).
- In terms of the types of support provided, the vast majority of respondents (94.7%) wanted support from trained workers (compared to information and advice).
- When asked what would make the biggest difference to them whilst waiting for an assessment, access to support around emotions was most commonly mentioned (46.5%), followed by having regular contact and updates about how they are progressing on the waiting list and expected wait times (41.9%). Being provided with information on where to get support whilst they wait was also requested by over one quarter of respondents (25.6%).

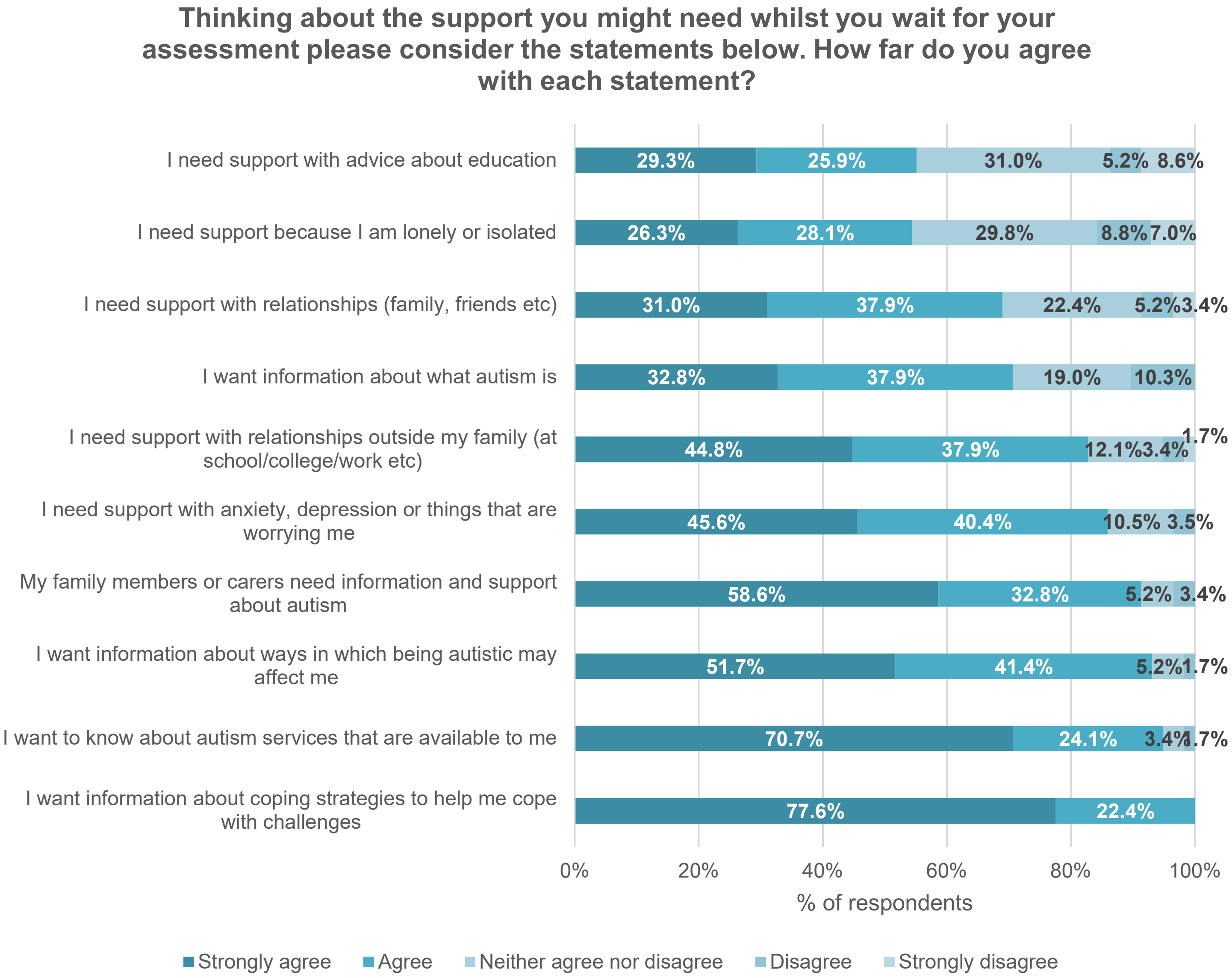
Accessing the service

- In terms of the format of this support, respondents wanted flexibility, with the option to have in-person and online access (68.5%). One-to-one face-to-face support was equally, strongly supported (68.5%). Fewer respondents would like group support, either in-person (29.6%) or online (22.2%) and support via telephone (25.9%) or text message (25.9%).
- Around two-thirds of respondents (64.2%) would be willing and able to travel to get face-to-face support and when asked about the likelihood of accessing a travelling hub three-quarters of this group (75.5%) answered positively.

Summary of findings

Respondents were initially asked to think about what support they might need whilst waiting for an assessment. They considered the following statements and were also able to identify other requirements not listed.

Support needed



No. of respondents: 58

- There was strong support for all types of support listed and all survey respondents identified at least one type of support that they would like.
- The chart shows that all respondents wanted information about coping strategies (77.6% strongly agreed and 22.4% agreed with the statement).
- The vast majority of respondents (94.8%) wanted to know about autism services available to them (70.7% strongly agreed and 24.1% agreed with the statement).
- A similar proportion (93.1%) wanted information about how autism may affect them (51.7% strongly agreed and 41.4% agreed with the statement).

- 91.4% felt that their family members or carers needed information and support about autism.
- 86.0% of respondents wanted support around anxiety, depression or things that worried them.
- There was less support for advice about education (55.2% strongly agreed or agreed) and support to overcome loneliness or isolation (54.4% strongly agreed or agreed).

Four respondents suggested other support:

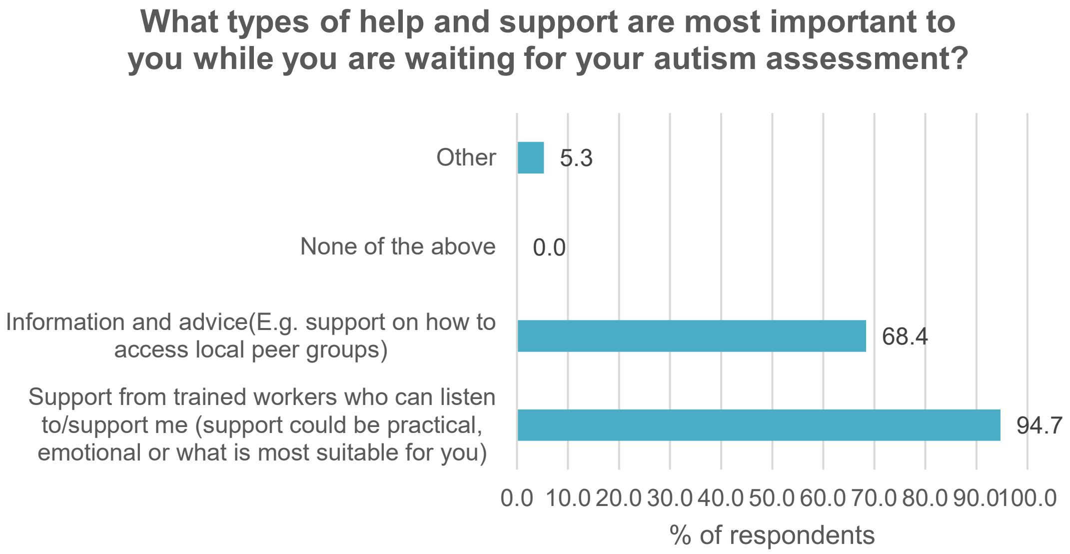
Other support	No. of respondents
Regular/consistent check-in/contact and updates whilst awaiting assessment	2
Physical relationships	1
Support with employment/reasonable adjustments	1
Emotional/mental health	1

No. of respondents: 4
Respondents could give more than one answer

"Support whilst waiting for my diagnosis would be massively beneficial. Not knowing how long diagnosis can take is a massive stress and this new identity is hard to adapt to with no support."

"More awareness particularly with bigger employers in the north east. Help with reasonable adjustments and understanding my own needs. Wellbeing support from the trauma of not knowing I was neurodivergent until 40."

Respondents were also asked what types of support were most important to them.



No. of respondents: 57
Respondents could give more than one answer

- 94.7% wanted support from trained workers.

- Over two-thirds (68.4%) wanted information and advice.
- Three respondents (5.3%) requested other support:

Other support	No. of respondents
Tailored/person-centred support	1
Behaviours	1
Understanding autism	1
Support for professionals working in the field who are neurodivergent	1

No. of respondents: 3
Respondents could give more than one answer

> **“Support to be tailored/person centred as with autism, unless it is specifically identified they will assume it does not apply to them as they don't hit every criteria.”**

Respondents were asked what would make the biggest difference to them while on the waiting list for an autism assessment.

Biggest difference	No. of respondents	% of respondents
Emotional Support - "someone to speak to"	20	46.5
Regular/consistent contact and updates whilst on waiting list	18	41.9
Information on where to get support whilst waiting	11	25.6
Reduced waiting times	8	18.6
Help with day-to-day/coping skills	6	14.0
Neuro-diverse tailored service and support	6	14.0
Recognition of impact of symptoms, pre-assessment	6	14.0
Reasonable adjustments (pre-assessment and post-diagnosis)	4	9.3
Advocacy support	2	4.7
Support for neurodivergent parents	2	4.7
Support with communicating with others	1	2.3

No. of respondents: 43
Respondents could give more than one answer

- Nearly half of respondents (46.5%) wanted emotional support and someone to talk to about how things are affecting them and managing their feelings.
- Having regular contact once on the waiting list to understand how they are progressing was requested by 41.9% of respondents whilst 18.6% wanted a reduction in the time they must wait for an assessment.
- One quarter of respondents (25.6%) wanted information on where to get support whilst waiting.

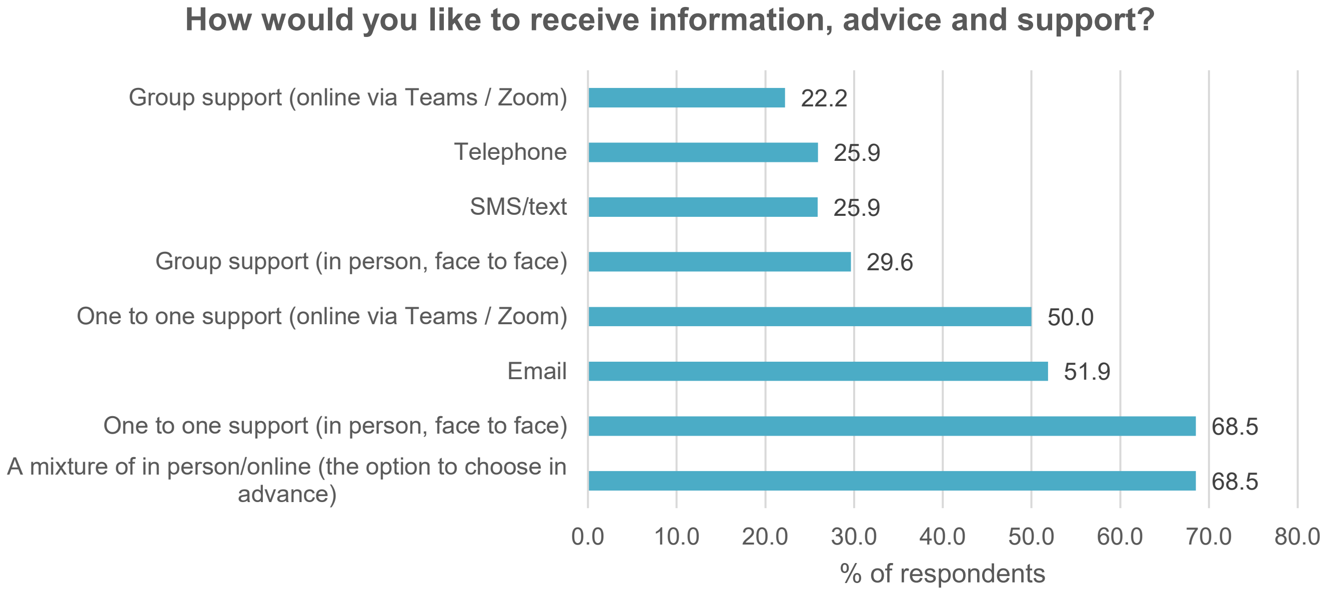
> **"Having someone to speak to while I wait. It's great that I've been put forward for an assessment however in the meantime I'm struggling and don't seem to get much more help as I've been referred. Learning some new coping skills or other things to help with day-to-day stuff which I can find overwhelming on my own."**

> **"It is lonely whilst waiting for assessment. The long waiting lists seem never ending. Regular updates on waiting lists would be beneficial so you know that the assessment is coming closer."**

> **"My daughter is on the waiting list for assessment and diagnosis and has been for two years. She was referred to the team and initially assigned a support worker after the initial pre-assessment however this person only had one call with my daughter before going on sick leave and then leaving. A new support worker was assigned after following this up with the service, but they rely on trying to contact my daughter by phone despite us advising them that this is not a comfortable way for her to communicate. No alternatives are offered."**

> **"Having a single contact who I could speak with (email/text) to help with issues, challenges, and to help locate good sources of support and information while waiting for assessment. Currently there are well-being check questionnaires but once filled out there is no further feedback around these."**

Format of potential support

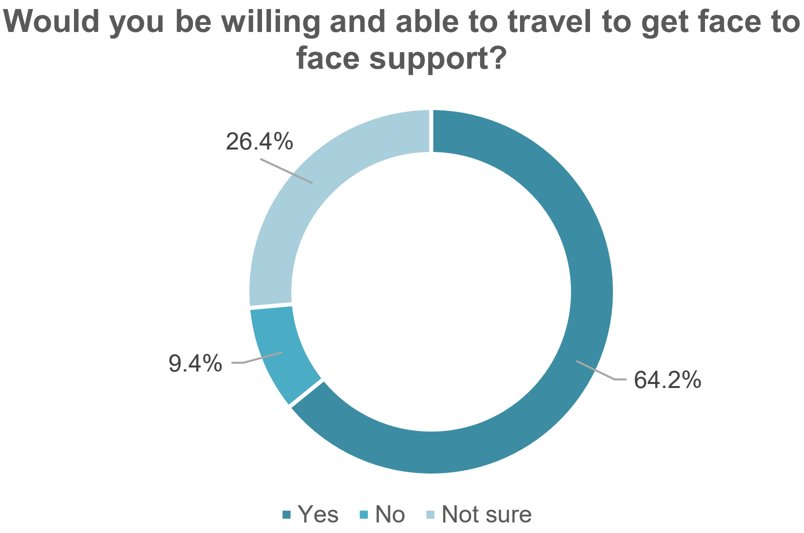


No. of respondents: 54
Respondents could give more than one answer

In terms of the format of this support:

- Over two-thirds of respondents (68.5%) wanted to be able to choose between in person and online.
- The same proportion (68.5%) would like one-to-one support in person.

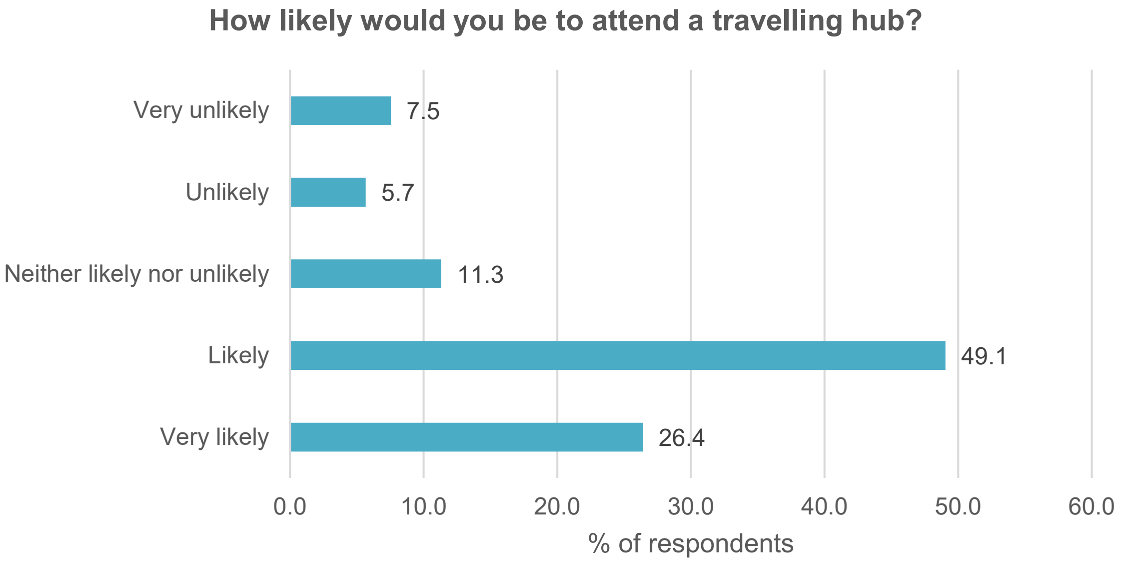
- Respondents were less likely to want group support whether it be online (22.2%) or in person (29.6%), support over the telephone (25.9%) or SMS/text support (25.9%).



No. of respondents: 53

Of those respondents who stated that they would like face to face support (53), almost two-thirds were willing to travel to get this support (64.2%).

This group were also asked about the likelihood of them attending a travelling autism hub in future. This could be a service that is open 5 days a week, but each day it is based at a different community centre or other site e.g. Monday at Middlesborough, Tuesday at Stockton. This would be to ensure that people have the widest range of options to attend i.e. you could select to attend on a day of a week that was most suitable or at a location that was closest to get to.

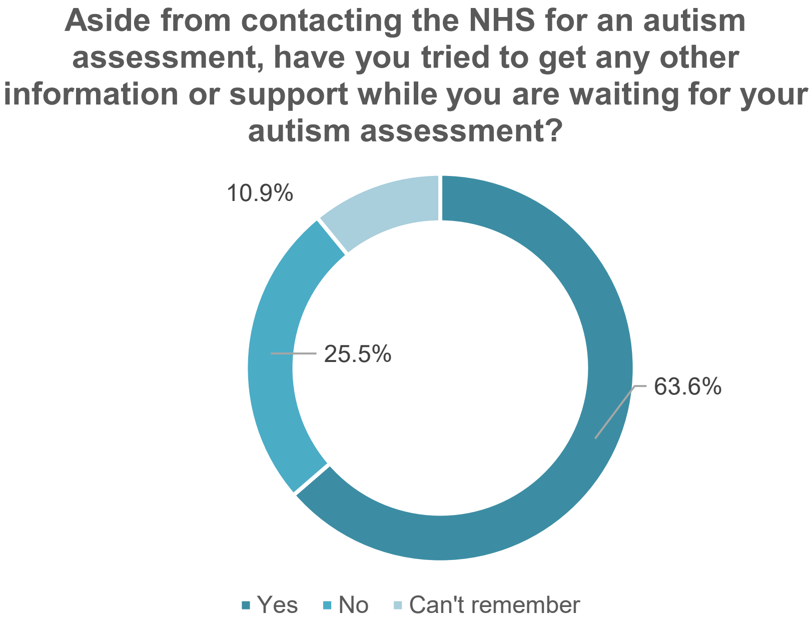


No. of respondents: 53

- Three-quarters of respondents (75.5%) stated that they would be likely or very likely to attend a hub.

- 13.2% would be unlikely or very unlikely to attend.

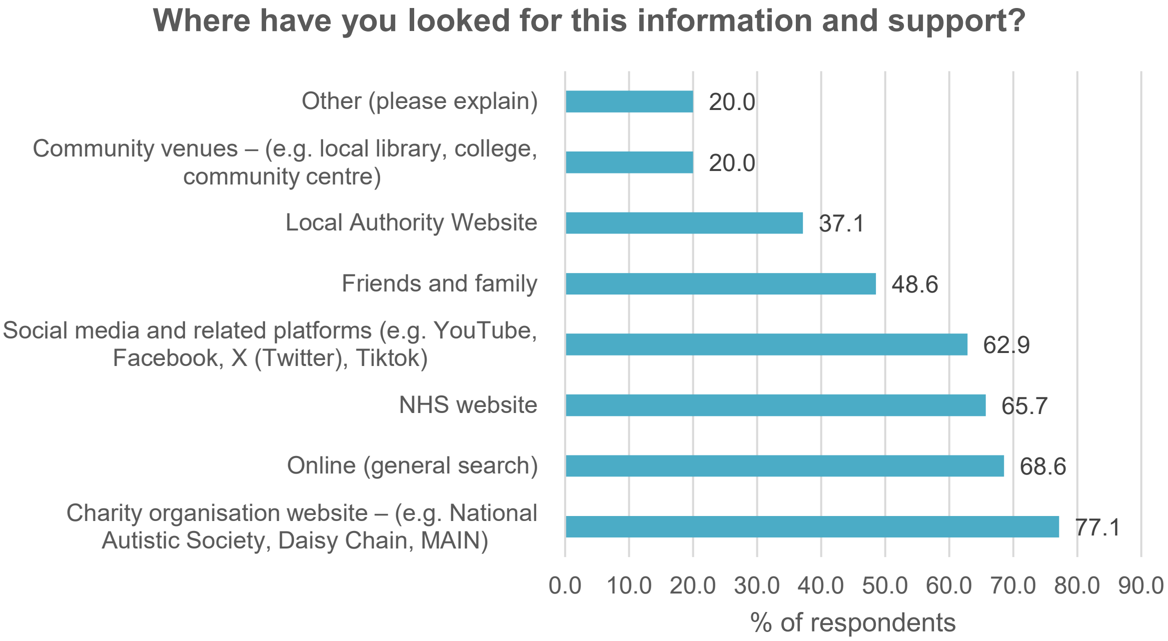
Current support



No. of respondents: 55

Respondents were asked whether they had tried to get any information or support whilst they wait for their autism assessment.

- Nearly two-thirds (63.6%) indicated that they had.



No. of respondents:35

- Over three-quarters of respondents (77.1%) had accessed charity websites.

- Over two-thirds of respondents (68.6%) had done general online searches for information and support.
- A similar proportion had accessed the NHS website (65.7%).
- Over six-in-ten respondents (62.9%) accessed social media platforms.
- Community venues (20.0%) and local authority websites (37.1%) were less likely to be used.
- Seven respondents (20.0%) had searched elsewhere:

Information/support source	No. of respondents
Books	2
Community Mental Health Team	1
Personal knowledge acquired through my job	1
Private health care support	1
Occupational health	1
Online communities linked through friends/contacts	1
TV programmes	1

No. of respondents:7
Respondents could give more than one answer

Focus group feedback findings – people awaiting an autism assessment

This section summarises the findings of a focus group with four people who are currently awaiting an assessment for autism.

Key themes

Service requirements

- It is important for people waiting for an assessment to have as much clear and accurate information as possible to allow them time to process and plan, alleviate anxieties and any concerns that they may have been forgotten. Participants requested:
    - A system for providing them with regular updates in relation to their ‘place in the queue.’ Some suggested that a text or email service would suffice.
    - They would also like to be provided with clear information when first added to the waiting list to understand the process they will go through whilst waiting for an assessment including regular contact points (the format of these contacts and their purpose), any support that is available to them and how this is accessed.
- To offer a service which is as accessible as possible, it was felt that staff needed a depth of understanding of autism. Participants felt that as a minimum, any staff employed by the service should have autism awareness training (and that this could be provided by autistic people) and ideally, some staff would be neurodivergent.
- Participants felt that the service should provide support around emotional wellbeing, to help people with coping strategies while they wait for their assessment. Their experience of mainstream Talking Therapies services was that pathways were not appropriate for neurodivergent people.
- One-to-one advocacy support or a named support worker was also suggested to help people access services they might not be aware of, as was support to access employment.
- It was also felt that being provided with a map of available community services would be useful.
- When asked to consider peer support, participants felt that it would be useful for connecting with like-minded people and to be ‘seen, heard and understood’ but identified barriers to group activities. They wanted the group to be made of people like them awaiting an assessment and not people already diagnosed. Some would prefer interest-based or identity groups whilst others did not have a preference.

Accessing the service

- Participants suggested that when communicating with people awaiting an assessment there should be an acknowledgement of how autistic people may process information. Sensitivity towards language used in written information such as letters should be applied.
- They felt that there should be flexibility in how support could be accessed to allow for individual needs and preferences. Group support, one-to-one, online, and in-person were all suggested, and the pros and cons discussed but all participants felt that, if limited by resources, one-to-one should be the initial offer.

- Clear written and visual information on physical spaces that would be accessed as part of the service was requested (an advocate or support worker could assist them to access these spaces). A text reminder service for any appointments was also suggested.
- A travelling hub was a difficult concept for participants to comment upon as there was no detail about what would be there, or how it would operate. To consider accessing a hub they would need to know in detail why they would go there – what would they access there, how to get there, what the building was like etc. They highlighted barriers to consider such as people who work full-time, being located in busy areas and sensory distractions within the building.

Summary of findings

What kinds of support do you think should be offered with a pre-assessment service?

Clear communication, information and updates about waiting times for assessment

One of the most frequent responses to this question was the need to have clear information about the whole process, but particularly at what stages people would be contacted and, where possible, what the time frames would be. Participants recognised that **"waiting lists exist,"** but that it would be more helpful for these to be 'realistic' and accurate.

> **"Realistic waiting times alongside information at meetings…correct information would be beneficial."**

It was also felt that this information should be communicated from the very start of being referred for autism assessment, and that any stated intentions regarding meetings or phone calls should be adhered to.

All participants described experiencing long periods without any communication from the health service, despite, for example, being advised that they would be contacted within a specified time.

It was suggested that regular updates would help people manage anxiety whilst awaiting assessment by reassuring them that they had not been forgotten about and to advise them of progress being made.

> **"Monthly texts about waiting times [as an indicator] would be helpful…to know where you're sitting [on the list] and what to expect."**

Participants described how ambiguity was a big trigger for anxiety, and that there currently is not enough information on each stage of the 'pathway' for accessing support.

> **"There isn't enough information on timescales and what [the purpose of] different meetings are or what they would look like."**

Struggling with ambiguity also included the way in which information was presented. For example, within the format of the focus group, being presented with a 'blank sheet of paper' requesting their views on what the service should provide, was not necessarily conducive to generating wider insights for those who are likely to be neurodivergent in their thinking processes.

> **"Being provided with a menu of options [of what the ICB are thinking could be support options] would have been really useful."**

Autism informed/specialist mental health and wellbeing and advocacy support.

Most participants spoke about a lack of understanding of autism across services more broadly as well as the stigma that they felt still exists about being diagnosed as autistic.

> **"I feel like I've experienced less stigma around being Trans than being neurodiverse. ….Almost more vulnerable being autistic."**

For those who were older, living with (potentially) undiagnosed autism, they felt had contributed to poor mental health, as well as a lack of confidence in a neurotypical health system to be able to support them.

Participants felt that a sensitivity to these experiences could be better conveyed through language used by the health service and by ensuring that neurodivergent individuals were employed within such a service.

> **"Support needs to be authentic. Neurodiverse people are present in all walks of life. They need to be also represented within the service."**

> **"A lot of the language needs to change, some of the letters aren't great...[the tone of correspondence made me feel like] if I receive a diagnosis, the benefit is for other people [i.e. professionals], to deal with you better. Not [conveying the message that] we would like to help." [Showing a letter explaining that if they weren't diagnosed as autistic, their case would be closed]. What do I do if my case gets closed? I still need support."**

> **"How many times have I heard 'Everyone is a little bit autistic' – Not helpful!"**

At least two participants had experienced difficulties accessing mainstream 'talking therapies' services. This was in part because of rigid systems or 'pathways' which did not typically take into account the emotional needs of neurodivergent individuals.

Participants described having to embark on the additional effort of repeatedly explaining how their potential autistic traits meant existing pathways were unsuitable to address their wellbeing needs, further compounding the stress and anxiety that had led them to seek support in the first instance.

> **"A 'Talking Therapy' service within an autism service would be beneficial. I had to keep explaining [why the standard time limited service of six sessions wouldn't work and had to access the service via 'the depression pathway' to have access to the correct therapy even though I wasn't depressed]."**

Participants agreed that advocacy support would assist them to access services they might not otherwise be aware of, and one participant suggested that a 'buddy' system might be considered for those on the waiting list for autism assessment.

The needs of marginalised communities were also discussed as important considerations for commissioners. It was felt that the neurodivergent population should not be treated as homogeneous, and that advocacy could play a role in highlighting the specific needs of different communities or where autism intersected with their religious background or gender identity.

> **"They need to be aware that support can't be a 'one size fits all'….I can advocate for others all day long but not for myself. I don't want to be the person that wants to ask for help."**

Employment support and education/training

Although additional needs of autistic individuals in employment were not explored in depth during this discussion, the recognition that employers needed better education around the needs of neurodivergent employees was noted (see also peer support).

Pathways into employment was suggested as something that would be useful for a new service to support with, and education for employers was highlighted as 'key'.

> **"I am looking for help to get back in to work as well as carrying on with my life."**

Training was also briefly touched upon, with participants recognising the contributions neurodivergent individuals could make to a new autism service, again to ensure authenticity.

> **"I think the lived experienced element is important, particularly with training."**

How do you think this support should be provided?

Flexibility in access to support with a focus on one-to-one offer

Participants shared how their preferences for contact with services differed, with some preferring the convenience of online and others finding that this format could be stressful. Likewise, though most believed there were plenty of benefits to group-based support, others felt there were downsides to this, and all felt that one-to-one support should be the default offer, particularly when awaiting diagnosis or whilst adjusting to a new diagnosis.

> **"All options are welcomed, but one-to-one support feels the most important."**

> **"Support should be provided face-to-face and not over Teams, more importantly it should be followed up, not just leaving the person with a diagnosis and no planned help."**

Clear written and visual information on venues and support available

In terms of accessing a new support service, one participant described how this could evoke high levels of anxiety prior to even getting through the door, and that any new service needed to be responsive to this when planning how and where support should be delivered.

> **“I almost need like a video tour of the building, where the toilets are etc. Little details that I don’t know can cause anxiety.”**

Again, participants felt that a designated contact who could help them on a one-to-one basis to navigate available services in the community, would be most useful at the start of the referral journey and that the intensity of such support would naturally lessen at they became more linked in with community-based support.

As mentioned, for basic updates for both appointments and waiting list progression, a text reminder was felt to be useful as would regular scheduled meetings with clinicians.

A map of community services was another practical suggestion participants felt would be useful to help them make sense of the support landscape, though only if detailed enough to help them make an informed decision about which services might best meet their needs.

> **“A map of who in the community offers [support]….so we know what the options are, even if we have to pay.”**

> **“I agree [with the idea of a map]….I wouldn’t know where to start. There could be a mark to indicate if a service was commissioned or not.”**

> **“I was given a scrap of paper with a list of charities, nothing specific.”**

> **“I was signposted to [a specific charity] but should have been told about all organisations...but we need to know what specifically they offer.”**

Participants agreed good quality information was crucial to be able to make informed decisions about whether or not to access a particular service.

Too much information was likewise felt to be problematic and one participant described having to ‘filter out’ irrelevant information and how much of their knowledge of autism (and services) has come via their children who were also on a pathway (for autism assessment).

> **“A lot of my understanding has come through [in relation to] my children. If I hadn’t had that, I wouldn’t have known where to look.”**

Transparency about the process and modifying (where possible) systems to accommodate neurodivergence

Participants stressed that following through with any stated actions was also crucial as many were already exhausted from having to fight for, and chase services, and again felt one-to-one support from a named person or advocate within a new service could potentially help with this.

> **“I struggle with people saying they will do something and then not doing it, for example, saying you will be contacted within six months and then having no contact. Be realistic and don’t make promises that you can’t keep.”**

Participants also felt despondent due to the length of time waiting to be diagnosed and, after having been on a waiting list for many years, stressed that when they finally begin the assessment process, they would like to avoid further waiting lists for actual support.

The recognition that autistic people require more time during verbal interactions to allow for processing information was also highlighted as something that the new service should factor in.

> **"Not having time limits [such as the 6 sessions typically offered for Talking Therapy support], easy access and not another waiting list."**

How useful would you find peer support and why?

Useful as an addition to one-to-one support

All participants felt some kind of peer support would be useful, but most felt like this was still secondary to their need for one-to-one support.

One participant suggested that community or peer support might be better organised organically from among those awaiting assessment rather than being set up as a managed group at the outset, but people were open to different ways of doing this.

The consensus was that peer support for this group should be for only those on the waiting list for autism assessment, although they would be open to perhaps having an autistic person come and talk to them as an invited speaker for example.

> **"Peer support [for this group] should be focused on just those on the waiting list…"**

> **"Not sure about there being a hierarchy [among those who are diagnosed and those who are awaiting assessment], but I agree there should be a separate support group [for those awaiting assessment] where we can discuss experiences. It's a long wait for diagnosis and I find the unknown hard to deal with. This has been helped by speaking to a friend who was recently diagnosed."**

Offer of broad peer support as well as peer support within employment

In discussing how else peer support might be organised, people agreed that there were benefits to having smaller groups based around characteristics such as gender or ethnicity, but that the practicalities of arranging these might be difficult.

As mentioned, some felt that any smaller, interest-based or identity groups were more likely to develop from an initial general group comprised of those on the waiting list. However, others felt more specific groups would be more appealing.

> **"I have friends who are followers of Islam who have children recently diagnosed as autistic. I think they might not get the same benefit within an open group [as in one specifically catered to their needs and identity]."**

> **"I would want to connect with likeminded people [in similar circumstances] so working parents with kids."**

> **“I would personally prefer female adults to be able to relate as close as possible to them.”**
> **“A mix of different aged adults over 18s and male and female to be able to get an idea of how other people cope with their autism.”**

For other participants, the notion of group-based support was recognised as beneficial for connecting with like-minded people and to be ‘seen, heard and understood.’ However, they still felt some anxiety about the idea of a group-based format more generally and, for those who worked in public facing roles, about running into clients and their capacity to be ‘vulnerable’ in front of people with whom they may also have a professional relationship. Others indicated the thought of meeting with strangers for the first time would be a significant hurdle in itself.

> **“I am not sure I would find peer support useful; I would find it uncomfortable at first being in a room with strangers, but I would find it a lot better than being on a remote Teams meeting.”**

This also led to a discussion about whether peer support might be better offered for some within the workplace where they felt additional support was needed at times. However, this also raised other dilemmas for those who had been managing in roles without support and again demonstrated the stigma that still accompanies diagnosis.

> **“Do you declare to your employer your diagnosis when you have worked there for ten years?...I’d be more inclined to join a group if I knew a bit more about it. [For example, within an organisation such as the Local Authority] a staff autism group could help employers understand neurodivergent staff and how to support them.”**

What would a travelling hub/support in the community look like to you?

For some participants, the concept of a travelling hub was difficult to grasp and was felt to be ‘complicated’ and potentially indicative of ‘lots of changes’. To reduce anxiety, participants suggested that they would need to know what the hub would provide, where it was and how to get there etc.

> **“We would need a clear agenda of what will be happening at the hub…”**

The ‘travelling’ description of the hub conjured an image of a bus for one participant, indicating that a clear outline of the concept was needed before people in this group could definitively say whether this was something they would want.

However, they agreed that a physical building that they could access rather than a temporary venue would be better and there was some discussion about community venues being a possibility. They also felt that commissioners should perhaps be talking to established community members and support agencies about linking in with existing provision.

> **“[Established provider of autism services] do a similar model. Depends on what is being offered [i.e. one-to-one or peer support]. I like the idea of being able to access support in the local area.”**

The difficulties of ensuring access for everyone was acknowledged, with the majority of participants' full-time work limiting their access to the service during normal working hours. Likewise, locations that might seem central for access may also create other barriers, such as a busier environment e.g. a town centre being more crowded on a weekend, even if the building itself were quieter.

Flexibility of when and how to access the service again seemed to be the key with everybody having different preferences but with sensory distractions being kept to a minimum, where possible.

> **"A weekday evening in a quiet place where possible would be a good time and place for me to attend. I would be willing to travel."**

Other suggestions

One suggestion was that it would be interesting to monitor the journey of individuals throughout their interaction with the new (and/or existing) service to see where people are experiencing barriers or falling through the cracks of service provision.

Survey findings - autistic people post-diagnosis

This section summarises the findings of:

- 59 respondents who live in Tees Valley.
    - 26 responded themselves.
    - 5 responded on behalf of someone who is autistic.
    - 28 responded as a family member or carer of someone who is autistic.

Please note that not all respondents answered every question.
Feedback from respondents living outside Tees Valley can be found in Appendix 4.

Key themes

Current support accessed

- Over nine-in-ten respondents (93.5%) are currently accessing information and advice about autism. They are most likely to look on social media and related platforms such as YouTube or Facebook (75.9%), visit charity websites (62.1%) or conduct general online searches (62.1%). Only 17.2% accessed NHS websites.
- Only 23.3% receive ongoing support from non-NHS organisations around their autism, seven respondents described this support - services provided by charities, peer support and advocacy.

Service requirements

- Mirroring the pre-assessment findings, there was strong support from autistic people for all listed suggestions. In particular, respondents wanted support with advocacy (all strongly agreed or agreed), emotions (96.8%), identifying where additional support might be needed (96.8%) and sensory issues (93.5%). There was less support for applying for housing (51.6%), advice about education (64.5%) and applying for benefits (67.7%).
- In terms of the types of support provided, the vast majority of respondents (90.3%) wanted support from trained workers who understand autism. 77.4% wanted access to information and advice and the same proportion (77.4%) would like support from people with lived experience of autism.
- When asked to think back to when they were waiting for an assessment, they felt that some education/information about what autism is, would have been helpful (52.2%). 43.5% requested transparency around waiting times and the autism assessment process and 39.1% requested regular contact/support whilst waiting for the assessment.
- When first diagnosed in particular they would have found the following helpful: access to emotional/mental health support (37.5%), peer/group support (37.5%) and information on coping strategies, understanding their diagnosis, types of support available and communicating their diagnosis to their family (33.3%).

Accessing the service

- In terms of the format of this support, most commonly mentioned were one-to-one in-person support (83.3%), email (76.7%) and the option to have in-person and online access (73.3%). Fewer respondents would like telephone support (23.3%) or group support, either online (40.0%) or in-person (43.3%).

- In terms of reasonable adjustments, respondents suggested being offered information and communications in a variety of ways to aid accessibility (50.0%), consistency in staff and processes (25.0%), flexibility in service delivery (25.0%) and accessible spaces (25.0%).
- Around half of respondents (51.7%) would be willing and able to travel to receive face-to-face support and when asked about the likelihood of accessing a travelling hub 69.0% of this group answered positively.

Family members/carers feedback

Service requirements for autistic people

- Again, there was strong support for all listed suggestions with responses broadly matching those of autistic people. All respondents felt that support to identify where additional support might be needed would be useful. Furthermore, 96.4% of respondents would like support with advocacy, 96.5% would like support with emotions and wellbeing, 96.3% wanted support with building social skills and 92.9% wanted support with sensory issues. There was slightly less support for employment/volunteering (81.5%) and support with applying for housing (81.5%).
- In terms of the types of support provided, the vast majority of respondents (92.9%) felt that the autistic person would want support from trained workers who understand autism. There was less support for meeting up with people who are recently diagnosed (32.1%) and taking part in ongoing information/awareness events (35.7%).
- When asked to think back to when their family member or person they care for was waiting for an assessment, they felt that in particular, information around coping strategies would have been helpful (53.8%).
- When first diagnosed they felt that general information around autism such as leaflets on different topics, videos to help them understand and the support available to them would have been helpful (50.0%). Practical support was also suggested (28.6%).

Accessing the service for autistic people

- In terms of reasonable adjustments and mirroring the findings of autistic people, there was a suggestion of flexibility in the provision of any support in particular (57.1%).

Current support accessed by family members/carers

- 85.7% of this group currently receive information and advice about autism and, in particular, conduct general online searches for information (75.0%), visit charity websites (50.0%) and social media and related platforms (50.0%). 29.2% access NHS websites.

Service requirements for family members/carers

- Fewer than one-sixth (14.8%) of respondents feel like they have enough information, advice or support about autism. Most commonly requested were things that would help them support their family member/person they care for, around practical day-to-day things (41.7%), and communication and socialising/social skills (33.3%).

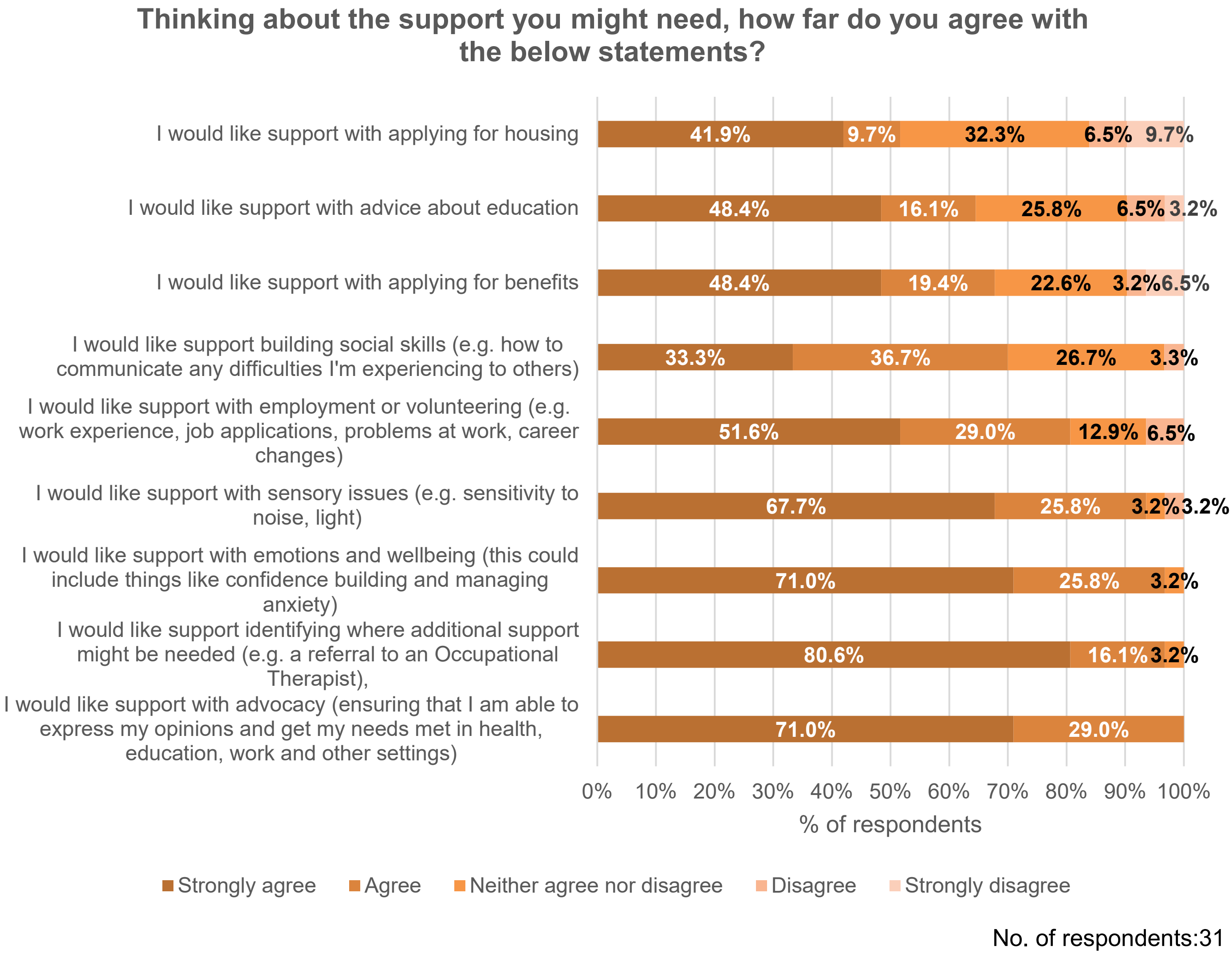
Accessing the service for family members/carers

- In terms of how they would like to receive this support, most commonly mentioned were one-to-one in-person support (60.9%), a mixture of in-person and online access (52.2%) and email (52.2%). Fewer respondents would like telephone support (8.7%), text (17.4%) or online group support (17.4%).
- Nearly two-thirds of respondents (63.6%) would be willing and able to travel to receive face-to-face support and 79.0% would be likely to access a travelling hub.

Summary of findings

Respondents were initially asked to think about what support they felt they needed since their diagnosis. They considered the following statements and were also able to identify other requirements not listed.

Support needed



- There was support for all types of support listed and all survey respondents identified at least one type of support that they would like.
- The chart shows that all respondents wanted support with advocacy (77.6% strongly agreed and 22.4% agreed with the statement).
- 96.8% of respondents wanted support with emotions and wellbeing (71.0% strongly agreed and 25.8% agreed with the statement).
- 96.7% wanted support identifying where additional support might be needed, such as referral to an OT (80.6% strongly agreed and 16.1% agreed with the statement).

- 93.5% of respondents wanted support with sensory issues, such as noise and light sensitivity (67.7% strongly agreed and 25.8% agreed with the statement).
- There was less support for housing (41.9% strongly agreed and 9.7% agreed with the statement), education (48.4% strongly agreed and 16.1% agreed with the statement) and applying for benefits (48.4% strongly agreed and 19.4% agreed with the statement).

Seven respondents suggested other support:

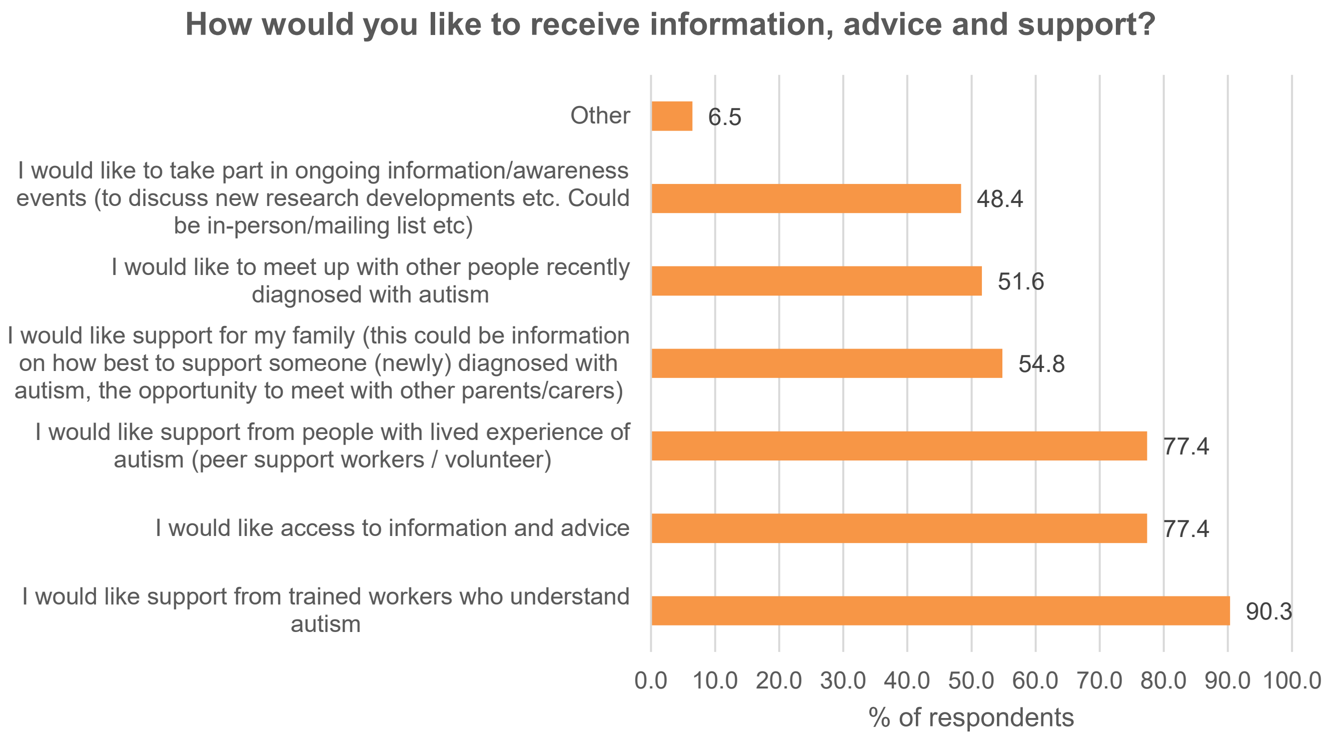
Other support	No. of respondents
Autism awareness training (autistic person led) for GP and other health and social care professionals	2
Access to a fast track for ADHD diagnosis	1
Advice/information about drug dependencies related to mis-diagnosed mental health conditions	1
How the autistic brain works and its impact on me	1
How to access autism support groups for older people	1
How to access peer support groups	1
How to access support groups for people with late diagnosis	1
How to make friends	1
Support process post-diagnosis	1

No. of respondents: 7
Respondents could give more than one answer

> **"Access to or signposting for possible support groups - for older people with autism-related problems…lots of mental health issues as a result of not being diagnosed until late in life, plus drug dependency issues as a result of being misdiagnosed with bipolar disorder, etc."**

> **"I'd like…some sort of manual or leaflet to explain the stages I might go through post-diagnosis and how an autistic brain works and what is happening and why it happens."**

Respondents were also asked how they would like to get information, advice and support from a new service.



No. of respondents:31
Respondents could give more than one answer

- 90.3% of respondents wanted support from trained workers who understand autism.
- 77.4% of respondents would like access to information and advice.
- 77.4% of respondents would like support from people with lived experience of autism.
- Respondents were less likely to want to take part in information/awareness events to discuss new research developments (48.4%), meet up with other people recently diagnosed with autism (51.6%) and have support for their family (54.8%).

Two respondents suggested other types of support:

Other support	**No. of respondents**
Resource hub	1
Support from trained workers who are autistic	1

No. of respondents: 2
Respondents could give more than one answer

“I'd like to have a place where I can go to see resources that other people in my area have found useful.”

“Ideally support from trained workers who understand autism AND are autistic - not peer support workers with no formal training outside of peer support or volunteers.”

Respondents were asked whether they could identify any reasonable adjustments they felt the new service could support them with.

Reasonable adjustments	**No. of respondents**	**% of respondents**
Accessible information/communication offered e.g. email	8	50.0
Consistency of staff/procedures/information	4	25.0
Flexibility in service delivery based on individual needs	4	25.0
Accessible spaces	4	25.0
Navigating services	4	25.0
Broader awareness and training for staff	3	18.8
Education/support	2	12.5
Help/involve carers in service	2	12.5
No phone calls	2	12.5
Communication skills	1	6.3

No. of respondents: 16
Respondents could give more than one answer

- Half of respondents (50.0%) asked for accessible information and communications.
- 25.0% wanted consistency in staff, procedures or information.
- 25.0% requested flexibility in how services are delivered to meet individual needs.
- 25.0% wanted thorough information when physically accessing new spaces and for those spaces to be accessible.
- 25.0% asked for support to navigate services.

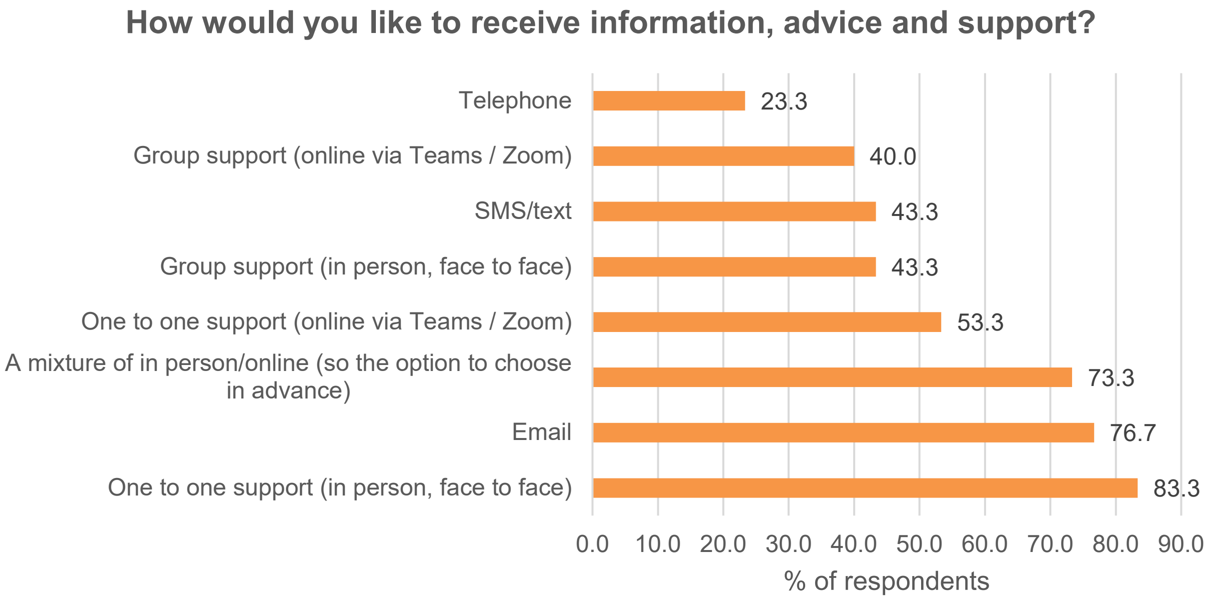
“No phone calls. So many services require making a phone call to access them and this is very difficult/impossible for autistic people.”

“Explanations of processes, services, ways of working. Often information is not accessible, information about buildings where to park who to speak to etc. Consistent workers where possible, not meeting new people every time.”

“Client centred flexibility. Think outside the box when organising.”

“Consider intro videos or images for people new to accessing the service. Also asking us if we want to support in training others. I would like to see new services have a video walk through of the premises on websites, video introductions to staff on websites and better use of technology to make communication easier.”

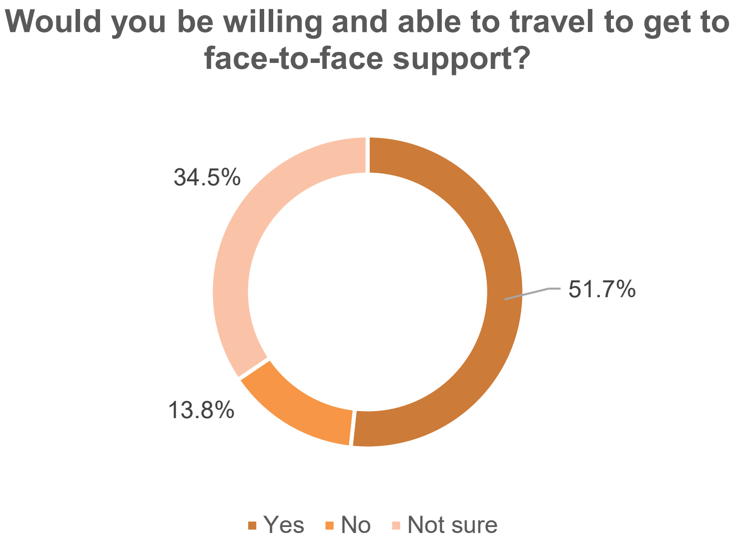
Format of potential support



No. of respondents: 30
Respondents could give more than one answer

In terms of the format of this information, advice and support:

- 83.3% would like one-to-one in-person support.
- Just over three-quarters of respondents (76.7%) would want information, advice or support via email.
- Almost three-quarters of respondents (73.3%) wanted to be able to choose between in-person and online support.
- Respondents were less likely to want telephone support (23.3%).

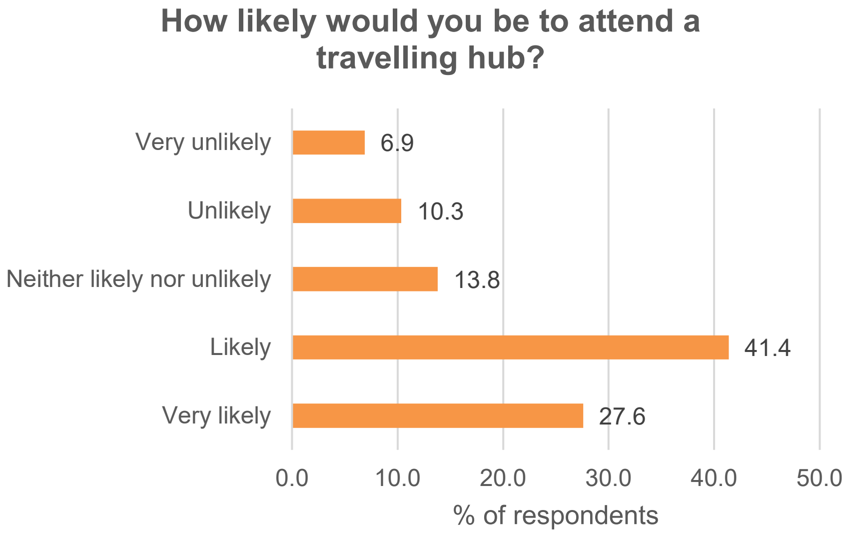


No. of respondents: 29

- Around half of respondents (51.7%) stated that they would be willing and able to travel to receive face-to-face support.

They were also asked about the likelihood of them attending a travelling autism hub in future and were provided with an example of how the hub could operate:

- Open 5 days a week, but each day, based at a different community centre or other site e.g. Monday in Middlesborough, Tuesday in Stockton. This would be to ensure that people have the widest range of options to attend i.e. you could select to attend on a day of a week that was most suitable or at a location that was closest to get to.

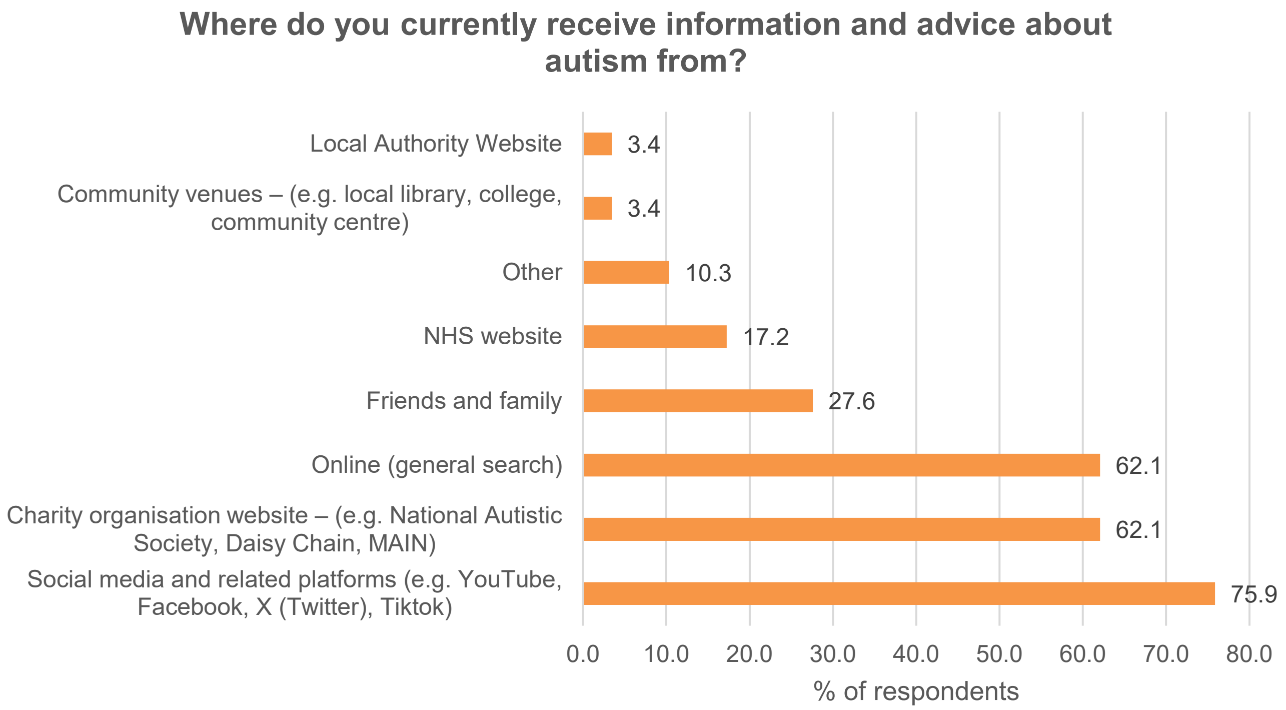


No. of respondents: 29

- Almost seven in ten respondents (69.0%) stated that they would be likely or very likely to attend a hub.
- 17.2% would be unlikely or very unlikely to attend.

Respondents were asked whether they currently receive information and advice about autism.

- The vast majority of respondents (93.5%) indicated that they did.



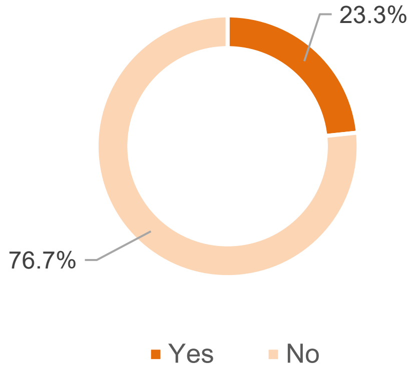
No. of respondents: 29

- Three-quarters of respondents receive information and advice from social media (75.9%).
- Over six-in-ten (62.1%) had visited a charity organisation website.
- The same proportion (62.1%) had done general online searches for information and support.
- Respondents were less likely to visit a local authority website (3.4%), a community venue (3.4%) or the NHS website (17.2%)
- Three respondents (10.3%) had searched elsewhere:

Information/support source	No. of respondents
Books	1
Paid for services	1
Tees Valley Buddies	1

No. of respondents: 3
Respondents could give more than one answer

Respondents were asked whether they currently receive support from autistic charities or other non-NHS organisations around their autism.



Do you currently receive ongoing support from autistic charities or other non-NHS organisations around your autism?

No. of respondents: 30

- Over three-quarters of respondents (76.7%) were not receiving support from any charities or other non-NHS organisations.
- Those receiving support were asked what type of support they received:

Type of support	No. of respondents
Autism charity services	3
Peer support	3
Advocacy	1
In-work support	1

No. of respondents: 7
Respondents could give more than one answer

All respondents were asked to think back to when they were waiting for a diagnosis and consider what types of information, services or support would have helped them most at that time.

Twenty-three people responded:

Information/support source	No. of respondents	% of respondents
Education/information about autism	12	52.2
Transparency about process/waiting times etc.	10	43.5
Regular support/contact whilst awaiting assessment	9	39.1
Coping strategies	7	30.4
Emotional/mental health support	6	26.1
Peer/neurodivergent led support	5	21.7
Workplace support and reasonable adjustments awareness	4	17.4
Sensitivity and autism awareness amongst professionals	3	13.0
Support in educational settings	2	8.7

No. of respondents: 23
Respondents could give more than one answer

- Over half of respondents (52.2%) felt that information about autism would have been helpful in advance of the assessment.
- 43.5% requested transparency around waiting times and the process they would follow.
- 39.1% felt that regular contact and support whilst waiting for an assessment would have helped.

“What to expect, what to do next, services and support available. We didn't get any of this.”

“Psychoeducation around how autism presents and reasonable adjustments I could make for myself.”

“Information on timescales of diagnosis times. Contact whilst on the waiting list. Information on autism for friends, family, employers.”

“Information packs, clearer updates/information about the path to diagnosis and timeline, help with coping strategies and managing imposter syndrome.”

“Face-to-face review appointments, I had irregular telephone appointments which I struggle with.”

Finally, all respondents were asked to think back to when they were first diagnosed and consider what types of information, services or support would have helped them or their families most at that time.

Twenty-four people responded:

Information/support source	No. of respondents	% of respondents
Emotional/mental health support (including access to therapy)	9	37.5
Peer/group-based support	9	37.5
Information	8	33.3
Late diagnosis support	7	29.2
Navigating/accessing other services	6	25.0
Coping strategies	5	20.8
Specialist/individualised support	3	12.5
Gender specific information	2	8.3
Information for family	2	8.3
Communication skills support	1	4.2

No. of respondents: 24
Respondents could give more than one answer

- Over one-third of respondents (37.5%) felt that emotional/mental health support would have been helpful at the time of diagnosis.
- The same proportion (37.5%) would have liked access to peer or group-based support.
- One-third of respondents (33.3%) would have liked information on:

    - Coping strategies.
    - Understanding my diagnosis.
    - Types of support available and how to access it.
    - How to communicate diagnosis to family.
- 29.2% asked for support for people who have been diagnosed later in life.

  “Understanding the grief and processing that happens when diagnosed. Understanding burn-out.”

  “Emotional support to come to terms with previous misdiagnosis.”

  “Access to psychological therapies that are designed for autistic people.”

  “I was diagnosed in 2022…and shortly after my diagnosis I was discharged from Foxrush House without being referred to any other autistic help or support groups. I think meeting other autistic people is really useful so a community group who can offer wellbeing activities is good.”

  “Support to talk to other newly diagnosed people in an informal setting.”

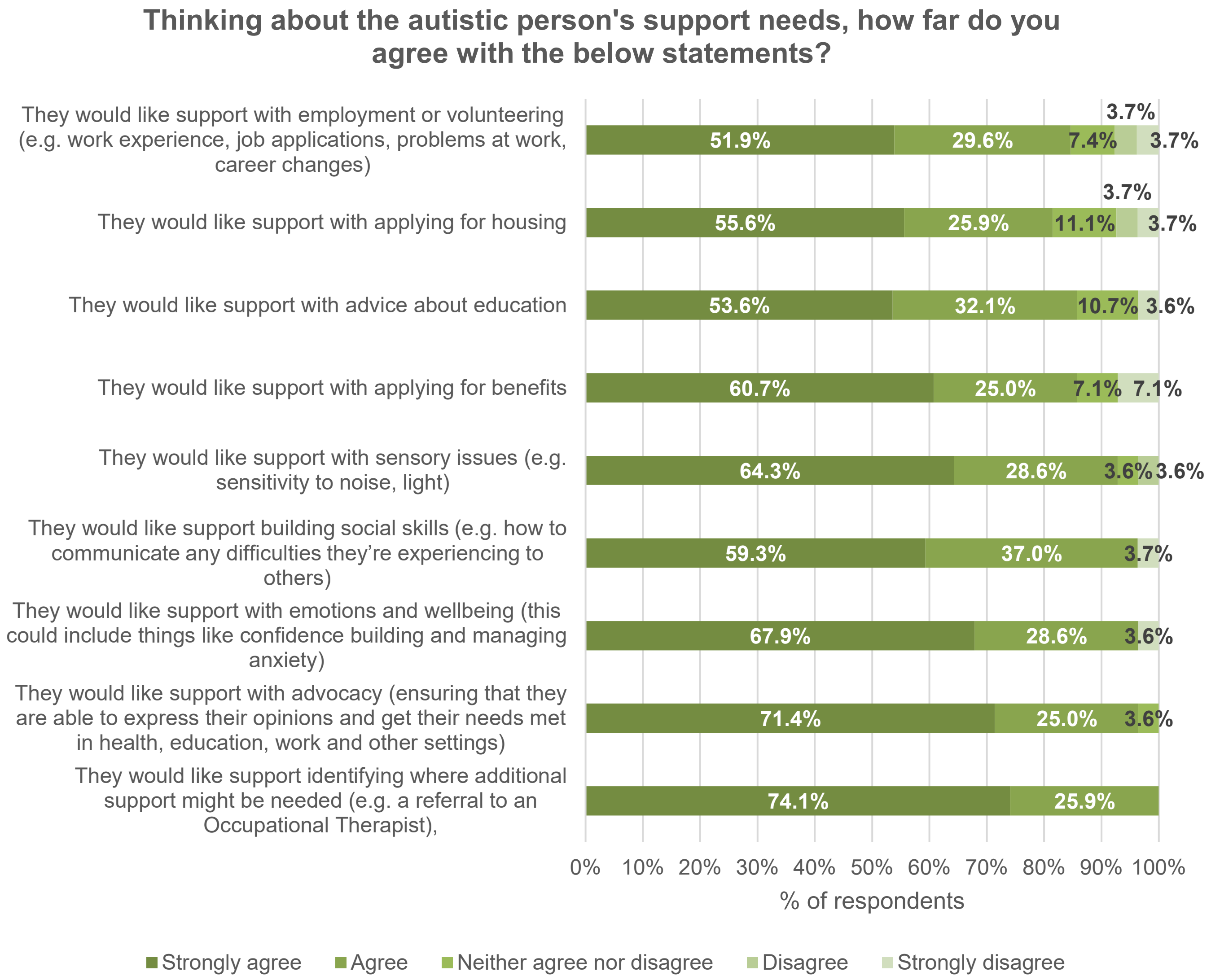
  “Just having information about autism would have been nice! I was told ‘you are level 1 autistic’ and that was pretty much it! I know what I know now because I have researched it and learned about myself more.”

  “Help coming to terms with my diagnosis and making sense of it, especially the missed opportunities in life and burn-out I experienced which has negatively affected my career and self-esteem.”

Carers/family members feedback

Respondents were initially asked to think about what support they felt the autistic person might need post-diagnosis. They considered the following statements and were also able to identify other requirements not listed.

Support for autistic people



No. of respondents:27-28 (some respondents felt unable to answer around housing, identifying additional support, social skills and employment)

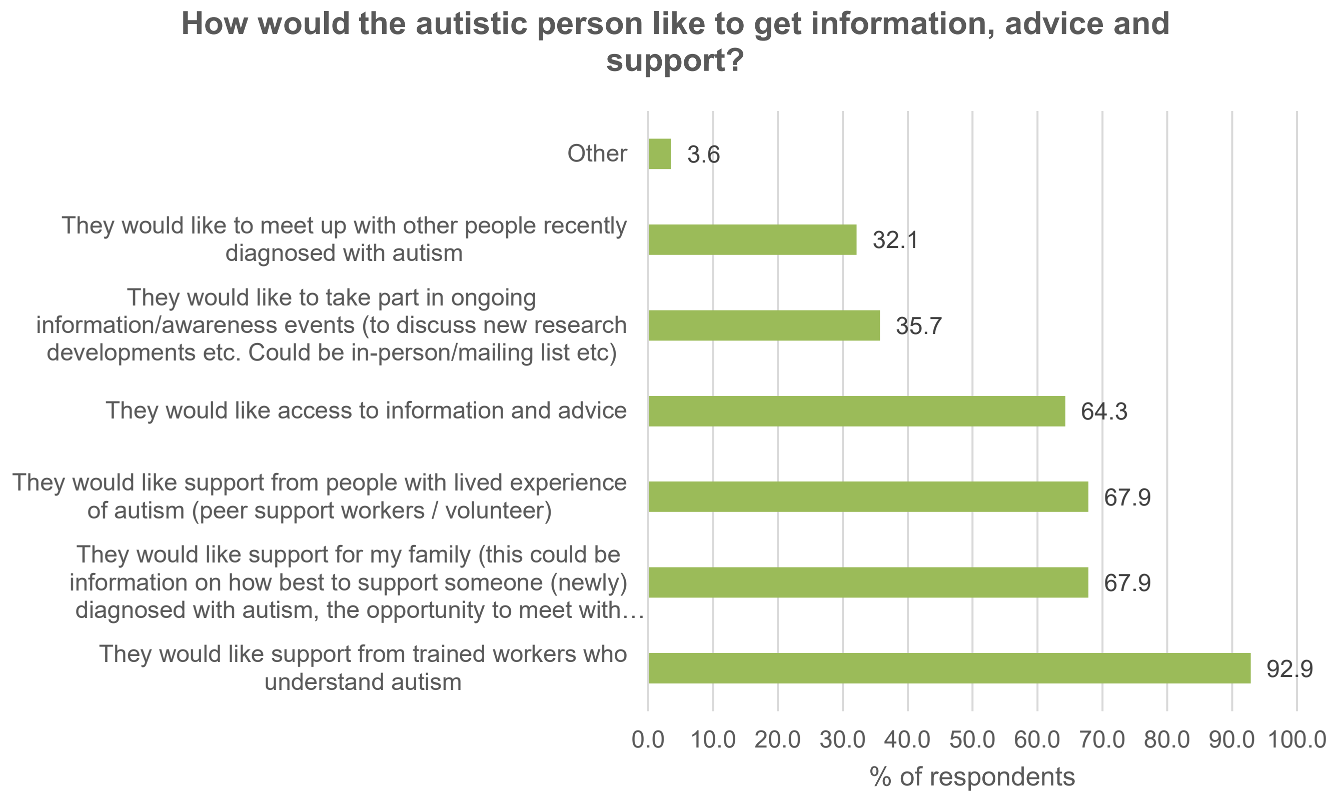
- There was strong support from respondents for all aspects of support listed.
- Responses broadly match those of autistic people.
- The charts show that all respondents wanted support identifying where additional support might be needed, such as referral to an OT.
- The vast majority of respondents (96.4%) wanted support with advocacy (71.4% strongly agreed and 25.0% agreed with the statement).
- The same percentage of respondents (96.4%) wanted support with emotions and wellbeing (67.9% strongly agreed and 28.6% agreed with the statement).
- 96.3% of respondents wanted support with building social skills (59.3% strongly agreed and 37.0% agreed with the statement) and 92.9% wanted support with sensory issues, such as noise and light sensitivity (64.3% strongly agreed and 28.6% agreed with the statement).
- There was slightly less support for employment/volunteering (81.5% - 51.9% strongly agreed and 29.6% agreed with the statement), housing (81.5% - 55.6% strongly agreed and 25.9% agreed with the statement).

- Five respondents suggested other support:

Other support	No. of respondents
Help with sleep	1
How to access autism support groups	1
Specialist psychotherapy for autistic people for help into adulthood	1
Transitioning to adult services	1
Trauma	1

No. of respondents: 5
Respondents could give more than one answer

Respondents were also asked how they would like to get information, advice and support from a new service.



No. of respondents:28
Respondents could give more than one answer

- 92.9% of respondents would like support from trained workers who understand autism.
- 67.9% of respondents would like support for family.
- 67.9% of respondents would like support from people with lived experience of autism.
- 64.3% of respondents would like access to information and advice.
- There was less support for meeting up with recently diagnosed autistic people (32.1%) or taking part in information/awareness/news events (35.7%).
- One respondent asked for other support – “information to be straightforward and explained plainly.”

Respondents were asked whether they could identify any reasonable adjustments they felt the new service could support the autistic person with.

Reasonable adjustments	No. of respondents	% of respondents
Flexibility re offer/provision of support	4	57.1
Sensory issues factored into environment	2	28.6
General autism awareness within services	1	14.3
Flexibility to accommodate caring/work commitments	1	14.3
Recognition of family's advocacy role	1	14.3

No. of respondents:7
Respondents could give more than one answer

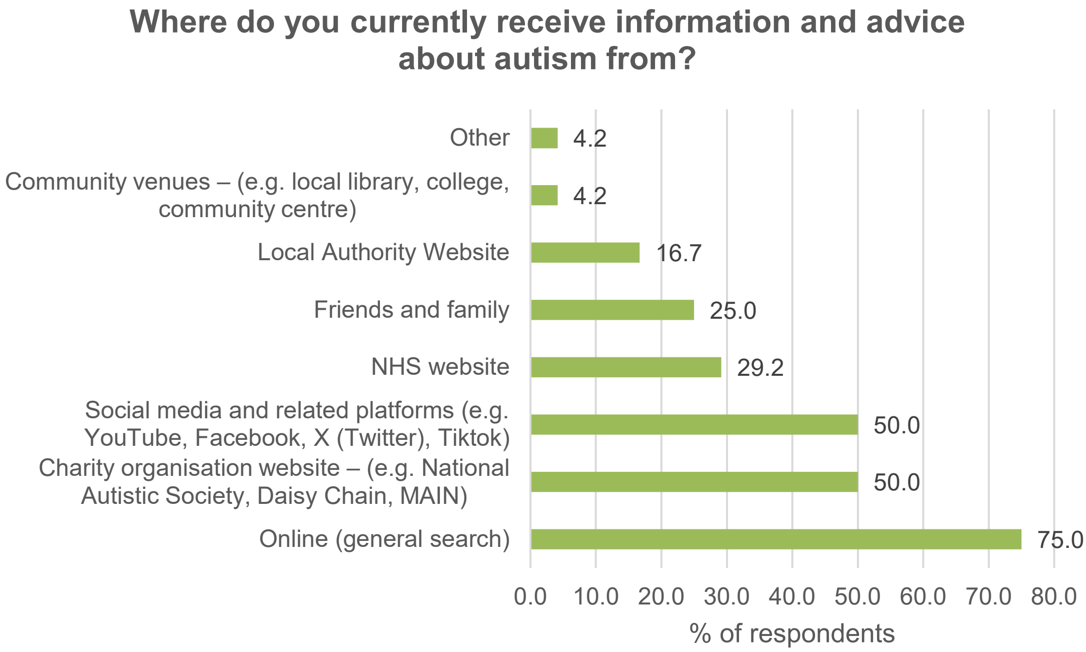
- Over half of respondents (57.1%) asked for flexibility from services such as giving them more time to respond to letters/requests and modes of communication.
- 28.6% wanted adjustments around sensory issues such as noise and light.

> **"Would need to be in-person or by online chat email. Video call and phone calls wouldn't work for a lot of people with ASD [autism spectrum disorder]."**

> **"Quieter waiting areas. Video of place to visit to allow for familiarity plenty of notice to allow time to adapt for change."**

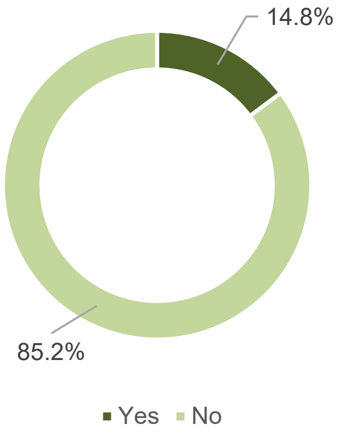
Support for carers/family members

Respondents were asked questions to understand what information, advice and support they, as a carer or family member of an autistic person, would want from a service.



No. of respondents: 24

- Three people stated they currently do not receive any support.
- Of the remainder:
  - Three-quarters (75.0%) of respondents had done general online searches for information and support.
  - Half visit social media platforms (50.0%) whilst half (50.0%) have visited a charity organisation website.
  - Community venues (4.2%) and local authority websites (16.7%) were less well used.
  - One respondent had searched elsewhere and received information or support from the adult learning disability respite service.



Do you feel like you have enough information, advice and support about autism?

No. of respondents: 27

- Fewer than one-sixth (14.8%) of respondents feel like they have enough information, advice or support about autism.
- This group were asked what additional information, advice or support they would like:

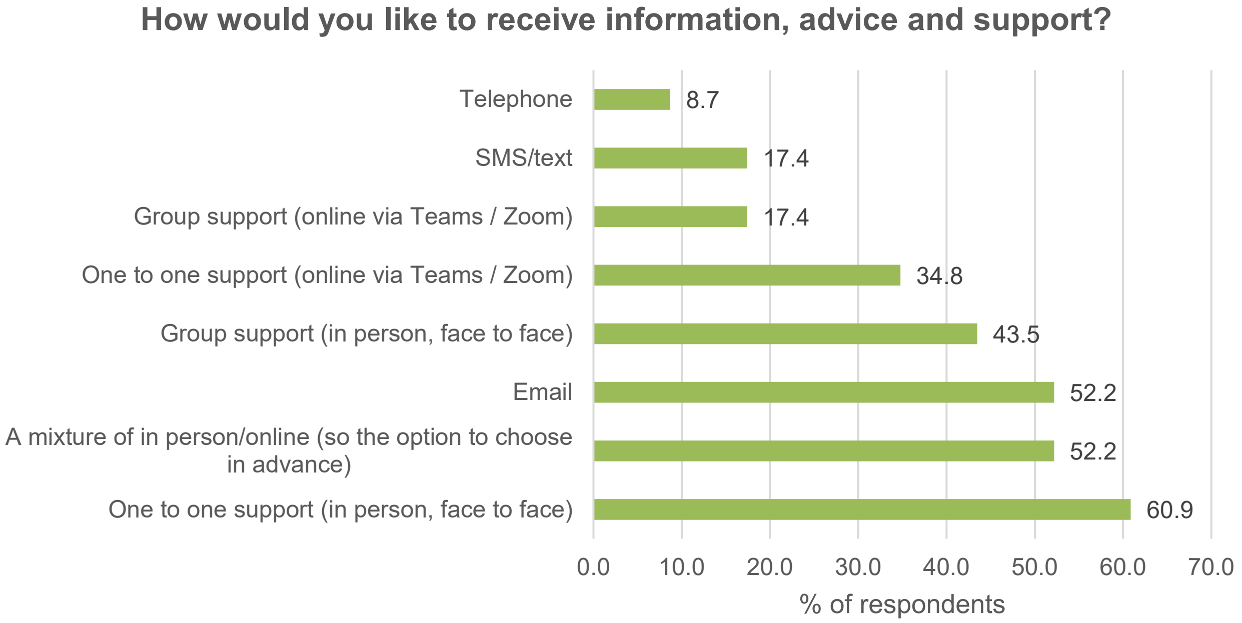
Information/advice/support	No. of respondents	% of respondents
Practical support	5	41.7
Communication and social skills support	4	33.3
Easily accessible information/support	3	25.0
Training from someone with lived experience	2	16.7
Opportunities to provide feedback	1	8.3
Specialist therapy	1	8.3

No. of respondents - 16
Respondents could give more than one answer

- Over two-fifths of respondents (41.7%) wanted training around how to support the autistic person with practical aspects of their lives such as sleeping habits, challenging behaviours and accessing education.
- One-third of respondents (33.3%) wanted support to help the autistic person with socialising or social skills.

“More strategies to help, specifically with meltdowns, challenging behaviours, running off, appropriate socialising etc. Ideally from someone with lived experience who can come to the home.”

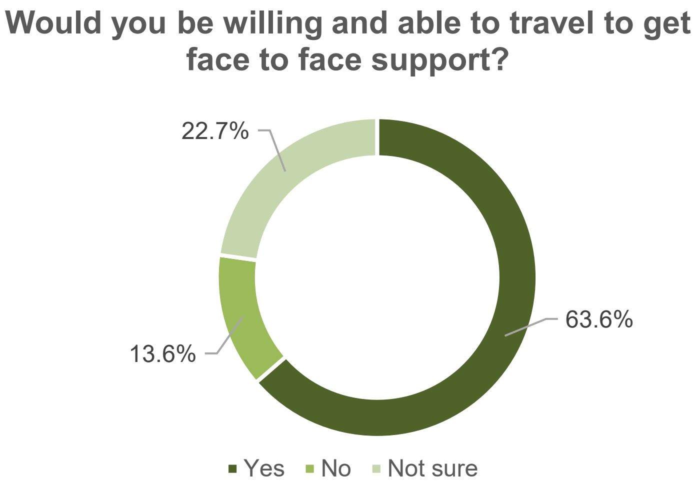
“To hear off other autistic people how to communicate effectively with people with autism, so I could relate it to my son.”



No. of respondents: 23
Respondents could give more than one answer

In terms of the format of this information, advice and support:

- 60.9% would like one-to-one in person support.
- 52.2% wanted to be able to choose between in-person and online.
- 52.2% would want information, advice or support via email.
- Respondents were less likely to want telephone, SMS/text or online group support (8.7%, 17.4% and 17.4%, respectively).

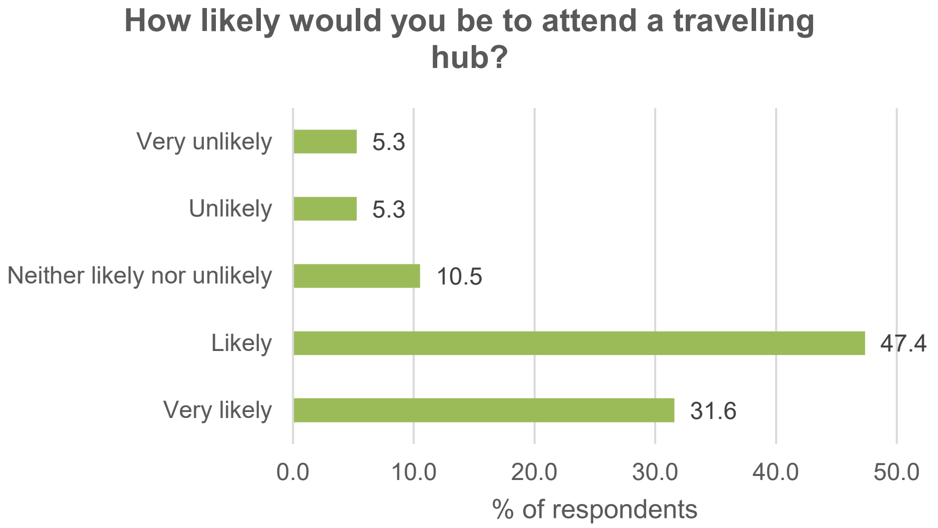


No. of respondents: 22

- Around six-in-ten respondents (63.6%) stated that they would be willing and able to travel to receive face-to-face support.
- 13.6% of respondents would not be able to travel for this support.

They were also asked about the likelihood of them attending a travelling autism hub in future. They provided with an example of how the hub could operate:

- Open 5 days a week, but each day, based at a different community centre or other site e.g. Monday in Middlesborough, Tuesday in Stockton. This would be to ensure that people have the widest range of options to attend i.e. you could select to attend on a day of a week that was most suitable or at a location that was closest to get to.



No. of respondents: 19

- 79.0% of respondents stated that they would be likely or very likely to attend a hub.
- 10.6% would be unlikely or very unlikely to attend.

All respondents were asked to think back to when their family member or person they care for was waiting for their autism assessment and consider what types of information, services or support would have helped them most at that time.

Thirteen people responded:

Information/support	No. of respondents	% of respondents
Coping strategies	7	53.8
Broader support/information	3	23.1
Help with understanding behaviours	2	15.4
Named person for updates	2	15.4
Reduced waiting times	2	15.4
Wider geographical coverage of support groups	1	7.7

No. of respondents: 13
Respondents could give more than one answer

- Over half of respondents (53.8%) felt that information and support around coping strategies would have been helpful.

  "How to deal with certain situations, e.g. anxiety, coping strategies, how to deal with frustrations and stressful situations."

  "Support on managing challenging behaviours, sensory sensitivities."

Finally, all respondents were asked to think back to when their family member or person they care for was first diagnosed and consider what types of information, services or support would have helped them most at that time.

Fourteen people responded:

Information/support	No. of respondents	% of respondents
General information/support	7	50.0
Tailored practical support	4	28.6
Peer support/social groups	3	21.4
System/process/services support	2	14.3
Regular follow-up appointments	2	14.3
Education support	1	7.1
OT support	1	7.1

No. of respondents: 14
Respondents could give more than one answer

- 50.0% of respondents wanted some general information around autism such as leaflets on different topics, videos to help them understand and the support available to them.
- 28.6% of respondents felt that practical support that was tailored to their needs would have been helpful.

  "Information on education, managing everyday living skills, ways of accessing support, a chance to discuss concerns. Anything other than what's happening at the moment which is "here's a diagnosis, goodbye."

  "Not being discharged from the service on diagnosis, regular follow-up appointments, OT support for the young person, not having to ask for this, understanding what may be available for the young person and for the carers."

Focus group/individual feedback findings – autistic people post-diagnosis

This section summarises the findings of six autistic people who took part in a focus group, two people who opted to provide written feedback and one carer of a younger person who took part in an interview.

Key themes

Service requirements

- Participants requested access to emotional/mental health support and for some a trauma-informed approach would be required. They cited reasons for not being able to access mainstream mental health services and felt that a service specifically for autistic people should be offered immediately after diagnosis when some felt particularly vulnerable coming to terms with and accepting their diagnosis. Examples of what the service might support with included behaviours and their impacts on relationships and for those diagnosed later in life, support around grief and anger – what their life could have been with an earlier diagnosis and the trauma of misdiagnosis was important.
- Access to an OT (who specialises in autism) to help people develop independent living skills and manage their daily routines (as impacted by fluctuating levels of functioning) was requested as the current system usually requires a mental health diagnosis to access it.
- Issues around looking after their health was also highlighted, with accessibility issues in terms of sensory overload and anxieties around having to physically go to places. Instructions around taking care of their health were not always communicated with neurodivergence in mind, leading to misunderstanding.
- Support around accessing and staying in higher education and employment was suggested. Participants also felt that support to write an impact statement (and review and renew it at regular intervals) to give to employers was key.
- Practical assistance (from someone with experience of supporting autistic people) to complete forms, navigate benefits etc was also suggested.
- Information/education for themselves (including the suggestion of a user manual developed by autistic people) to understand autism and the process after diagnosis was requested as was information for family. Participants highlighted issues their family had in understanding their diagnosis and what it meant for them, and felt it would have been useful to have information or support from professional to be able to communicate this.
- A designated contact to assist with navigating services (particularly in relation to accessing education and transitioning to adult services) was suggested by one participant alongside a post-diagnosis action plan.
- One-to-one support to develop social skills for young people unable to attend education was also suggested.
- When asked to consider peer support, most participants felt that access to it would be useful, and for some, it was crucial to coming to terms with their diagnosis. It enabled them to connect with like-minded people, model neurodivergent behaviours, gain confidence, and support each other. Some were less supportive of the concept, they felt that a group environment provided additional barriers to their ability to express their

authentic selves, mask behaviour and consider others. Offering peer support in groups of limited numbers, on a one-to-one basis, online or with a focus on an activity was suggested as ways to make peer support more accessible. Clear information on number of sessions, the venue etc and flexibility in times would also improve accessibility. There was concern from some that an offer of peer support might be at the expense of one-to-one support.

  - Some thought that established community organisations would be best placed to provide a peer support service whilst others felt it should be the responsibility of the NHS and cautioned of barriers associated with some community organisations.

Accessing the service

- It was felt that support should be offered immediately after diagnosis but with an acknowledgment that some people need time to process/come to terms with the diagnosis. So, the offer should not be a 'one time only' or within a rigid time frame.
- Participants wanted flexibility in how support could be accessed to allow for individual needs and preferences. Group support, one-to-one, online, and in-person were all suggested to enable people to engage in a way they felt comfortable and the physical environment should be considered.
- They suggested employing autistic people within the service to facilitate trust and provide understanding.
- Clear written information was requested alongside visual information on physical spaces that would be accessed as part of the service. Video calls and text messages are preferred to telephone calls.
- Participants were generally apprehensive about a travelling hub. The inconsistency of a permanent base was unsettling for some and others requested non-NHS buildings due to sensory overload. An accessible location was an issue for some who relied on lifts and for housebound people, online access would be important. In order to consider accessing a hub they would need to know in detail, why they would go there – what they would access there, how to make an appointment (drop-in sessions felt too uncertain for some), reminders of sessions, how to get there, what the building was like etc. and again requested a video walk-through. Offering hours outside of standard work times would be crucial to ensuring working carers could attend.

Summary of findings

Focus group feedback

What kind of support do you think should be provided?

Trauma-informed emotional/mental health support

A wide variety of experiences were recounted among both focus groups in relation to their experience of first being diagnosed.

A common theme was feeling 'forgotten about' following diagnosis and that this compounded internalised ableism, stigma and contributed to poor mental health. One participant highlighted how the period immediately post-diagnosis could be a vulnerable time for autistic people, even if they were not outwardly seeking support or communicating distress.

> **"The first year after diagnosis was bad, I didn't know who I was. I think counselling needs to be involved."**

> **"I had a similar experience [following diagnosis], 'here's your letter, off you go!"**

Likewise, some participants needed time to process a diagnosis and felt that the offer of emotional support should be made alongside building in processing time for people who might not be ready to take up an offer of support immediately.

Several participants recounted grieving for what their life might have been upon receiving their diagnosis and how emotional support to process these feelings would have been beneficial.

> **"I rejected my diagnosis...took me two years to start learning about autism…Almost like stages of grief…[you need] a lot of acceptance, what works, what doesn't. Trial and error."**

> **"Support around the mental health aspect, coming to terms with a diagnosis. I was elated for a month, a new me, but then I experienced the trauma response of thinking how I could have lived my life if I had realised it was not depression, anxiety, not down to work, nothing I could have controlled. No one prepared me for the dip."**

> **"Massive period of grieving. Not finishing medical training, not having kids, looking back at what I've missed out on."**

A lack of access to mental health support for those with autism was identified. For some, this was due to structural issues meaning that existing 'pathways' to access support were not available to them. For others, it was felt that existing mental health services had little awareness or knowledge of autism or symptoms of autistic burnout and responses to this (such as autistic shut down) meaning their care was not appropriate and it was felt that on occasions, contributed further to their distress.

> **"I experienced autistic shutdown during the pandemic and became catatonic. People didn't understand...their responses complicated things and contributed to my trauma."**

> **"There is a lack of tailored therapies such as CBT."**

> **"[There should be] recognition of the trauma of incorrect diagnosis."**

The need to be sensitive and responsive to the elevated risk of autistic people experiencing trauma or post-traumatic stress was a theme across both focus groups. Participants in one group cited recent research into autistic people's increased susceptibility to trauma responses to (neurotypically perceived), non-traumatic events, and how this often went unrecognised by services.

> **"Anxiety is just a baseline autistic people have."**

OT provision and recognition of the impact of autism on other areas of health

The benefits of OT support to develop people's independent living skills was mentioned in both focus groups. As with mental health services, accessing OT was described as difficult or nonexistent, with one participant having accessed it through a glitch in a rigid process that would otherwise not have enabled them to access such provision without a diagnosed mental health condition.

> **“OT support should be accessible via primary care [so people aren’t having to access it via secondary/acute services].”**

Another participant described how they ‘finally felt seen’ during the assessment process which was conducted by both a neurodivergent psychologist and an OT specialising in autism. However, that this level of specialist professional support could not be continued beyond the assessment process was experienced as traumatic and highlighted how much other professionals lacked in knowledge and awareness of autism in all subsequent interactions.

Participants felt support to organise and manage their daily routines via an OT could help them to minimise incidences of reduced or fluctuating functioning. For one participant, the fact they held down a 9 to 5 job concealed the effort required to function day-to-day. Full-time work took its toll on the weekend where they detailed **‘not making any decisions [for themselves] between a Friday evening and a Monday morning,’** demonstrating levels of functioning could be highly variable for those who seemed to be ‘managing’ to the outside world.

The complex interaction between autism and other health conditions was also highlighted during one focus group. Participants described how autism impacted on their ability to access wider health care due to the lack of adjustments e.g. A&E being too over stimulating for someone already in a state of dysregulation but who needed to be monitored due to blood pressure being too high. The emotional toll of even routine health appointments was also felt to be the result of a lack of accommodation for neurodivergent ways of experiencing the world.

> **“I experience performance anxiety when I go to appointments. Will have to mask, but still have to bring forward [some] of the real me [to communicate the health issue].”**

However, systemic issues were also highlighted in the planning of services where research on autism and other health conditions (such as the link with weight gain) didn’t appear to be drawn upon. One participant described being able to adhere to advice from clinicians when being actively supported by the weight management team, but that their neurodivergence meant maintaining control without active oversight and guidance was difficult. They described going into ‘compliance mode,’ taking advice to ‘eat anything you want within an 8-hour window’ literally without really understanding the nuances of such advice.

> **“75% of autistic people struggle with weight gain – why are people planning these services not aware of these issues.”**

Employment support

Participants had very different experiences in relation to employment, but all agreed that support to gain and stay in employment was needed.

One participant recounted their experience of struggling in an unsuitable working environment where sensory overload and the unpredictability of shift work contributed to ill health and the eventual decision to leave work. It was this experience that led to them seeking a diagnosis, but the experience left them worrying about the possibility of never being able to work. They were fortunate enough to be supported back into employment via a support agency and emphasised how instrumental this additional support had been in overcoming barriers including anxiety resulting from previous negative employment experiences.

> **"Employment support was really helpful…I thought it was just me...it helped me to move forward."**

Linked to this was the need for a high-quality impact statement to help employers know how best to support neurodivergent people. One participant highlighted that a downside to the 'Right to choose' option within health care was that people who received an autism diagnosis through alternative (private) providers were not always provided with an impact statement. For those who did receive an impact statement, it was felt that any new service should have a role in ensuring that these were tailored to the individual and could be reviewed and renewed at distinct stages in the future as people's needs changed or reduced.

> **"When you're diagnosed with autism, you should receive a robust impact statement. Some are absolute garbage!...[if done well] it should remove the burden from the person from having to tell each new employer what their support needs are."**

> **"I was one of the lucky ones. [My impact assessment was developed] through conversations and observations of how I presented. Though some of it's now redundant...I did get in touch recently to ask about an update."**

Practical assistance

Participants described struggling with tasks such as completing forms and navigating the benefits system. All agreed that practical assistance offered from a new service would be welcome, particularly with activities such as document completion for example.

Although it was recognised that there are existing agencies that assist with this (such as the Citizens Advice Bureau), it was felt that a new service could possibly offer practical assistance with tasks of this nature if people were going to be accessing support on a 'one stop shop' basis.

Knowing that they could access support in an environment that was already sensitive to their needs would be a bonus for autistic adults, particularly if such an environment could minimise sensory distractions and offer flexibility that a more general service could not.

> **"Filling out forms, applying for benefits. Citizens Advice does this but is a noisy environment. People could also be supported to complete medical passports which they can take with them to any health service, telling people 'I don't like being touched, bright lights, etc."**

Information/education on autism (including for family members)

Most participants talked about how they felt supported by family members but that it had nevertheless been a journey to reach this point. They felt that support would have been beneficial to help family members understand how their experiences differed from those of neurotypical adults and reduce stigma. However, this should also be tempered with a strong acknowledgment of the diversity within neurodivergence which will not necessarily be captured by a checklist of attributes.

Younger participants talked about how parents had expectations about employment and independent living and that additional professional support to help manage such expectations could be useful.

> **"There was a lot of pressure…It would have been helpful if my family could have had education, or family liaison."**

> **"From the perspective of working with autistic adults and their families, there can be a lot of difficulties with family expectations...there is a lack of psychoeducation [within the health service]."**

> **"Support for my family that I'm not crackers, I've just been misdiagnosed for decades...support to explain and how to talk to my family about my diagnosis after they've also been living with me for years."**

Education on the specific sensory needs of autistic people was also highlighted by one participant who talked about how liberating finding out about a 'sensory diet' had been for them. Guidance on emotional regulation was felt to be key to mental health and resilience.

> **"I now understand how different my nervous system is . Having that understanding [has helped me to keep going]."**

One participant suggested that they would have found some kind of leaflet to 'walk a person through the process' of being diagnosed helpful to understand what to expect and to minimise anxiety. They suggested that such a guide would be useful to explain terms such as 'impact statement' and would provide the 'human connection' if written by a person who had been through the process themselves.

> **"A patient/user-led manual, not NHS speak, [would have been useful]...There is a lot of stuff for kids, nothing for adults...[such a manual would have helped create] the feeling of someone holding your hand."**

How should this service be provided?

Flexibility and choice

The overriding response to this question was that all delivery formats for the service should be offered including face-to-face and online support, as well the option to be supported on a one-to-one basis and in groups. Participants felt this was important to ensure people were comfortable and felt able to engage with a service.

> **"Support should be tailored to the person rather than a 'one size fits all'...home visits should be offered as the outside world [for me] involves too much sensory overload."**

The importance of establishing trust was highlighted, and employing autistic people within the new service was suggested as one way to do this, as well as to reduce barriers to access by ensuring people felt comfortable using the service.

> **"Lived experience within the service…acceptance [is important]. It's exhausting to have to explain something unusual [that I might be experiencing] to a neurotypical person."**

> **“Each individual is different, got to make each individual comfortable…[thinking about things like] lights, fidget toys etc.”**

Some discussion took place about how long support needed to be provided for. It was recognised that open-ended support was unlikely but that the option to dip in and out of a service should be available, if possible, as ‘some people needed more support than others.’

The need for clear written documentation was also noted. Video calls and text messaging were suggested as preferable to phone calls.

> **“Is assumed we will just slot into this world. I can talk to you or listen to you but not both [simultaneously]. If I receive a text, I don’t have to take on board peripheral information, it cuts to the chase. My mind can’t cope. Small talk [that accompanies a telephone call for example] is a no.”**

Both groups suggested additional support being made available to help people access any new support, including video walkthroughs for those attending the hospital/community site for first time (i.e. to show where to park, how the parking meter works, door to use etc).

How useful would you find peer support and why?

Benefits

The majority of participants from one group felt that support from their peers was crucial for people’s wellbeing, particularly post-diagnosis, but also as soon as they were referred into the service (i.e. whilst awaiting assessment).

For one participant, the support of **“others like them”** had been the most influential aspect in helping to support their wellbeing and others concurred that peer support or ‘community’ was pivotal.

> **“I think it’s vital. The most important thing. [It has the knock-on effect of] supporting other’s confidence….to get a job, move on with your life.”**
>
> **“...as you grow up [autistic] you take on lots of shame. People are apologising [for neurodivergent behaviours] all the time. [During peer support activities] you have permission to be different. We can model [neurodivergent] behaviour, share our experiences.”**
>
> **“I don’t feel I need it now, but it would have been so much easier if I’d had this in the earlier days...Just knowing it’s there. A safety net.”**

The benefits of peer support to people’s mental health and wellbeing were also stressed, not only through feeling less alone by hearing other’s people’s stories, but also through the sense of purpose it afforded some by knowing they were helping others.

> **“Peer support is preventative, it helps to avoid crisis, so people won’t need services.”**
>
> **“It’s why I tell my story...to help others.”**

An identified benefit was the feeling that this was another route to high quality and more up to date information on autism than that provided by organisations on some occasions.

Concerns and considerations

However, the opposite was expressed by participants in another group who felt that a group environment provided additional barriers to their ability to express their authentic selves. This was due to a concern for the wellbeing of others, should they themselves become dysregulated, and the potential for anxiety and burnout through having to mask and consider the wellbeing others.

> **"I lose all my skills if I experience autistic burnout...I'd become stressed about interrupting peers as I find timings [turn taking in social situations] difficult. [The environment of peer support] would be too demanding, I'm better on one-to-one. I need to practice being with other people but it's hard taking other people's needs into consideration."**

For those who were sceptical of peer support, the way it would be provided was a concern and something that would have to be carefully thought through to ensure that it was not perceived as tokenistic and there as an additional resource rather than supplanting the one-to-one support needed to meet individual need.

> **"I like the idea in principle, but I'm concerned it is the lazy, cheap option. Feels like to get support, we're having to be bundled together."**

For those who were more hesitant to join with peer support, suggestions for different formats and organising principles were made that might make this option more palatable to them. Careful consideration was necessary to avoid it being a negative experience that might put people off returning or taking up a similar opportunity in the future.

> **"[Outside of work hours], potentially online, a themed activity that I would know in advance."**

> **"I fixate on the bad experience [even if everything else went well]."**

> **"I won't go back to places if I've had one bad experience."**

One participant gave the example of being part of an online crochet club during lock down which had worked well because there was no pressure to interact, they had something to occupy their eyes and hands and that this focus on an activity had helped reduce their anxiety about having to participate.

> **"I'd get anxious about attending support sessions if I didn't have something to say."**

Several participants were already involved with peer support and described how they often met for walks or for a coffee and, because the focus of their coming together was often activity based, it was not necessarily on their experience of autism.

For some, meeting with others provided the impetus to leave their house and get outside their own 'comfort zone,' though they recognised that this wouldn't be the same for everyone.

> **“For example, I like being out of the house so I can talk to people, get out and about but others would prefer to be in the familiarity of their home. It’s individualised.”**

Service provider

Participants discussed whether they thought funding to provide a peer support might be better directed towards existing voluntary/community organisations, with some feeling that expertise developed within communities should be built upon and supported.

However, others with professional experience within the health service felt that the new service should provide a place for peer support to be delivered, both to remove any barriers associated with specific autism providers and in recognition that improving wellbeing was a health responsibility that should not necessarily be outsourced to the voluntary sector.

> **“Different [types of] group support should exist. There are barriers for people accessing [large third sector provider of autism services] for example. There would be less barriers if it [peer support] was seen to be NHS led.”**
>
> **“If professional led, it still needs to have lived experience.”**

What would a travelling hub/support in the community look like to you?

Participants from both groups were generally apprehensive about the idea of a travelling hub, with concerns expressed about access difficulties and the potential lack of commitment conveyed if it was unable to have a base.

> **“Horrified! Don’t like the idea of a travelling hub...drop-in, drop-out. No commitment. Already have lots of services that don’t commit...Have experience of a previous service being between two places...never sure which base I would get an appointment at.”**

One participant felt that consideration of sensory issues should be prioritised when thinking about suitable buildings to host the service, with NHS buildings often felt to be too overwhelming.

> **“It shouldn’t be in an NHS building...the lights are awful, not sound proofed... sensory-wise it is a nightmare.”**

Accessibility was a key concern, particularly for participants of one area of Tees Valley that was felt to be geographically spread out without a well-defined urban area that was easy for everyone to get to. One participant noted that a similar hub idea had been trialled within another health service but had not been successful due to the specific geography.

Issues with unreliable public transport were also voiced as was the needs of friends or family upon whom autistic people were often reliant on to get to places.

> **“Lots of people don’t drive, are reliant on public transport or others to bring them...or [the service needs to be] out of hours if people are working.”**

Both groups talked about the anxiety invoked by any new appointment and how a massive amount of preparation was required by autistic people prior to engaging with any new situation.

"Accessing anything is a process [of planning]...where the building is, how to get inside, how to get there, how long we will have to wait, why we are going there, what will be available."

> **"Picture or a video of the location would be good. Preparation is key."**
>
> **"Can't eat or drink [if I have a late afternoon appointment] when I'm in 'waiting mode.'**

For one housebound participant, the idea of the hub was a non-starter, unless access was available in hybrid form to enable them to participate online.

That all options should be presented was the overriding theme to increase access and to ensure that the onus shouldn't be on autistic people to have to make the request for adjustments.

> **"Accessibility should be baked in."**

Individual feedback (2 respondents)

What kind of support do you think should be provided within a post-diagnostic service?

Emotional support

Support to understand the personal impact of diagnosis was suggested, with the needs of those ordinarily deemed 'high functioning' given equal priority. The differences between neurodivergent and neurotypical people's behavior and the impact of this on relationships was suggested as something education and support could address and to help foster understanding between all neuro types.

Practical assistance/navigation support

As with focus groups, respondents felt that additional support to navigate specialist neurodivergent support and mainstream services would be useful. Practical assistance with benefits and advocacy support were both mentioned as possible ways of supporting autistic adults within a new service.

How do you think this support should be provided?

Flexibility

It was again felt that the new service should offer flexibility to increase access and engagement. To accommodate the wide variety of experiences and needs of neurodivergent people, all delivery formats should be offered including one-to-one support as a priority (with home appointments where needed), group provision and online resources and training or courses. The inclusion of those with lived experience of autism delivering support alongside professionals was also suggested.

How useful would you find peer support and why?

Peer support was felt to be quite useful, providing careful consideration was given to how it was implemented and delivered:

- Lived experience was felt to be a necessary requirement for group sessions delivered by professionals (and was felt to also be important for one-to-one support for some people)
- Smaller-sized groups were preferred to ensure people were not overwhelmed by too many unfamiliar faces.
- Organising groups according to age would be a consideration.
- Knowing how many sessions would be arranged was important.
- To ensure accessibility, flexibility over dates, times and locations with the inclusion of weekend provision to enable those at work during the week to attend was suggested.

What would a travelling hub/support in the community look like to you?

In order to access a hub, specific and timely information (i.e. provided well in advance) about the location of any new venue for a hub service would be required.

Feedback indicated that planning is an important consideration for autistic people that warranted extra details being provided. This included things like:

- Uncomplicated parking arrangements.
- Choice of appointment times (including weekends).
- Comprehensive guide of what to expect at the appointment.
- How to get to a venue (including how to get into or around the venue).
- Advance notice/reminders of sessions.

Offering the service on a drop-in basis was considered, but not if it increased the risk of a person having to wait to be seen or being unable to access support if demand was too high.

Interview with carer of autistic younger person

What kinds of support do you think should be provided within a post-diagnosis service?

Designated contact and plan of action

It was suggested that a consistent designated contact to speak to about what support was available and to assist with navigating or coordinating services and processes was needed. Furthermore, a post-diagnosis plan, particularly in relation to education would be useful.

> **“Post diagnosis we struggled to get anyone coming up with a plan for anything...someone to help us understand what is available and with insight on what works and what doesn’t [would be helpful.]”**

Parents recognised that services existed but emphasised that support options could be overwhelming.

They felt that in such an unsettling period (such as immediately post-diagnosis) their ability to navigate the service landscape was compromised by the stress of having to deal with their autistic young person’s day-to-day struggles and this affected their confidence to judge which provision would best meet their needs.

> **“What would a professional recommend for her, based on her needs and anxiety.”**

By having a documented plan that could be shared across agencies and settings, it was felt that a ‘multiagency approach’ would work better. This would ensure a holistic lens was applied to the support and health needs of younger autistic people that would make clear the responsibilities of each agency and reduce the anxiety of ‘not knowing’ who to contact for parents and carers.

> **“...[CAMHS would] shut down requests for support [and redirect us to X (third sector autism charity) saying they couldn't meet autism related needs]. At the bottom of this is a teenage girl.”**

Support in educational settings

The inability of mainstream schools and higher education to meet the needs of some autistic children was also highlighted. The availability of support during the teenage and transitional years was thought to be crucial and likewise, further support around employment was also felt to be necessary.

The participant recounted their dismay at finally getting their child into further education, only to find that no SEN (special educational needs) support had been put in place upon starting college. Again, a plan to support young adults going forward would be helpful to ensure they could start feeling hopeful about the future.

> **“She doesn’t like to look into the future… how do we help her?...We were told to throw out the rulebook [for parenting] – but what do we do now? No one knew what to suggest. Is she the only teen girl in the area with autism?”**

Support to connect with others

Isolation, often through a lack of opportunity to socialise with others, was highlighted as problematic for autistic young people, particularly those who were unable to access mainstream educational settings. One-to-one support was felt to be the best way to deliver specialist support to young autistic adults who were struggling with social skills, to help them develop and practice these within the context of a safe supportive professional relationship.

It was felt that peer support was unlikely to work for those who had already struggled to manage in group settings and that efforts should be concentrated on relationship building on a one-to-one basis at first. The skills of the professional delivering such support would be crucial and would need to tap into the interests of young autistic people to leverage motivation and ensure effective engagement.

This could then be extended to encourage and access more group-based support or provision, as a **“stepping stone to leaving the house.”**

> **“My daughter had attended an autism for girls group but said that she ‘doesn’t want to be in a room with a lot of people like her,’ wants to be with ‘normal’ people.”**

How should this service be provided?

Flexibility

As indicated, one-to-one support was felt to be the best mode of delivering support for some autistic young people who struggle in group-based, over-stimulating environments.

As with other responses it was felt that the offer of engagement should include all delivery formats including in-person and online and should be responsive to the individual communication needs of autistic people.

> **“My daughter struggles to engage with video/facetime, hates phone calls and struggles to respond to texts. For her, online makes sense but for some reason doesn’t work…the only thing that has ever worked is one-to-one support.”**

What would a travelling hub/support in the community look like to you?

Although this was felt to be a good idea in principle, the participant conveyed that their young person would be unlikely to access it at the current time due to their anxieties around leaving their house and being in public spaces.

As with other groups, they had questions about how the provision would work and how resources would be allocated and so it was difficult to support a concept that had yet to be fleshed out.

The benefits of using existing settings to access professional support from a physical hub were commented upon, with places such as GP practices being identified as familiar to most people, with its facilities and associated social etiquette being known to most people by the time they reached adulthood.

> **“It is somewhere a neurodivergent person would go, a setting they’re used to… waiting and taking their turn.”**

For parents who were supporting young people to access a hub in person, consideration of opening hours was crucial, with hours outside of standard work times being offered to ensure access.

They recognised that hub support was to be for the direct benefit of autistic people themselves and commented that previous experience of peer support for parents/carers was often poorly attended and therefore did not express desire to access this kind of support for themselves via a new hub-based service.

Conclusions and recommendations

In response to the findings of this engagement exercise, some conclusions and related recommendations can be made. It is suggested that commissioners in Tees Valley take time to analyse the findings of this report to help inform the scope of the pre-assessment and post-diagnostic autism services and ensure that services provided meet the needs of patients/carers.

Key recommendations

Developing pre-assessment and post diagnosis services

The findings show that there is strong demand for a service to support those waiting to be assessed for autism and those already diagnosed. A large proportion of survey respondents (including carers/family members) strongly agreed or agreed that they would like all of the types of support listed. This was illustrated by the fact that over two thirds of those waiting for an assessment were looking outside of the NHS for information or support whilst over nine-in-ten autistic people were seeking support from elsewhere.

- **It is recommended that pre-assessment and post diagnosis services are developed to support the needs of patients during this period and beyond their diagnosis.**

Gathering further feedback

It is so important for the NHS to get the services right as engagement revealed that autistic people often have ‘no go’ places and based on just one bad experience, they will never return to the service, shop or organisation. Moreover, focus group participants highlighted difficulties in answering questions about what they would want from a service when not provide with some examples or suggested ideas.

- **It is therefore recommended that once the services are planned in draft form, people are given the opportunity again to provide feedback on this draft service.**

- **It is recommended that at the outset, feedback mechanisms are put in place and regularly reviewed to enable the services to adapt to user need.**

Other recommendations

Service requirements – people awaiting an autism assessment

There was strong support for all listed options within the survey. The top four most popular types of support (where over nine-in-ten respondents agreed) were: coping strategies (also highlighted by carers/family members of autistic people), autism services available to them, how autism may affect them (also suggested by autistic survey respondents) and support and information about autism for family members. Focus group respondents also requested a resource to show community autism services available to them.

- **Whilst acknowledging the finite amount of resource available, it is recommended that in the first instance, the service looks to prioritise these types of support. The other types of support could be revisited once the service is established.**

    - **In the development of a resource for available services, this should be clearly laid out in table format and include the name, what the service/organisation can offer, whether this is time limited and whether it is free or paid-for.**

When survey respondents were asked what would make the biggest difference to them whilst waiting for an assessment access to support around emotions was most commonly mentioned. Focus group participants also requested emotional support, providing examples of mainstream services such as Talking Therapies not being fit for purpose for them.

- **It is recommended that the service also provides support around emotions.**

Around two-fifths of survey respondents felt that having regular contact and updates about how they are progressing on the waiting list and expected wait times would make the biggest difference to them whilst waiting. This finding was supported by focus group participants who emphasised the need for clear and accurate information to allow them time to plan and prepare for any interactions and crucially, alleviate concerns that they had been forgotten or were making no progress on the list. It was also supported by autistic survey respondents who identified that transparency around waiting times and the assessment process and regular contact/support whilst waiting for the assessment, would have helped them.

Carers/family members also highlighted coping strategies in particular.

- **It is recommended that at the outset patients are made aware of the process whilst on the waiting list with regular check-ins arranged (with dates and times provided), how this check-in will happen (and options for the format of this e.g., in-person, online, telephone, email), what they can expect from it and what is expected of them.**

- **It is recommended that a text service could provide them with for example, 12-weekly updates as to their progress on the waiting list.**

Focus group participants felt that a peer support group for those awaiting an assessment (not diagnosed autistic people) would be beneficial.

- **It is recommended that the provision of peer support groups should be explored.**

Format of support for people awaiting an autism assessment

Over nine-in-ten survey respondents requested that any support be provided by trained workers and focus group participants felt that they should be specifically trained in autism awareness; they also felt that employing some neurodivergent staff would be beneficial.

- **It is recommended that all support is provided by workers who as a minimum, are trained in autism awareness.**

Survey and focus group feedback all pointed to the need for flexibility in the services provided to ensure that people's individual needs are met and barriers are not created to exclude anyone from using them. There was greatest demand from survey respondents for a mixture of in-person and online access and one-to-one face-to-face support. Furthermore, around two-thirds of survey respondents stated that they would be willing and able to travel to get face-to-face support. Focus group participants requested one-to-one support from a named support worker in particular.

- **It is recommended that a variety of formats are provided to ensure equity of access to support but in particular, that this is offered on a one-to-one basis and that options are available for those who cannot travel to get this support. Having access to a named worker who could help navigate services and support should also be explored.**

When asked about attending a travelling hub, three-quarters of survey respondents said that they would be likely to attend, whilst focus group participants felt that it was a difficult concept to consider without more detail about how it would operate. They cautioned that in order to allay any anxieties associated with visiting a new space they would need to know:

- Why they would go there/what would they access there.
- How to get there and parking facilities etc.
- What the building was like including a video tour.

They highlighted barriers to consider such as people who work fulltime, being located in busy areas and sensory distractions within the building.

- **It is recommended that the option of a travelling or moveable hub is explored taking into consideration busyness of location, opening times, sensory overload and crucially, the provision of detailed information about it.**

Service requirements – autistic people

There was strong support for all options listed within the survey. The four most popular types of support (where over nine-in-ten autistic respondents agreed) were: advocacy, emotional support, help to identify where additional support might be needed and sensory issues.

Focus group participants and those providing individual feedback strongly highlighted the need for emotional/mental health support (current services do not meet their specific needs). They also requested access to a specialist autism OT (OTs cannot currently be accessed without a mental health diagnosis or other specific health conditions) to help people develop independent living skills and manage their daily routines. Someone to provide practical assistance to help with completing forms, navigate benefits and write (and update) impact statements for employers was also requested. They wanted access to information for themselves and family to understand autism and the process after diagnosis. Carers/family members also suggested support building social skills was important.

- **Again acknowledging the finite amount of resource available, it is recommended that in the first instance, the service looks to prioritise these types of support. In terms of emotional support, grief and anger around late diagnosis should be considered, as well as behaviours and their impact on others. Other types of support identified could be revisited once the service is established.**

When thinking back to when they were first diagnosed, survey respondents stated that emotional support, access to peer support and information on coping strategies would have been most helpful.

- **It is recommended that consideration be given to the types of support which could be provided but also at what stage this support might be appropriate.**

For younger people (aged 16-25) who shared their views with the CCG in 2022, their service suggestions generally matched those highlighted above, however they also requested support around going to school or higher education. They shared experiences of having little or no support which for some, resulted in them having to leave. This was echoed by a participant providing individual feedback during this most recent engagement activity whose autistic daughter had been offered support attending college and having found the confidence to attend, discovered that no support was in place.

- **It is recommended that support is provided to help young people who are transitioning to further or higher education.**

The participant providing individual feedback also suggested that during the transition from children's to adult services, it would have been beneficial to have a named support worker to help navigate services and support available (including educational support).

- **It is recommended that having a named support worker is considered during transitioning to adult services.**

Focus group participants and individual respondents generally felt that peer support would be useful although group settings with people unfamiliar to them was a barrier for some.

- **It is recommended that peer support be offered but not at the expense of one-to-one support which was more strongly requested. This support should be again offered in a variety of formats (including one-to-one) such as small groups and activity focused with clear, detailed information on how to access it, what to expect, venue etc. provided as standard. If outsourcing this support to an established organisation, consideration should be given to potential barriers people may have based on previous interactions.**

Format of support – autistic people

Focus group participants discussed the timeliness of any support, identifying that people may be more open to support at different stages, post diagnosis.

- **It is recommended that support is offered immediately after diagnosis but if this is not taken up at this time, workers should follow this up at regular intervals to give people the opportunity to take part at a later date.**

Around nine-in-ten survey respondents (and a similar proportion of carers/family members) requested that any support be provided by trained workers who understand autism whilst around three-quarters wanted support from people with lived experience of autism. Focus group and individual participants suggested employing autistic people within the service.

- **It is recommended that support is provided by workers who as a minimum, are trained in autism awareness.**
- **It is also recommended that support could be provided by peer support workers.**

As with the service for those awaiting an assessment, survey and focus group and individual feedback reflected a need for flexibility in the services provided to ensure that individual needs are met and support is accessible to all. There was greatest demand from survey respondents for one-to-one face-to-face support, email, a mixture of in-person and online access. This flexibility was echoed in responses to what reasonable adjustments respondents felt would be helpful, with communication in a variety of ways and flexibility in service delivery (also identified by carers/family members) highlighted. They also requested consistency in staff.

A half of survey respondents stated that they would be willing and able to travel to get face-to-face support.

- **It is recommended therefore, that a variety of formats are provided to ensure equity of access to support but in particular, that this is offered on a one-to-one basis, either face-to-face or online and that options are available for those who cannot travel to get this support. Having consistency in the workers they interact with should also be the aim.**

When asked about attending a travelling hub, around seven-in-ten survey respondents said that they would be likely to attend. However focus group participants were generally apprehensive about a service without a permanent base. They felt that in order to consider accessing a hub they would need to know:

  - Where the building was (NHS buildings were felt to not be fit for purpose due to sensory overload).
  - That it was in an accessible location.
  - How to get there and parking facilities etc.
  - What the building was like including a video tour.
  - How to make an appointment (a drop-in facility felt too uncertain for some).
  - Why they would go there/what would they access there.
  - Be able to access the service remotely.
  - That the service was accessible outside of work.

- **It is recommended that the option of a travelling or moveable hub is explored taking into consideration the information requested above.**
- **It is recommended that a virtual hub also be available to those who cannot leave their house.**
- **It is recommended that the hub is not just open within working hours.**

Service requirements – family members/carers of autistic people

There is demand for the service to provide support to carers and family members of people who have been diagnosed with over four-fifths of respondents seeking out information and advice, usually from an online source. Fewer than one-sixth feel like they have enough information, advice or support about autism.

Most commonly requested were things that would help them support their family member/person they care for, around practical day-to-day things and communication and socialising/social skills.

- **It is recommended that in the first instance, the service looks to prioritise these types of support. The other types of support could be revisited once the service is established.**

Format of support – family members/carers of autistic people

In terms of how they would like to receive this support, most commonly mentioned were one-to-one in-person support, a mixture of in-person and online access and email. Nearly two-thirds of respondents would be willing and able to travel to receive face-to-face support and would be likely to access a travelling hub.

- **It is recommended that a variety of formats are provided to ensure equity of access to support but in particular, that this is offered on a one-to-one basis, that options are available for those who cannot travel to get this support.**
- **It is recommended that the travelling hub could be used to accommodate the needs of family members/carers.**

Appendices

Appendix 1: Profile of respondents awaiting an autism assessment

Please note that not all respondents chose to complete these questions

Are you answering for yourself, or on behalf of someone else?	No. of respondents	% of respondents
Myself	38	55.1
On behalf of someone else	31	44.9
Total	69	100.0

How old are you?	No. of respondents	% of respondents
16 – 24	11	19.0
25 – 34	13	22.4
35 – 44	17	29.3
45 – 54	14	24.1
55 – 64	3	5.2
65 - 74	0	0.0
75 – 84	0	0.0
85 or older	0	0.0
Prefer not to say	0	0.0
Total	58	100.0

Which best describes you?	No. of respondents	% of respondents
Female	50	84.7
Male	7	11.9
Non-binary	2	3.4
Prefer not to say	0	0.0
Prefer to self-describe	0	0.0
Total	59	100.0

Is the gender you identify with the same as your sex registered at birth?	No. of respondents	% of respondents
Yes	56	94.9
No	3	5.1
Prefer not to say	0	0.0
Total	59	100.0

Which of the following best describes your sexual orientation?	No. of respondents	% of respondents
Straight or Heterosexual	44	80.0
Gay or Lesbian	6	10.9
Bi or Bisexual	3	5.5
Prefer not to say	3	5.5

Prefer to self-describe	2	3.6
Total	58	100.0

Self-description:
Asexual
Pansexual

How would you describe your ethnic group?	**No. of respondents**	**% of respondents**
Asian or British Asian	0	0.0
Black, Black British Caribbean or African	2	3.4
Mixed or multiple ethnic groups	2	3.4
White	54	91.5
Other	1	1.7
Prefer not say	0	0.0
Total	59	100.0

What is your religion?	**No. of respondents**	**% of respondents**
No religion or belief	25	43.9
Christian (including Church of England, Catholic, Protestant, and other Christian denominations)	25	43.9
Buddhist	0	0.0
Hindu	0	0.0
Jewish	0	0.0
Muslim	1	1.8
Sikh	0	0.0
Other	1	1.8
Prefer not to say	5	8.8
Total	57	100.0

Do you have any physical or mental health conditions, impairments, or learning differences that impact on your ability to carry out day-to-day activities?	**No. of respondents**	**% of respondents**
Long term health condition	15	34.9
Physical impairment or mobility issues	3	7.0
Sensory impairment, such as blindness or visual loss and deaf or hearing loss	1	2.3
Mental health condition	19	44.2
Learning disability	3	7.0
Neurodivergence	20	46.5
Prefer not to say	15	34.9
Total no. of respondents	43	100.0

Are you pregnant or have you been pregnant in the last six months?	No. of respondents	% of respondents
Yes	2	3.4
No	55	93.2
Prefer not to say	2	3.4
Total	59	100.0

Postcode	No. of respondents	% of respondents
DL1	1	1.9
TS1	2	3.8
TS4	1	1.9
TS5	2	3.8
TS6	3	5.8
TS8	4	7.7
TS10	6	11.5
TS11	1	1.9
TS12	3	5.8
TS14	4	7.7
TS15	2	3.8
TS17	1	1.9
TS18	1	1.9
TS19	3	5.8
TS20	1	1.9
TS23	2	3.8
TS24	2	3.8
TS25	1	1.9
TS27	1	1.9
DH1	1	1.9
DH6	2	3.8
DL5	1	1.9
DL8	1	1.9
DL10	1	1.9
HG5	1	1.9
SR7	1	1.9
TS21	1	1.9
YO7	1	1.9
YO15	1	1.9
Total	52	100.0

Appendix 2: Profile of autistic respondents

Please note that not all respondents chose to complete these questions.

Are you answering for yourself, or on behalf of someone else?	No. of respondents	% of respondents
Myself	34	87.2
On behalf of someone else	5	12.8
Total	39	100.0

How old are you?	No. of respondents	% of respondents
16 – 24	3	9.4
25 – 34	11	34.4
35 – 44	6	18.8
45 – 54	8	25.0
55 – 64	3	9.4
65 - 74	1	3.1
75 – 84	0	0.0
85 or older	0	0.0
Prefer not to say	0	0.0
Total		100.0

Which best describes you?	No. of respondents	% of respondents
Female	19	61.3
Male	9	29.0
Non-binary	3	9.7
Prefer not to say	1	3.2
Prefer to self-describe	0	0.0
Total	31	100.0

Is the gender you identify with the same as your sex registered at birth?	No. of respondents	% of respondents
Yes	27	84.4
No	3	9.4
Prefer not to say	2	6.3
Total	32	100.0

Which of the following best describes your sexual orientation?	No. of respondents	% of respondents
Straight or Heterosexual	17	54.8
Gay or Lesbian	5	16.1
Bi or Bisexual	4	12.9
Prefer not to say	3	9.7
Prefer to self-describe	2	6.5
Total	31	100.0

How would you describe your ethnic group?	No. of respondents	% of respondents
Asian or British Asian	0	0.0
Black, Black British Caribbean or African	0	0.0
Mixed or multiple ethnic groups	1	3.1
White	31	96.9
Other	0	0.0
Prefer not say	0	0.0
Total	32	100.0

What is your religion?	No. of respondents	% of respondents
No religion or belief	21	65.6
Christian (including Church of England, Catholic, Protestant, and other Christian denominations)	7	21.9
Buddhist	0	0.0
Hindu	0	0.0
Jewish	0	0.0
Muslim	0	0.0
Sikh	0	0.0
Other	3	9.4
Prefer not to say	1	3.1
Total	4	100.0

Do you have any physical or mental health conditions, impairments, or learning differences that impact on your ability to carry out day-to-day activities?	No. of respondents	% of respondents
Long term health condition	15	51.7
Physical impairment or mobility issues	10	34.5
Sensory impairment, such as blindness or visual loss and deaf or hearing loss	2	6.9
Mental health condition	21	72.4
Learning disability	5	17.2
Neurodivergence	26	89.7
Prefer not to say	1	3.4
Total no. of respondents	29	100.0

Are you pregnant or have you been pregnant in the last six months?	No. of respondents	% of respondents
Yes	0	0.0
No	31	96.9
Prefer not to say	0	0.0
Not applicable	1	3.1
Total	32	100.0

Postcode		No. of respondents	% of respondents
DL1		1	3.4
TS3		1	3.4
TS5		1	3.4
TS6		3	10.3
TS8		1	3.4
TS10		6	20.7
TS11		2	6.9
TS12		1	3.4
TS14		1	3.4
TS15		1	3.4
TS17		2	6.9
TS20		2	6.9
TS21		1	3.4
TS23		1	3.4
TS25		1	3.4
TS26		1	3.4
TS29		1	3.4
HG5		1	3.4
YO15		1	3.4
	Total	29	100.0

Appendix 3: Profile of carers/family members of autistic people

Please note that not all respondents chose to complete these questions.

How old are you?	No. of respondents	% of respondents
16 – 24	4	15.4
25 – 34	1	3.8
35 – 44	8	30.8
45 – 54	11	42.3
55 – 64	1	3.8
65 - 74	1	3.8
75 – 84	0	0.0
85 or older	0	0.0
Prefer not to say	0	0.0
Total	26	100.0

Which best describes you?	No. of respondents	% of respondents
Female	24	92.3
Male	2	7.7
Non-binary	0	0.0
Prefer not to say	0	0.0
Prefer to self-describe	0	0.0
Total	26	100.0

Is the gender you identify with the same as your sex registered at birth?	No. of respondents	% of respondents
Yes	26	100.0
No	0	0.0
Prefer not to say	0	0.0
Total	26	100.0

Which of the following best describes your sexual orientation?	No. of respondents	% of respondents
Straight or Heterosexual	24	92.3
Gay or Lesbian	1	3.8
Bi or Bisexual	0	0.0
Prefer not to say	1	3.8
Prefer to self-describe	0	0.0
Total	26	100.0

How would you describe your ethnic group?	No. of respondents	% of respondents
Asian or British Asian	1	3.8
Black, Black British Caribbean or African	1	3.8
Mixed or multiple ethnic groups	0	0.0
White	24	92.3
Other	0	0.0
Prefer not say	0	0.0
Total	26	100.0

What is your religion?	No. of respondents	% of respondents
No religion or belief	11	42.3
Christian (including Church of England, Catholic, Protestant, and other Christian denominations)	13	50.0
Buddhist	0	0.0
Hindu	1	3.8
Jewish	0	0.0
Muslim	0	0.0
Sikh	0	0.0
Other	1	3.8
Prefer not to say	0	0.0
Total	26	100.0

Do you have any physical or mental health conditions, impairments, or learning differences that impact on your ability to carry out day-to-day activities?	No. of respondents	% of respondents
Long term health condition	5	29.4
Physical impairment or mobility issues	2	11.8
Sensory impairment, such as blindness or visual loss and deaf or hearing loss	0	0.0
Mental health condition	3	17.6
Learning disability	2	11.8
Neurodivergence	7	41.2
Prefer not to say	1	5.9
Total no. of respondents	17	100.0

Are you pregnant or have you been pregnant in the last six months?	No. of respondents	% of respondents
Yes	1	3.8
No	25	96.2
Prefer not to say	0	0.0
Not applicable	0	0.0
Total	26	100.0

Postcode	No. of respondents	% of respondents
DL1	1	4.2
TS5	2	8.3
TS6	4	16.7
TS8	1	4.2
TS10	1	4.2
TS12	6	25.0
TS14	2	8.3
TS15	1	4.2
TS16	1	4.2
TS17	1	4.2
TS18	1	4.2
TS19	1	4.2
TS27	1	4.2
SR8	1	4.2
Total	24	100.0

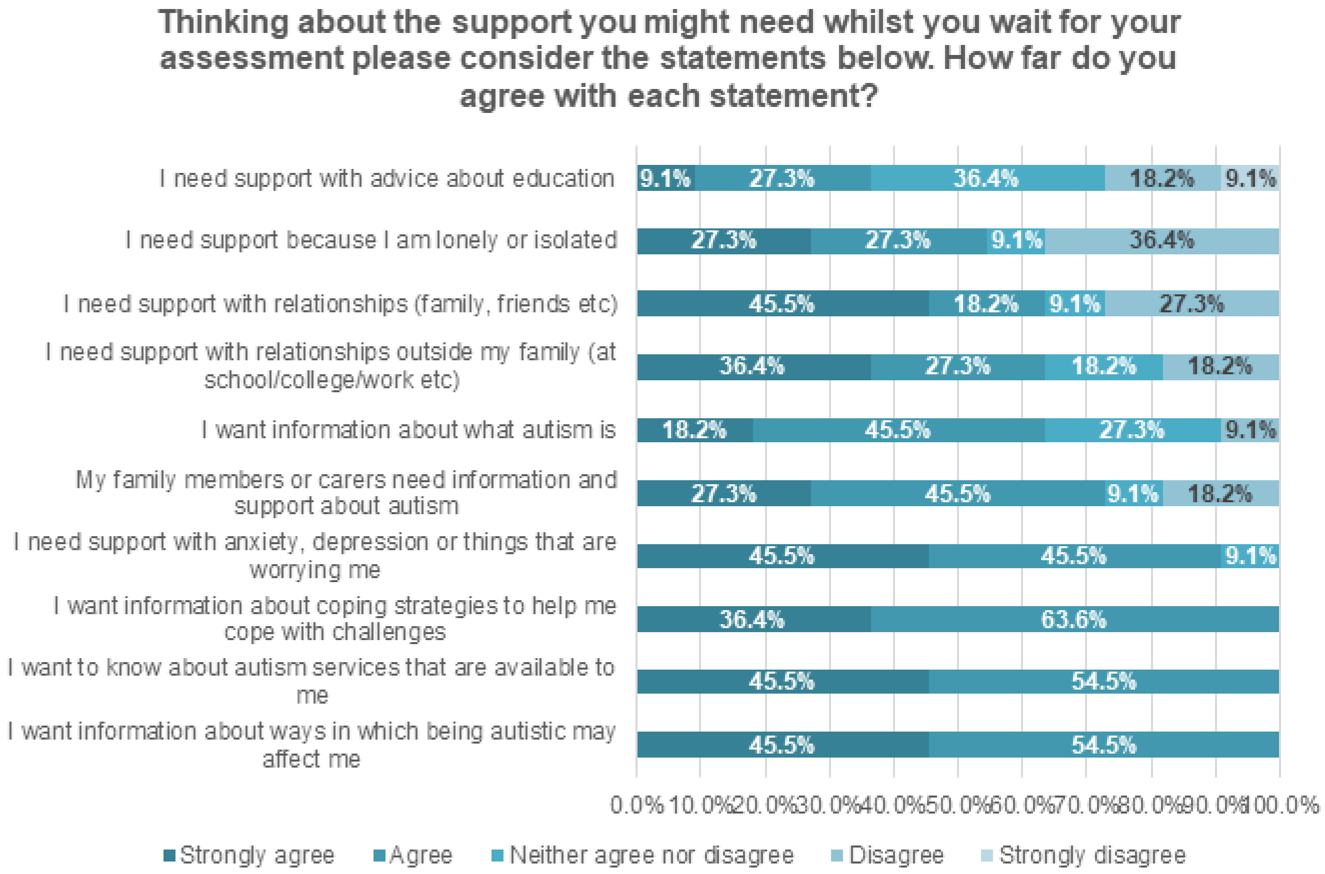
Appendix 4: Out of area survey responses

Please note that not all respondents answered every question.

People awaiting an autism assessment

Eleven survey respondents lived outside of the Tees Valley area (Durham, Sunderland and North Yorkshire) which is outside of the scope of this project. Their feedback however is valid, and for completeness, has been summarised briefly below.

- 10 people responded themselves.
- 1 person responded on behalf of someone awaiting an assessment.



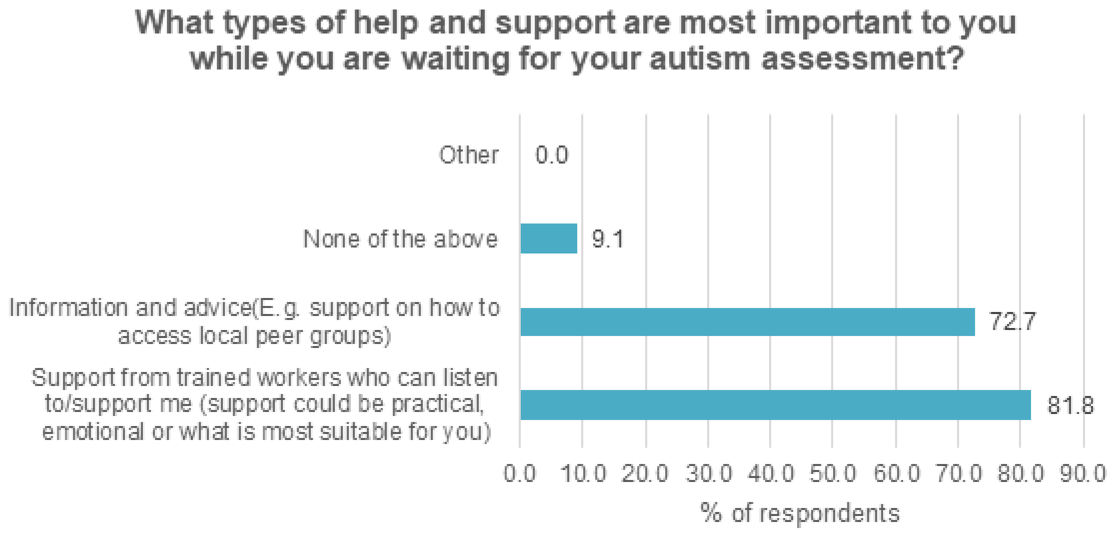
No. of respondents:11

- All 11 respondents indicated that they wanted some type of support from the options listed.
- Four people requested other support not listed:

Other support	No. of respondents
Regular/consistent check-in/contact and updates whilst awaiting assessment	2
Contact via phone whilst waiting (not letters)	1
Information on support available after diagnosis	1
Peer support	1
Validation of lived experience	1
Emotional/mental health	1

No. of respondents: 4

Respondents could give more than one answer

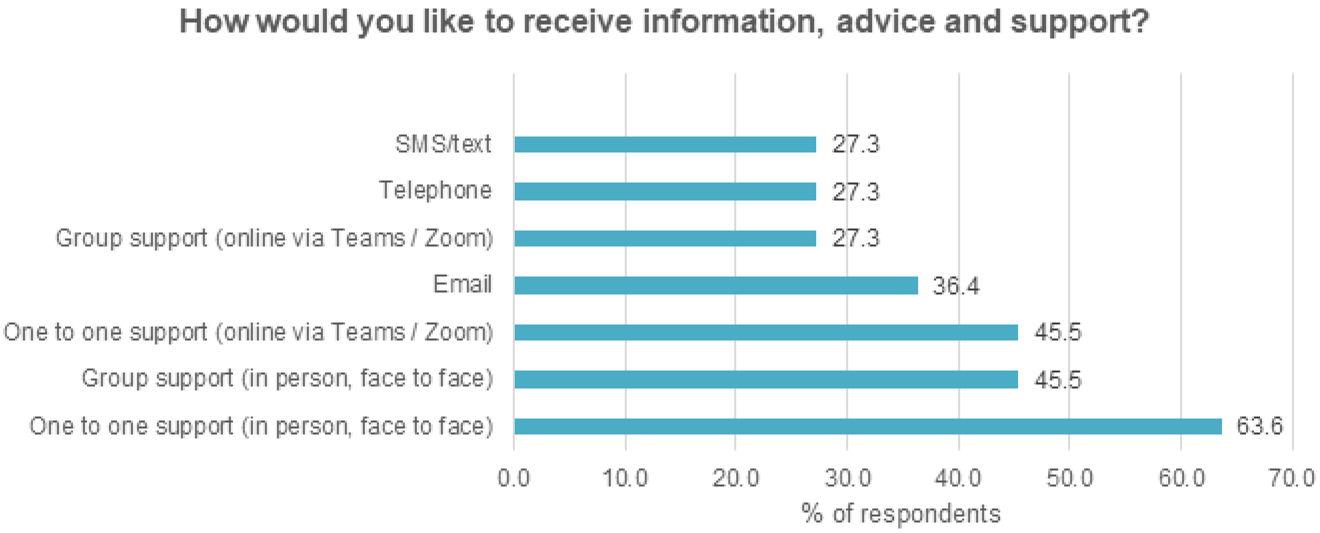


No. of respondents:11

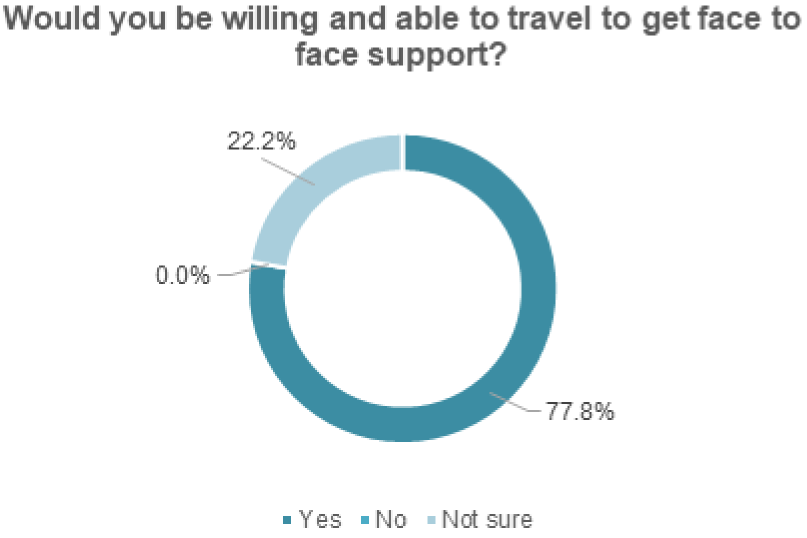
They felt that the things that would make the biggest difference to them whilst on the waiting list for an assessment were:

Information/support	**No. of respondents**
Emotional Support - "someone to speak to"	4
Peer support	3
Reduced waiting time/quicker assessment process	2
Regular/consistent check-in/contact and updates whilst on waiting list	2
Information about the assessment process and what happens after a diagnosis	1
More localised support	1
Support with employment/reasonable adjustments	1

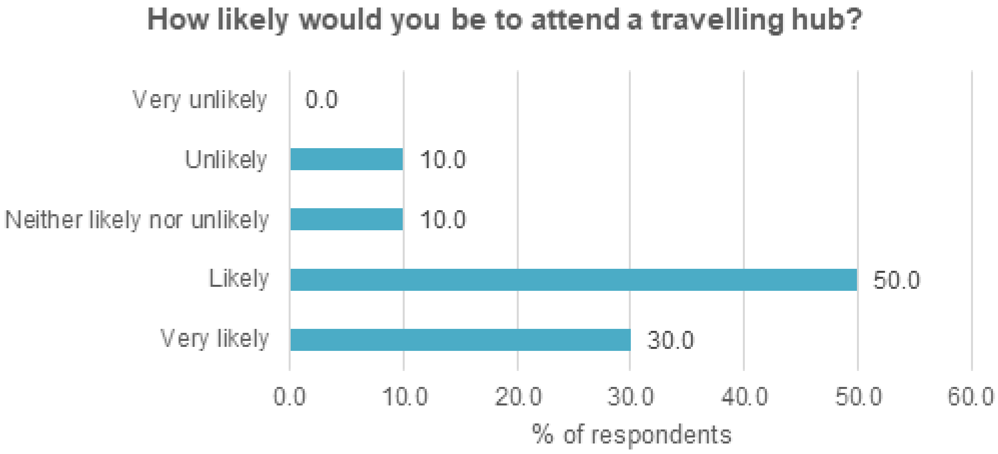
No. of respondents: 9
Respondents could give more than one answer



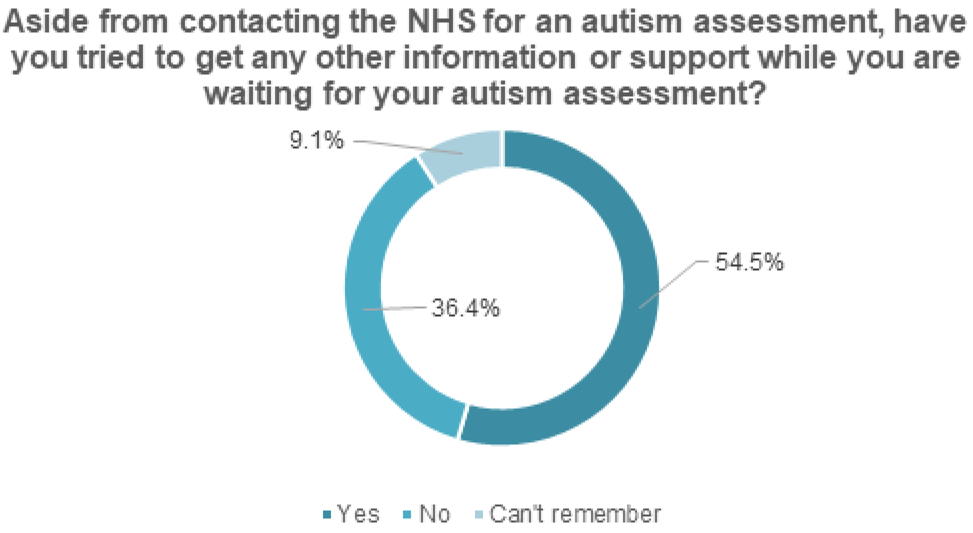
No. of respondents:11



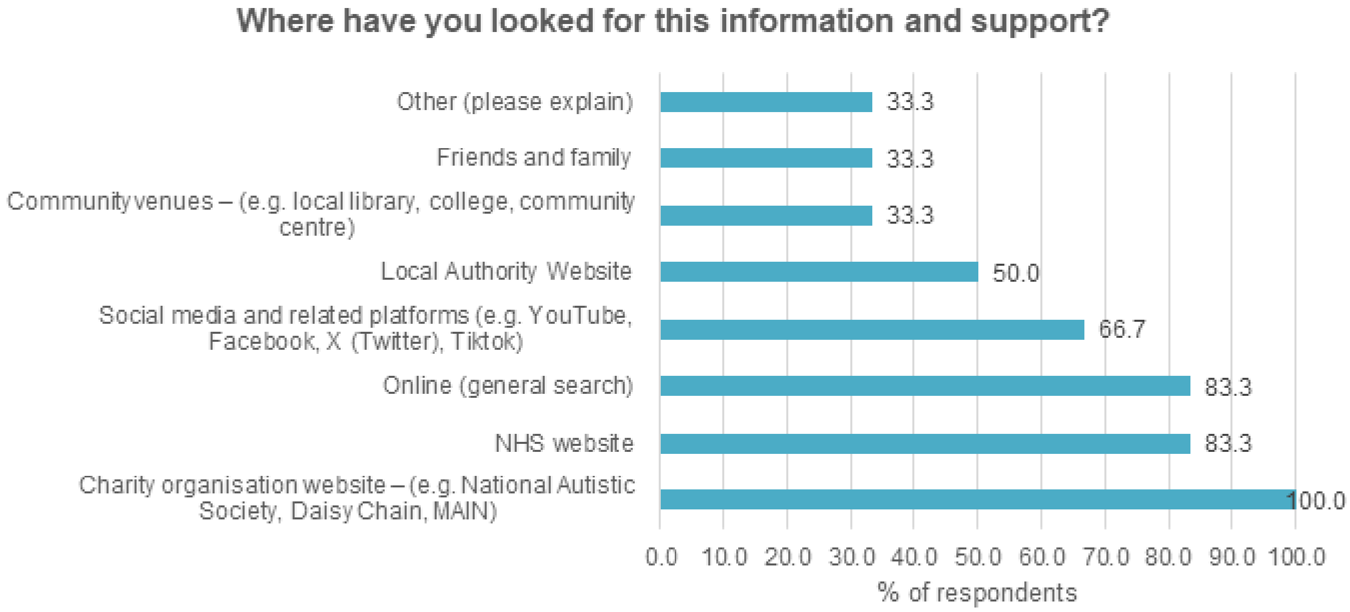
No. of respondents:9



No. of respondents:10



No. of respondents:11



No. of respondents:6

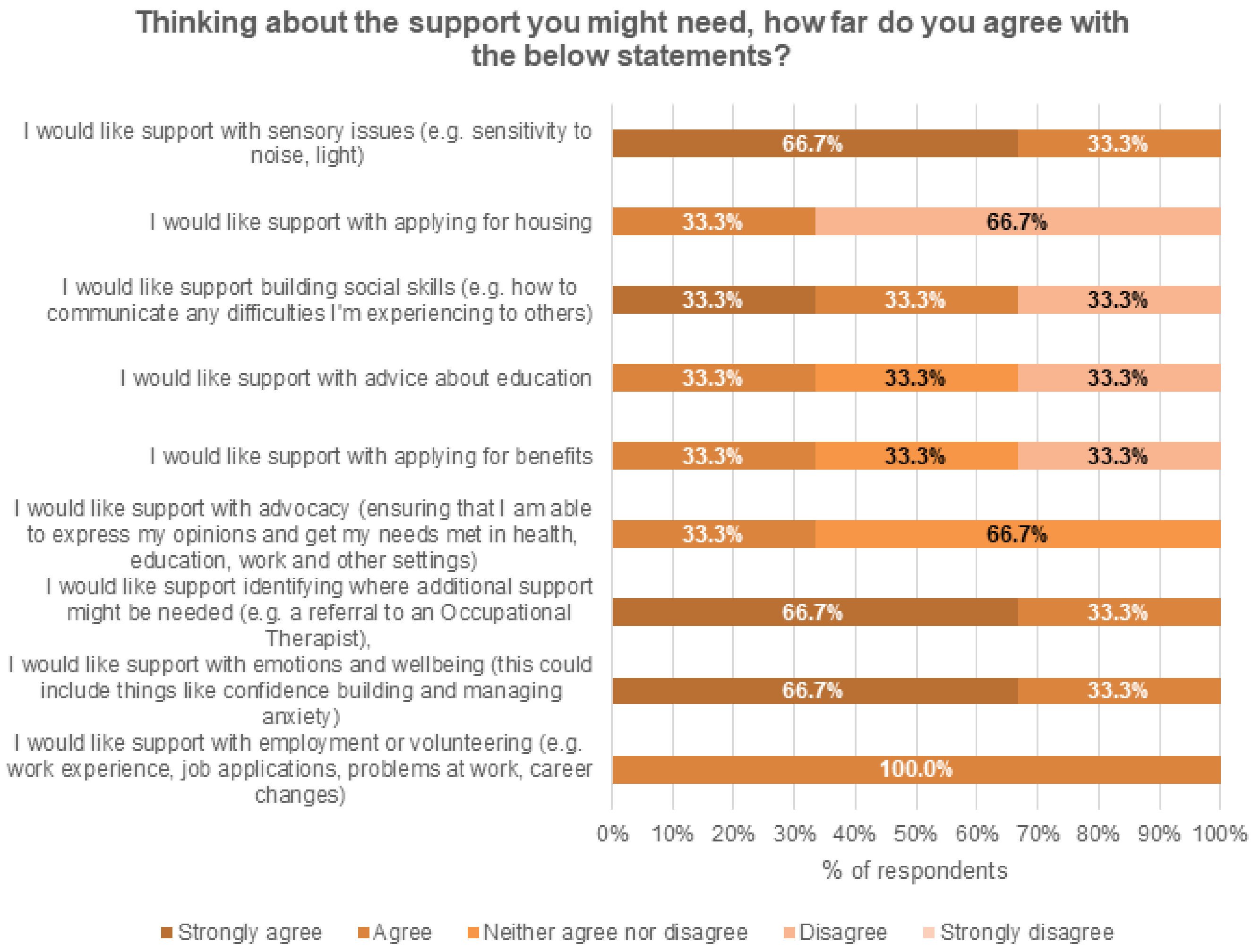
Autistic people – post-diagnosis

Five survey respondents lived outside of the Tees Valley area (Durham, Sunderland and North Yorkshire) which is outside of the scope of this project. Their feedback however is valid, and for completeness, has been summarised briefly below.

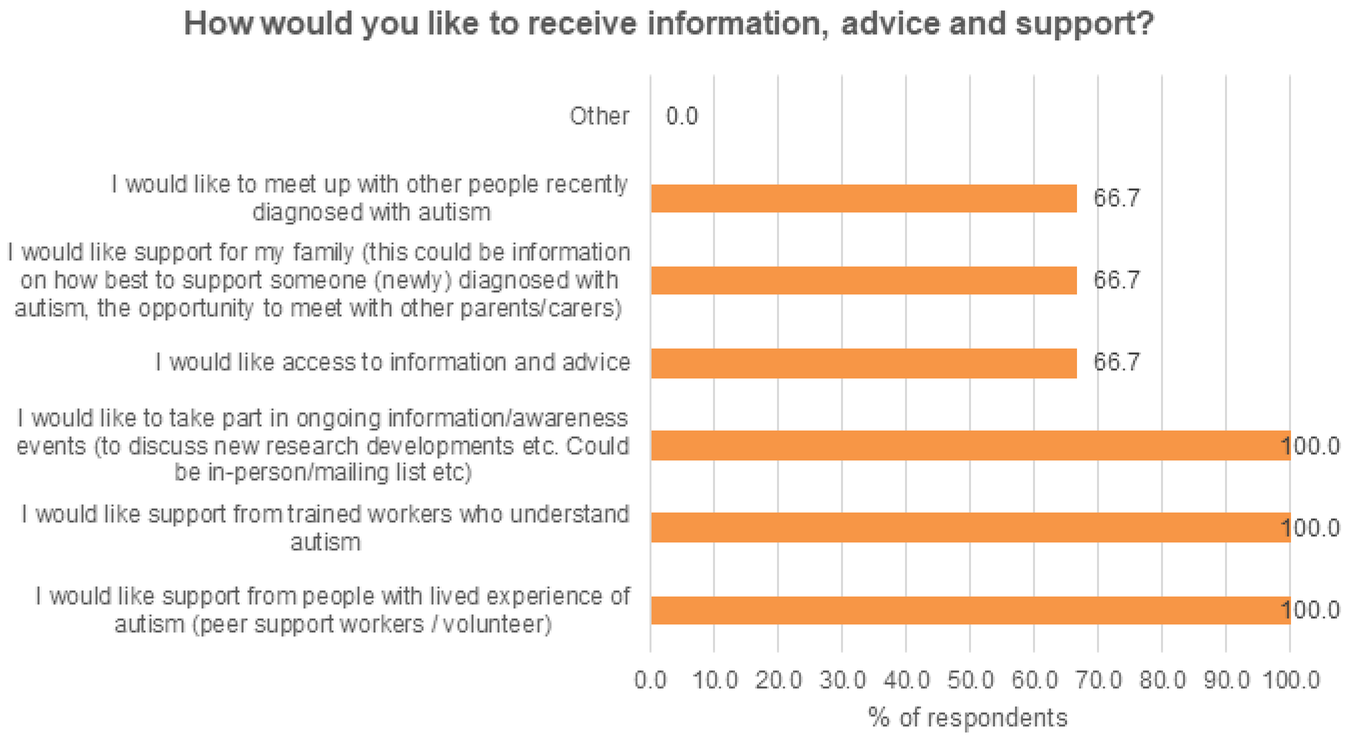
- 3 people responded themselves.
- 2 people were family members/carers of an autistic person.

Responses from autistic people (3 respondents)

Type of support



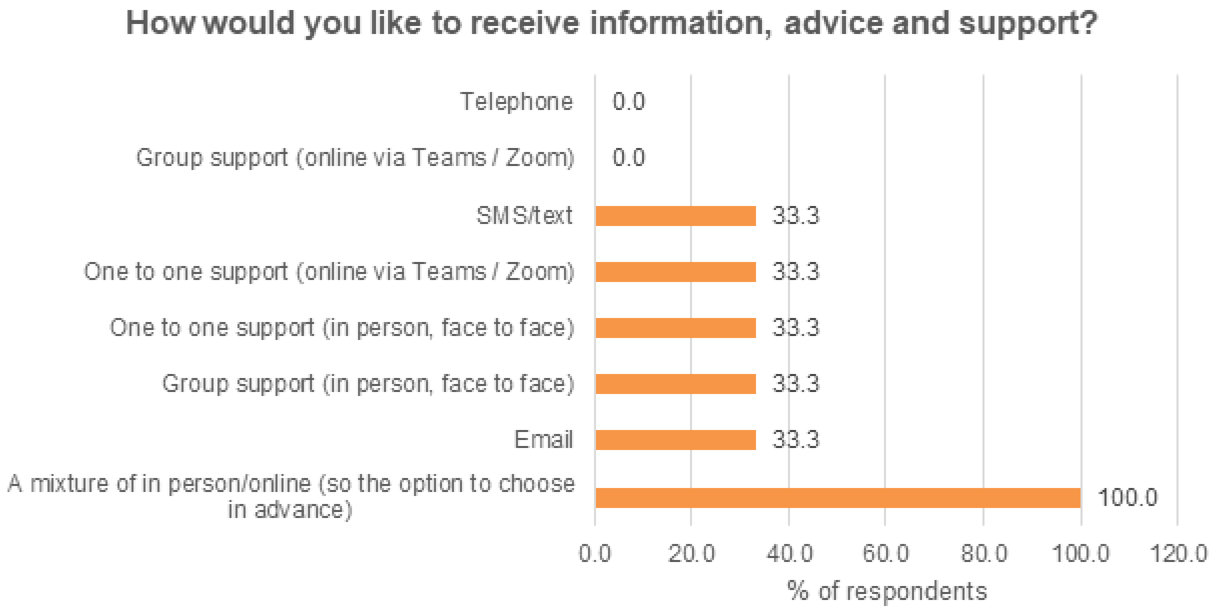
No. of respondents: 3



No. of respondents: 3

One respondent suggested the following adjustments:

- Education and awareness
- Flexible service delivery based individual needs
- Accessible information/communication offered e.g. face to face, online, text, phone, email
- Longer sessions/response times
- Physical spaces that are autism friendly



- All respondents would be willing and able to travel to get face to face support and all would attend a travelling hub (33.3% very likely, 66.7% likely).
- Two respondents (66.7%) currently receive information and advice about autism from charity websites, social media, general online searches and friends and family.
- One respondent (33.3%) currently receives support from non-NHS organisations around their autism. This is in the form of one-to-one post-diagnostic support.
- Whilst waiting for an autism assessment, peer support groups, coping strategies, education about what autism is and therapy would have helped them.
- Once diagnosed, peer support groups, information on what will happen next, information for their family would have been useful.

Responses from carers/family members of autistic people (2 respondents)

- In terms of what support they think is needed for the autistic person, advocacy, building social skills, emotions and wellbeing, sensory issues, education, employment and additional support available.
- One respondent asked for shorter waiting times when asked about reasonable adjustments.
- This support should be provided by trained workers who understand autism, people with lived experience of autism and be available to family members/carers.
- Respondents currently receive information and advice about autism from social media, charity websites, community venues and the NHS website. Both felt that this support was not enough and requested a family support service, support around behaviours associated with autism.
- This support should be offered online and in-person, one-to-one, via email or telephone.
- Both respondents would be willing and able to travel to get face to face support and would be very likely to attend a travelling hub.
- Whilst waiting for an autism assessment one respondent would have liked sensory advice and support and this would also have been helpful post-diagnosis.