



brain in hand

**24/7 on-demand
support – needs and
barriers**



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This report presents findings from research conducted by the Brain in Hand research team to explore the needs, expectations, and potential barriers related to Brain in Hand's 24/7 on-demand support service. The study draws on data collected from attendees at the 2024 Autism Shows, including autistic and ADHD participants, professionals, and supporters. The insights aim to inform service development and ensure the on-demand support continues to meet the needs of Brain in Hand users.



Key findings

- ✓ There were large differences between perceived barriers for autistic and ADHD participants compared to the 'other' 'group'.
- ✓ Compared to the 'other' group, 31% more autistic and ADHD participants found 'I don't want to feel like I am wasting the services time' and 20% more autistic and ADHD participants found 'I think someone else may need it more' to be a barrier compared to 'other'.
- ✓ 89% of autistic participants selected an option related to problem solving to be an expectation of what an on-demand service should support with.
- ✓ Personalisation was a concept that was not included in the survey; however it was found that people value this as a unique aspect.
- ✓ Information sharing came up as a barrier by 53% (not knowing what to expect/ unfamiliar).
- ✓ Some professionals that we spoke to felt that Brain in Hand could be useful for parents of neurodivergent children.

Brain in Hand is a support system based in the United Kingdom, designed for neurodivergent people (particularly autistic and those with ADHD) and people experiencing anxiety. Brain in Hand's support system consists of 1-1 coaching, an app and an on-demand support service. This report focusses on the on-demand support service.

The on-demand support service is available 24/7 for all Brain in Hand users to access and request support from a 'responder'. Support is requested in the Brain in Hand app, and responders will get back to the user within 30 minutes via call or text, dependant on user preference. The Brain in Hand responder can see the information from the user's account, timeline, and information already inputted into the app related to how the user would like support. This personalised approach means the responder can draw on strategies already utilised by the user. The on-demand support service is not a crisis line, rather a tool to help Brain in Hand users get their day back on track by supporting with challenges that could significantly impact on their day.

Other on-demand support services are currently available to the public. Primary distinctions between these services and Brain in Hand are that these are available for people who may be experiencing a mental health crisis, however, they are not personalised for the person calling. Table 1 summarises further details about these public on-demand services in the UK.

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Introduction

Support service	Description
Campaign Against Living Miserably (CALM)	<ul style="list-style-type: none">• 5pm–midnight every day• Use if you're affected by suicide or suicidal thoughts.• Phone or webchat service.• Offers tools and resources.
Mind	<ul style="list-style-type: none">• A safe space for you to talk about your mental health.• Advisors are trained to listen to you and help you find specialist support if needed.• Open 9am to 6pm, Monday to Friday (except bank holidays).
National Suicide Prevention Helpline UK	<ul style="list-style-type: none">• Offers a supportive listening service to anyone with thoughts of suicide.• 6pm to midnight every day.
NHS 111	<ul style="list-style-type: none">• You can contact NHS 111 any time to access support for your health. To get urgent mental health support.
Papyrus HOPELINEUK	<ul style="list-style-type: none">• For those under 35 and struggling with suicidal feelings or concerned about a young person who might be struggling.• Available 24/7.
Samaritans	<ul style="list-style-type: none">• You can contact Samaritans 24 hours a day, 365 days a year:
SANEline	<ul style="list-style-type: none">• Open 4:30pm-10pm every day.• Use when experiencing a mental health problem or supporting someone else.
Shout	<ul style="list-style-type: none">• Text service.• Available 24/7.• Providing support if you are in crisis and need immediate help.
Youngminds	<ul style="list-style-type: none">• Offers signposting and support to young people and parents of young people.• Helpline open 9.30am-4pm Monday to Friday.• If further support is needed, they will arrange a 50-minute telephone call with a mental health professional.

Table 1: Other on-demand support services available in the UK.

Justification and Key Aims

Feedback from routine survey data collected from our users in February and March 2024, indicated a slightly lower satisfaction level with the on-demand support service as reflected in the CSAT scores than the other elements of Brain in Hand at 69%, compared to 73% (overall), 70% (app/website), and 77% (coaching). This observation combined with interest from the Senior Leadership Team around better understanding feedback we receive from users on the service, instances where it is useful, and how the service can improve were the main drivers for the Research team to undertake a scoping study on our 24/7 on-demand service. The opportunity of in-person interviews at the autism shows in May and June 2024 represented an ideal location to conduct this research.

The key aims of the research scoping study outlined in this paper was to gather insights around three key areas:

- **Expectations:** what users would expect the Brain in Hand on-demand support service to provide.
- **Barriers:** what barriers users might face with using the Brain in Hand on-demand support service.
- **Impact:** the potential impact of having access to a service like this may have for a user.



Methodology

Data collection and sampling approach

Data was collected in person via surveys. To collect the data, two researchers attended three 'Autism Shows' in Manchester, London and Birmingham. The shows were over two days, a Friday and Saturday. Data was collected on an excel sheet on the researchers' phones or on a Brain in Hand owned iPad. Initially, we sought to speak primarily to people at the shows who were autistic. It was understood from previous years that attendance saw a higher number of professionals on Fridays, and that Saturdays saw a higher percentage of autistic people and families. However, across all the shows we found both days to have a considerable number of professionals attending.

Therefore, due to opportunity sampling, we spoke to a higher number of professionals than anticipated. This created a need to make adaptations to how we asked some of the questions to capture the point of view of the professional or a supporter, who did not identify as autistic or ADHD themselves, since in most cases they were answering on behalf of the autistic individuals they support. An example of this was changing the question 'What would you expect the on-demand support service to provide for you?' to 'What do you think someone you support would expect the on-demand support service to provide for them?'.

Data collection tool

The tool itself was designed to be a 5-minute street survey, comprising of 6 questions. However, we occasionally found it to take much longer with some conversations lasting up to an hour due to participants speaking more generally around their own, or the person who they support's neurodivergence and support available. While these conversations were in-depth and people shared a lot of information, this was not captured verbatim due to the survey structure. Most frequently these conversations were with professionals or parents of children who are neurodivergent.

The tool combined a mix of qualitative and quantitative questions. The purpose was to keep the survey as short as possible, with four context specific questions understanding diagnosis, why they were at the show, and knowledge of Brain in Hand, two qualitative questions on what accessing the support service would mean for them, and when they may use it, and two quantitative questions on barriers to accessing a support service, and what they would expect from the service.

Design of a visual aid

When developing the research tool, we aimed to integrate insights from the [Doing Research Differently](#) (Brain in Hand, 2023) project. This project explores strategies for conducting inclusive research with Neurodivergent individuals. We did this by creating a printed version of the tool which can be found in box 1. This visual aid was used to support with information processing, as it allowed the participant to follow along with the survey more easily, as interviewers were using excel on their phones or tablets to record answers, which alone wouldn't have been an effective way to deliver the survey.

The printed tool was particularly useful to show the options in the multiple-choice questions and for the participant to see the prompts used for one of the open questions (question 3). We used the branding palette for Brain in Hand for the design which included muted pastel colours, chosen for being soft and welcoming. We also utilised graphics, as visual aids are useful for conveying ideas and to add interest to the document. This helped with communicating effectively. The tool was well received by participants, with some wanting to hold it themselves and others wanting to read along while the interviewers held the printout.



Box 1. The visual aid of the survey questions

Main findings

The sample

Participants were asked whether they were autistic or have ADHD. 25% (27/109) of the sample shared they were autistic, 24% (26/109) shared they were both autistic and have ADHD, and 6% (7/109) identified as having ADHD only. Two participants did not respond to this question.

For the purposes of the analysis in this paper, we disaggregated the findings by diagnosis using three categories that made sense based on diagnosis and sample size: (1) Autistic only (n=27), (2) ADHD with or without autistic (referred to as ADHD) (n=33) and (3) neither ADHD nor autistic (referred to as 'Other' (n=49). We did not receive diagnosis information for two participants. In some instances, the analysis is presented for (1) and (2) combined to increase the sample size.

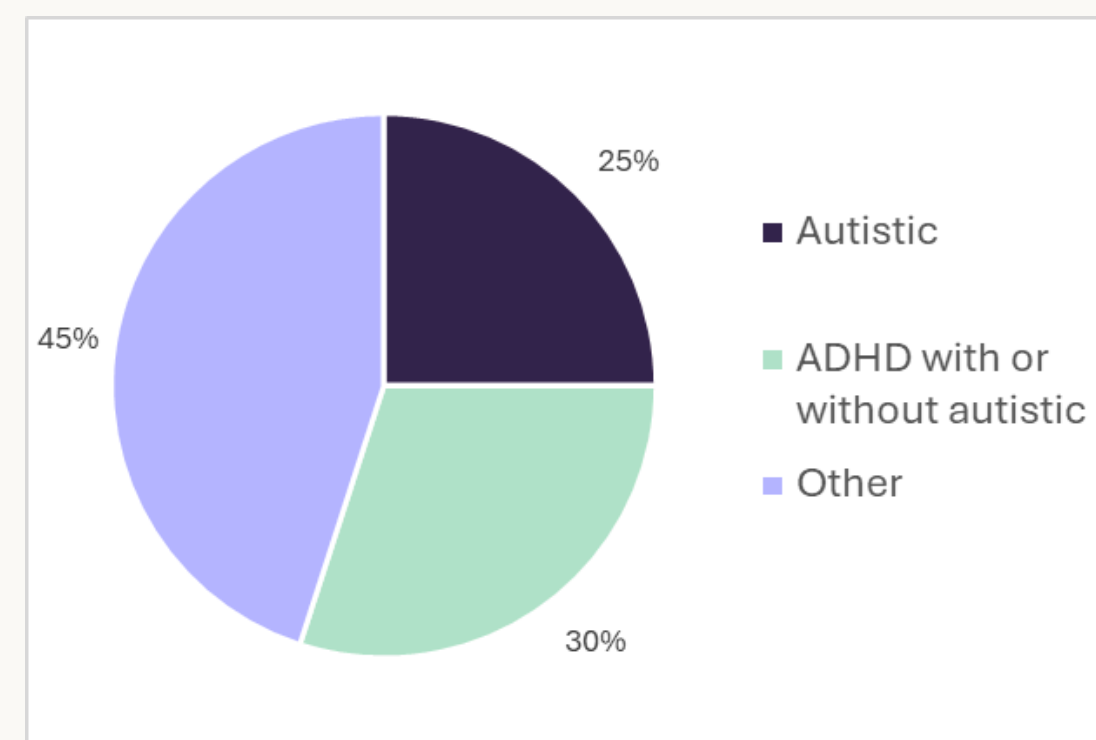


Figure 1: Pie chart showing participants diagnosis by autistic, ADHD with or without autistic^[1] and other.

[1] ADHD participants (7) have been combined with autistic and ADHD sample (26) to make (33) ADHD group.

Participants were asked why they were at the show. We provided the options ‘I am autistic’, ‘I am a professional’, and ‘I am a supporter of an autistic individual’. When conducting the interviews, participants often fell into one or more of these options (Table 2). Most frequently these were professional and autistic/ADHD (10%, 11/110), and professional, supporter, and autistic/ADHD (9.1%, 10/110).

Reasons for attending the Autism show

Why were you at the show?	Count (n = 110)	Percentage (%)
Autistic	19	17%
Autistic and/ or ADHD	13	12%
Professional	30	27%
Professional and autistic and/ or ADHD	11	10%
Professional and supporter	9	8.20%
Professional and supporter and autistic and/ or ADHD	10	9.10%
Supporter	10	9.10%
Supporter and autism and/ or ADHD	8	7.30%

Table 2: Why participants were attending the autism shows.

Participants were asked whether they had heard about Brain in Hand before. This question had 110 responses (figure 2). Over half of the sample had not heard of Brain in Hand at the time of the survey (54%, 59/110). 46% (51/110) participants had heard of Brain in Hand in some capacity. Participants were initially given several options that fell under ‘yes’, however, after speaking to the participants, it was clear the level of knowledge around Brain in Hand varied.

For example, some participants had heard of Brain in Hand prior to the show (27%, 30/110). Some of these participants found Brain in Hand as an option for support under DSA or Access to Work. Others had been to the stand at the show so had a demonstration of the app or a coaching session (15%, 16/110). A small percentage of the participants we spoke to were current Brain in Hand users (5%, 5/110).

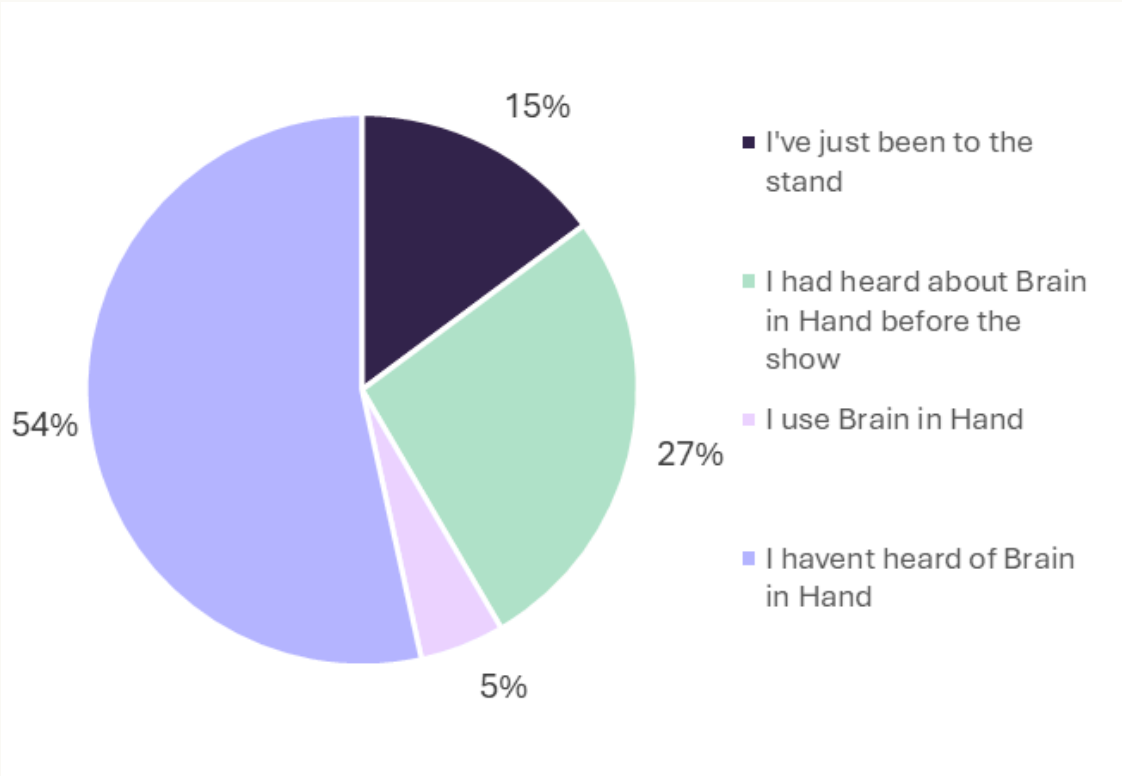


Figure 2: Have you heard of Brain in Hand before, shown as a pie chart.

When an on-demand service would be used

Most participants (74%) thought the service would be useful for them or the person they supported with many mentioning examples related to speaking about their emotions and day-to-day challenges.

After participants were provided with an explanation of the on-demand support service, they were asked whether they could think of a time when they may use it. 102 people responded to this question, with 61% (62/102) providing an example of when they felt they may have utilised the service. 23% (23/102) shared they were unsure if it would be useful for them or someone they support, and 13% (13/102) shared they thought it could be useful for themselves or someone they support but were unable to think of an example in the moment. A small proportion (3.9% 4/102) of participants responses were classed as ‘not relevant’[2].

Responses were coded and themed to understand areas where participants felt they could utilise the service[3]. **55% of participants were coded under the theme of ‘utilising the service to speak to someone about their emotions’.**

“Very recently, I played snooker over 3 days, quite exhausting and overwhelming, held it in and struggling to recover and not sure what to do nice to have something there to guide help to get regulated” Diagnosed autistic participant.

“I struggle to motivate, takes me a long time to get into work, distraction and I'm back to square one, professional support to talk me through would be beneficial.”
Participant is autistic and has ADHD.

[2] Examples of responses classified as ‘not relevant’ were two participants sharing they did not feel it would be applicable for people they support due to their ages, “For a lot of our children no, top end of key stage 4 and 5 may be able to use”, and “I can see this being useful when my son is older, having support to hand, always there.”

[3] Some participants shared more than one example, or their example spanned across two or more themes

Support for day-to-day challenges was mentioned by a third of people.

Examples varied but participants generally spoke about an in the moment situation they would like support with, generally an incident that could not be prepared for.

“I got overheated and thought I was dying, tell me what I was feeling was normal, reassurance [and] guidance.” Participant who is autistic and at the show in a professional capacity.

23% of participants gave examples relating to how parents of neurodivergent children could benefit from accessing the service. Examples included in moments of their child having a meltdown, or someone to turn to for advice around their children.

“Professionally, children’s behaviour escalating parents to use to calm down and manage challenging behaviour to have on demand support.”- Participant at the show in a professional capacity, they are not autistic or ADHD

“Support for parents, dysregulation of the child.”- Participant is a supporter of a neurodivergent individual, they are not autistic and do not have ADHD

21% of participants shared they felt it would help in work/education.

“Work related meltdowns, cognitive overwhelm, helping when dysregulated, validation and moving forward from incidents, ADHD impulse regulation (getting frustrated and risking my workplace, practical steps to preserve wellbeing in the context of difficulties at work).”- Participant at the show in a professional capacity, they are autistic and have ADHD

“I used it a lot when I first started my job, because I didn’t really know, for me knowing it’s there has been big, can stop things deteriorating.”- Participant is autistic and a Brain in Hand user

18% of participants shared they would use it when other services were unavailable.

“I have had a couple of times where I’ve not known who to contact, local MH crisis took 8 hours, 111 couldn’t get through, Samaritans unhelpful.”- Participant is a supporter of an autistic individual, and autistic and ADHD.

“[My] Son suffers with anxiety and depression, lacks help and support from GP and school, wont discuss feeling with people at school, contacts from GP weren’t available, finding advice, help, support really difficult. someone on hand to discuss worries, he’s overwhelmed and confused.”- Participant is a supporter of autistic individual.

10% of participants shared they felt the on-demand support service could support with independence.

“Individuals we support who are ready to move from residential to supported living or are independent enough to benefit from a service like this.” Participant at the show in a professional capacity and a supporter of an autistic individual

The data was disaggregated to identify any differences between autistic/ADHD respondents and respondents classified as ‘other’ (see Table 3). Autistic and ADHD participants were more likely to say they would use the service to speak to someone about their emotions (64% compared to 42%), and that they would use it in work and/or education (31% compared to 8.3%). Respondents classified as ‘other’ were more likely to give an example of how a parent of a neurodivergent child could benefit from this service (46% compared to 5.6%).

When an on-demand support service would be used

Theme	Total (n=62)	Autistic and ADHD (n=36)	Other (n=24)
Someone to turn to to talk about my emotions	55% (34/62)	64% (23/36)	42% (10/24)
Support for day to day challenges	29% (18/62)	28% (10/36)	29% (7/24)
Parents use	23% (14/62)	5.6% (2/36)	46% (11/24)
Work/Education	21% (13/62)	31% (11/36)	8.3% (2/24)
When other services aren’t available	18% (11/62)	14% (5/36)	21% (5/24)

Table 3: When an on-demand service would be used, by autistic and ADHD and ‘other’.

What the impact would be

68% of participants provided an example of what having access to the support would mean for them, mentioning getting their day back on track, and having someone there to listen.

Participants were asked what having access to an on-demand support service would mean for them. 88% (98/111) of participants responded to this question. 68% (76/98) provided an answer of what it would mean for them, and 22% (22/98) said they could not think of a response, their answer was not relevant, or they felt it could be beneficial but did not expand on their answer. Some respondents who sat within that 22% shared “I already have a support network”, and “I am independent”[4].

Most of the responses could be coded under the same themes as the previous question since there were a number of responses from the first question (Can you think of a time recently where you might have used the on-demand support service?) that fed into what it would mean for them. See Box 1 for an example.

[4] Both of these quotes were from autistic participants

Box 1: Impact of accessing on-demand support

Example 1: Participant is autistic

Can you think of a time recently where you might have used the service?

“I used it a lot when I first started my job, because I didn’t really know, for me knowing it’s there has been big, can stop things deteriorating.”

What would having access to this service mean for you?

“It means a lot, it’s meant that when I got overwhelmed, I had a safe space to talk to, with the best will in the world I can talk to my manager, but they aren’t for overwhelmed autistic people, allowed me to feel safer with my manager.”

Example 2: Participant at the show in a professional capacity, a support of an autistic individual, and they are autistic and have ADHD

Can you think of a time recently where you might have used the service?

“For a friend with complex needs, lots of support around her but isn’t always available, feels burdensome on others, I can’t always be there to support such as when at work.”

What would having access to this service mean for you?

“I’d feel she had support she could turn to even if it was just to remind her, she’s loved and has support, need a voice to just say you aren’t alone.”

68% of participants shared that it would mean having in the moment, external support and understanding[5].

“For my daughter, knowing she has back up, that would be the biggest thing for her.”- Participant at the show in a professional capacity, a support of an autistic individual, and they have ADHD.

“Listening support, reassuring if having a wobble, to get my day back on track.”- Participant at the show in a professional capacity, a support of an autistic individual, and they are autistic.

“For the parents, round the clock support mechanism, feeling alone, someone’s always there to listen.”- Participant at the show in a professional capacity, they are not autistic and do not have ADHD.

“Reduce anxiety, wouldn't be left on their own if usual support network wasn't there.”-Participant at the show in a professional capacity, they are not autistic and do not have ADHD.

29% of participants shared it would mean they could talk to someone about their emotions. This was often when their support network was unavailable, or they did not have a support network who they could speak to.

“Different people might have different needs. Support would mean if there was something that I need help with for example emotional needs.”- Participant at the show in a professional capacity, they are not autistic and do not have ADHD.

“I'd feel more at ease, more supported, it's difficult not having many autistic people in my support network.”- Participant is autistic.

[5] We did not have diagnosis information for one respondent

18% of participants shared that having access to the on-demand support would be useful for parents of neurodivergent children.

“Support for parents to be able to support their child in difficult moments.”- Participant at the show in a professional capacity, they are not autistic and do not have ADHD.

“Give them somewhere to go in a crisis offer some real needed support a listening ear something for the child with autism, someone else’s voice to give her strategies to maybe listen more.”- Participant at the show in a professional capacity, they are not autistic and do not have ADHD.

Some participants (14%) shared that having access to the on-demand support service may help with independence.

“Help in the moment allowing more independence.”- Participant is autistic

“If I ever have issues, I can figure it out with their help, Independence.”- Participant is autistic and has ADHD

“Potentially if effective, it would allow some of my young people to be more independent, such as with employment or living.”- Participant at the show in a professional capacity, who is autistic

A small number of responses (8%) were related to work and/ or study.

“Productivity at work, specifically presentations/public speaking.”- Participant is autistic and has ADHD

Data was disaggregated by those who were autistic/ADHD, and respondents classified as ‘other’ to identify any differences in the themes (table 4). Four autistic and ADHD participants, and nine respondents classified as ‘other’ were not included for analysis[6]. Findings show that most often, for all respondents, the value would be in the moment, external support and understanding. More often, autistic and ADHD participants shared the impact would be related to parents use and support (39% compared to 4.7%). Respondents classified as ‘other’ were more likely to share it would support with independence (21%) compared to neurotypical participants (6.5%).

What would be valued from an on-demand support service

	Total (n=76)	Autistic and ADHD (n=43)	Other (n=31)
In the moment, external support and understanding	68% (52/76)	70% (30/43)	68% (21/31)
Someone to turn to, to talk about my emotions	29% (22/76)	23% (10/43)	39% (12/31)
Parents Use	18% (14/76)	4.7% (2/43)	39% (12/31)
Independence	14% (11/76)	21% (9/43)	6.5% (2/31)
Work and/or study	7.9% (6/76)	9.3% (4/43)	6.5% (2/31)

Table 4: What participants would value from an on-demand support service

[6] These participants either did not provide an example, did not respond to the question, or their response was not relevant.
[7] Apart from the optional ‘other’ option

Expectations of an on-demand service

Based on the description provided, participants were asked to select the service(s) they, or someone they support would most expect the Brain in Hand on-demand support service to provide. Participants were asked to select all relevant answers from a list of 8 options, and the choice of ‘other’. Four participants did not answer this question.

All options were selected by 45% of participants[7], with the highest number of participants selecting ‘someone to listen as I talk through a problem’ (84% - See graph 1).

“Someone impartial, practical support in day to day, grounding those moments and maintaining coping strategies.” - Participant was at the show in a professional capacity, and is autistic and has ADHD

The following three most frequently selected options (also shown in graph 1) were ‘someone to help me understand the problem I am experiencing’ (73%), ‘someone to provide advice on what to do when I face a problem’ (72%) and ‘understanding and managing my emotions (71%). Signposting to relevant support services was selected least (64%).

“Someone to take control of the situation, recognise you have hit the button and need to work backwards to regulation, so responders have their own guidance too and prompting” - Participant is a supporter of a neurodivergent individual and is autistic and has ADHD

13% (14/111) selected ‘other’. Responses to this included “Having someone who already knows the problem”, “I like that they don’t tell me what to do, they help me calm down then guide me” (current BiH user) and mentioning “body doubling” for motivation.



Graph 1: Overall expectations for what an on-demand service should provide.

Data was disaggregated to look for any differences between those who are autistic, ADHD and other (graph 2).

Autistic participants were least likely to select all options provided (11%, 3/26), compared to ADHD (50%, 16/32), and other (58%, 28/48). This may provide an explanation to why the percentages shown in graph 2 are lower for autistic participants. Since autistic participants were answering for themselves and what they would expect from the service, they may not have found all options relevant to their needs.

Graph 2 shows that autistic participants would most likely select that they expected the on-demand support service to provide ‘someone to listen as I talk through a problem’ (65%, 17/26), ‘advice on what to do when I face a problem’ (62%, 16/26), and someone to help me understand the problem I am experiencing (58%, 15/26).

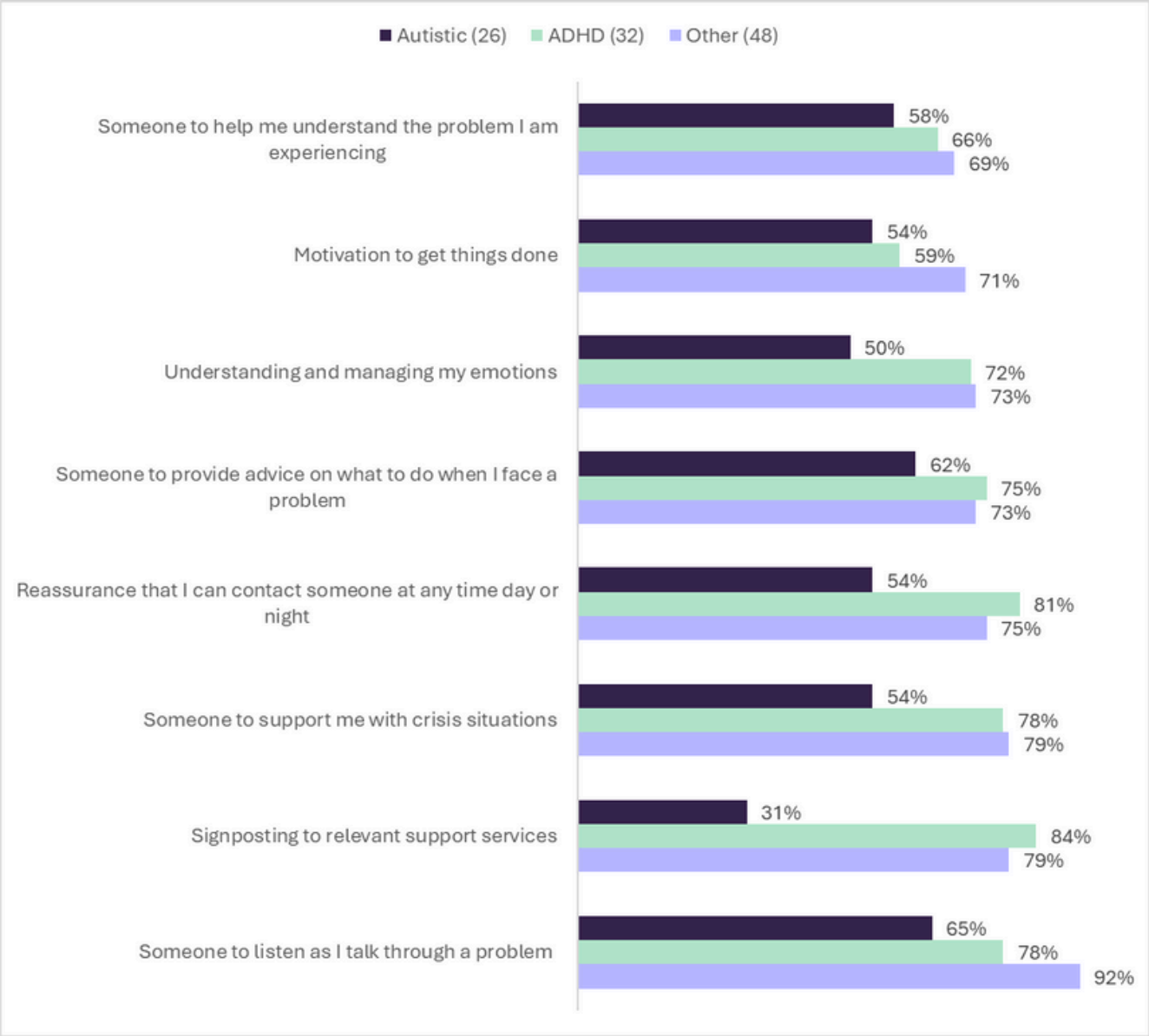
Interestingly all these options are related in that they are all linked to problem solving and finding solutions. This was also selected the most by respondents classified as ‘other’ (92%, 44/48). When analysing the data and combining those related to problems, 89% (23/26) of autistic respondents selected one or more options related to problems.

Signposting to relevant support services was selected most often by ADHD participants (84%, 28/32) and least often by autistic participants (54%, 8/26), and was viewed as important for respondents classified as ‘other’ (71%, 38/48).

Respondents classified as ‘other’ were most likely to select ‘someone to listen as I talk through a problem’ (92%, 44/48), this was also selected most often by autistic participants (65%, 17/26)

Reassurance that I can speak to someone at any time of the day or night was selected most by ADHD participants (81%, 27/32) yet nearly 30% less by autistic participants (54%, 14/26), respondents classified as ‘other’ also felt this was important (75%, 38/48).

For further breakdown of the autistic and ADHD participants, see annex 1.



Graph 2: Expectations for what on-demand support should provide, disaggregated by autistic, ADHD and other.

Barriers to use

Participants were asked to select the barriers they, or someone they support, would most likely experience in accessing the Brain in Hand on-demand support service. Participants were provided with nine options to choose from and could select all the options they felt were relevant (Graph 3). 15% selected all nine options. Twelve participants did not answer this question.

Graph 3 shows the barrier chosen the most often was ‘not knowing what to expect/ unfamiliar’ (54%). The following three most selected overall were ‘not knowing the person I was going to speak to’ (49%), ‘Having to explain a situation I was finding difficult’ (48%), and ‘Having to wait up to 30 minutes’ (47%).

The barriers selected least were ‘previous negative experiences with support services’ (39%), ‘I think someone else may need it more’ (38%) and ‘I don’t know if the reason I want to use it is the reason I should use it’ (36%).

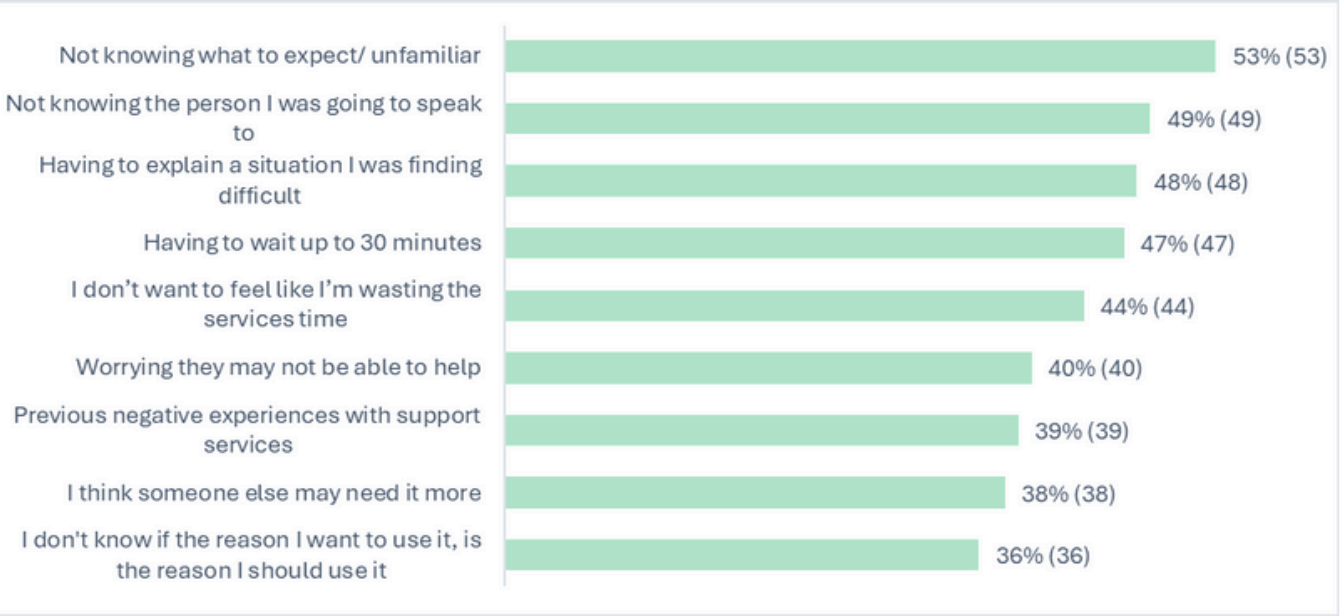
29% Selected ‘other’. Examples include cost, access to the technology (technology literacy and technology poverty), not knowing enough about/ understanding the service (such as that it is 24/7), and language barriers. There were also instances of participants querying the level of training the responders have. One participant who was an autistic researcher mentioned thwarted belongingness[8].

“Thwarted belongingness, not really feeling services are for us (as autistic). From my research greater than 60% of people feel services aren’t for them unless specified for” - Participant is an autistic researcher.

Linked to the autistic researcher’s perception on barriers, ‘feeling like I’m wasting the services time’ was chosen by 44% of the sample, but also somewhere BiH seems to have strengths.

“Even if service is for me, I worry about wasting time” - Participant is autistic and has ADHD.

“You [Brain in Hand] sent out info about appropriate use and this helped with worry that I was wasting time” - Participant is autistic and a Brain in Hand user.



Graph 3: Overall selections for what participants expect would be barriers to accessing the on-demand service.

[8] Thwarted belongingness is closely related to theory of perceived burdensomeness. (Cassidy., 2020). Perceived burdensomeness refers to the enduring sense that one is a burden to others and the mistaken belief that one’s death would be of greater benefit than one’s life, which has been linked to elevated suicide risk (Lieberman et al., 2023).

Graph 4 shows data disaggregated between autistic and ADHD and ‘other’ (not autistic or ADHD).

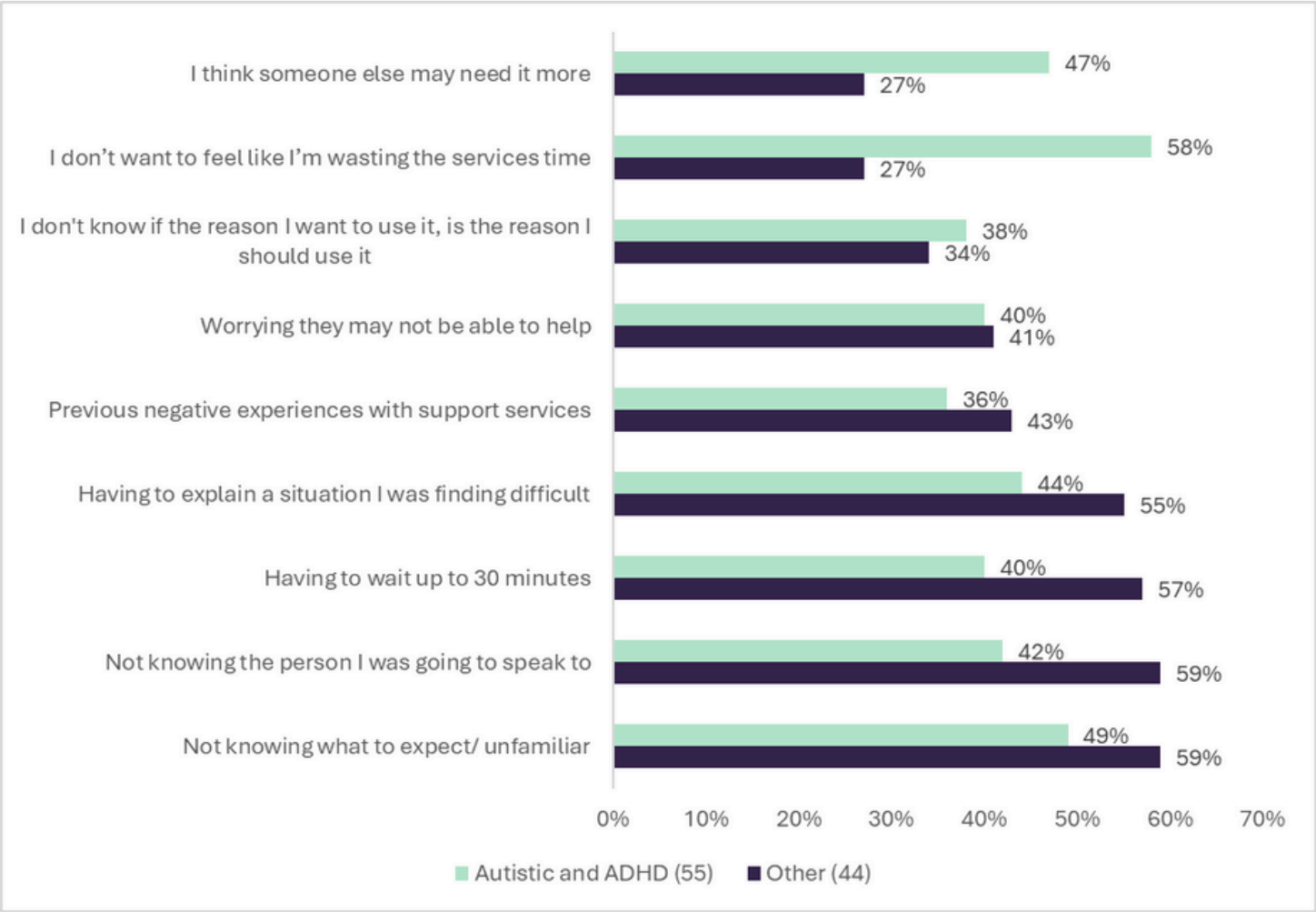
The data shows similarities in perceived barriers between these groups for ‘I don’t know if the reason I want to use it is the reason I should use it’, ‘worrying they may not be able to help’ and ‘previous negative experiences with support services.’ Shown in graph 4.

Respondents who identified with ADHD were more likely to select they think ‘someone else may need it more’ and ‘I don’t want to feel like I’m wasting the services time’.

Graph 4 also highlights a notable difference between the two groups. Responses such as “I think someone else may need it more” and “I don’t want to feel like I am wasting the service’s time” were selected by 47% and 58% of autistic and ADHD participants, respectively, compared to only 27% of those classified as ‘other’.

In contrast, participants in the ‘other’ group were more likely to select options related to practical considerations, such as wait times, knowing who they would be speaking to, understanding what to expect, and the challenge of having to explain a difficult situation.

For a table of overall responses, see annex 2.



Graph 4: what participants expect would be barriers to accessing the on-demand service, disaggregated by autistic and ADHD and ‘other’.



Discussion

This research highlights how autistic and ADHD participants, as well as other attendees, perceive Brain in Hand's on-demand support service. Findings show that neurodivergent individuals value accessible, personalised support to help manage challenges, but also face barriers such as uncertainty about using the service and concerns about being a burden. These findings are now discussed in relation to existing evidence on accessibility, user confidence, and support for neurodivergent people

People attending the show

There were many newly diagnosed older people at the shows who were seeking to learn about themselves, what support they may need and what resources are available. This led to deeper conversation, delving into how Brain in Hand could act as a more comprehensive solution; in these cases, we would encourage the discussion and direct people to the stand to have a conversation around the whole product – since the research was primarily focussed on the on-demand support. There were also professionals in attendance that completed the survey who wanted to discuss their respective fields and how the on-demand support, or Brain in Hand as a whole package could provide additional support to the individuals that they work with.

Autistic people at the show were keen to find support designed specifically for autistic people.

A Brain in Hand user at the show highlighted that the terms of use email sent out by Brain in Hand on the on-demand support service was valuable for understanding how they can use the service, and how frequently. They shared that when our terms and conditions were updated, they got an email outlining the terms of use and fair usage, they said that 'this helped with worry that I was wasting time', in relation to how often they used it, and what they were using it for. They also spoke about how they value the summary they receive after using the on-demand support.

Problem solving and getting back on track

Findings show that most often participants would want support from the on-demand support service to listen as they talk through a problem and to be available day or night. These findings are positive as the on-demand support service is available 24/7 for users and the purpose is to get user's days back on track (Brain in Hand., 2024). It is also evident in other Brain in Hand research and speaking to users that users find the on-demand support service useful for talking through a problem and having 24/7 access such as in this case study: Brain in Hand helps Katie thrive (Brain in Hand., 2024) where they say they used the on-demand support in the middle of the night to support them. The Brain in Hand user survey runs in 3-month cycles, collecting feedback from users (see Box 2). We often receive feedback around use of the on-demand support to get your day back on track which aligns without expectation for how people would use the service.

Box 2: Narratives from the Brain in Hand User Survey

“Extreme overwhelm/panic due to a situation, where I couldn't think clear. I pressed the red light and was able to speak to someone about what happened and why I was feeling that way. I was able to hear myself and my thoughts out loud, which helped to make sense of things.” Brain in Hand user survey respondent, April 2024

“Brain in hand helped me when I was overwhelmed by personal circumstances. I had a meltdown and panic attack. I pressed the red button and was able to have a calm conversation with the support person. It made all the difference. I was able to continue my day.” Brain in Hand user survey respondent, May 2024

Meeting the needs of neurodivergent people

A service such as the on-demand support service is valuable for neurodivergent people as it provides a safe space with an impartial listener. This came up in question 3 around ‘can you think of a time recently where you might have used the on-demand support service?’ and most responses fell into the theme of having someone to ‘speak to someone about their emotions’ (55%, 34/62). It was also noted as a theme in response to question 4 ‘what would having access to a support service like this mean to you?’. Previous studies highlight that autistic adults report a significantly higher number of unmet support needs than the general population (Cassidy et al., 2018), and autistic young adults (16-25 years old) experience challenges accessing appropriate support for mental health difficulties (Crane et al., 2018). Conversations at the Autism shows support this, with a number of attendees disclosing they had been recently diagnosed and looking for support. Adequate support is often not readily available for autistic people, and even more difficult to access for those without a diagnosis which is of particular significance due to challenges faced in obtaining a diagnosis through the NHS currently with waiting lists being up to and even exceeding two years (Brain in Hand., 2023).

In question 5 ‘what would you expect the on-demand service to provide?’ autistic people were more likely to select options related to problem solving and finding solutions (‘someone to listen as I talk through a problem’ (65%), ‘advice on what to do when I face a problem’ (62%), and ‘someone to help me understand the problem I am experiencing.’). These all fall under a similar theme around support for facing problems and finding solutions. Overall, findings imply that autistic people would find great value in this service for support talking about emotions and wellbeing, or talking through specific problems and unplanned difficulties.

Perceptions around barriers differ for autistic people and those with ADHD

There was also the suggestion that there may be a disparity between perceived barriers for autistic people and those with ADHD[8] when compared with respondents classified as ‘other’. For example, autistic people and those with ADHD were more likely to report worrying that they are wasting the services time, or that others may need it more, than those classified as ‘other’.

Literature around this sits more in the healthcare field and suggests negative experiences with healthcare may be attributed to providers incorrect assumptions about the needs of autistic people (Nicolaidis et al., 2015). Differences in perceived barriers are also seen here (Adams and Young., 2021) acknowledging the general lack of knowledge around autism or understanding of autistic traits and needs as being a common barrier. Further research from Brain in Hand (Brain in Hand., 2023) also highlights that support often does not meet the needs of the autistic person, with 24% of participants stating the support offered did not meet their needs.

We also began to see some differences between autistic only and ADHD only in regard to perceived barriers, however there was not a big enough sample size of ADHD participants to draw conclusions. Future research may look further into this topic, especially with the high co-occurrence of ADHD and autism.

[8] We have combined autistic and autistic/ADHD cohorts to highlight the differences between neurodivergent participants and participants who are not neurodivergent.

Not a crisis line

The Brain in Hand on-demand support service is not a crisis line, it is there for users to ‘get their day back on track’ and find a solution to a challenging situation. However, when explaining what the Brain in Hand on-demand support service is to participants, we intentionally did not share this in order to capture whether this is something participants would expect the service to provide or is a gap in current support offerings. When asked, 39% of participants selected they would like the on-demand support service to support them in crisis situations. This suggests there may be a gap in the current offering of the on-demand support, or that current crisis lines may not be a preferred tool for participants.

In addition, when speaking about use of this service during a crisis, some respondents talked about using a service like this after a crisis, as a debrief of what went wrong and to discuss strategies to prevent a crisis situation occurring again.

Personalisation as a unique and valuable aspect

Some participants were interested to know more about the personalisation of support with the on-demand support service, and how it compares to other services such as Mind or Samaritans. Some provided suggestions which have potential to feed into future improvement of this service. These included being given an estimated wait time for when the responder will be available and bio information so that they know a little about the responder who will be reaching out ‘pictures and bio of who they are going to speak to’. The general feeling was the more personalised this service could be the more valuable this service would be. They were also interested in understanding what training the responders have.

Participants also suggested personalisation such as having a “standard set of things to get you back on track that the responder can see” alongside the benefit of not having to explain your situation as the responder can see your timeline (“I’d feel more comfortable to use the service. It’s a barrier to say the issues every time”). This suggests that the more personalised the service can be the more useful it could be. Another suggestion we might consider is how we communicate with users who are waiting “It’s good to know someone is responding to you. Human being. Some keep you waiting for 2 hours.” Potential improvements could include sharing some information about our responders, and sharing updates of who is going to contact them with an estimate of when.

Value to parents as well as users

Some of the people we spoke to were parents/professionals who support early years foundation stage children and their parents, who discussed how they would use the response service to support them in supporting their child/the parent such as to diffuse a situation or to feel less alone with the challenges they face. There is evidence to suggest that autism is likely to be hereditary (Sandin et al., 2017) so there is a high likelihood that parents of autistic children may also be autistic themselves, though we did not see this in our small sample. Through conversations with parents talking more broadly about their needs and the offering of Brain in Hand, there was a general feeling that parents thought it could be useful to record their child's behaviours, to help with seeing patterns and triggers related to their child's behaviour, recorded using the traffic lights or logged as activities/problems and solutions. Parents felt that the coaching could be useful for discussing these behaviours, the situation they were caused by and how they as the parent dealt with them, to help with managing meltdowns, and prevention of future difficulties. This was not recorded formally as it was outside of the scope of the survey. For the on-demand support service specifically, parents mentioned this could be a useful addition to their toolkit as somewhere to turn for in the moment support and reassurance during their child's meltdown to find another way to help their child. Other ways they may utilise the service may be for after a meltdown to talk through what had happened, how they managed it and what could be done better next time.

Parents of autistic children are more likely to experience high levels of stress and anxiety, potentially lowering quality of life (Turnage & Conner, 2022). Given the heritability of autism (Sandin et al., 2017), many parents of autistic children may also be autistic themselves. This does not imply reduced parenting capability, shared lived experience may help autistic parents better understand and support their child's needs. However, autistic adults can face additional day-to-day demands and may benefit from personalised support for their own wellbeing. In these cases, Brain in Hand could be funded for and used by the parent to support themselves, which may in turn positively impact the support they provide to their child.



Case studies

The following case studies present a range of perspectives from individuals who engaged with the research, including users, professionals, and supporters. Together, they offer insight into how different people perceive the value and potential of Brain in Hand's on-demand support service, as well as the barriers that may affect engagement and access.

Case study 1: A Professional

This participant was at the shows in the capacity of a professional. They had heard of Brain in Hand before the Autism Shows. They identified as ADHD without a diagnosis, and did not identify as autistic. They recognised they struggle with overwhelming emotions when things don't go to plan and feeling in control in those moments and mentioned they could see the values in having someone to talk/think things through with.

They felt they wouldn't use the on-demand support for themselves as they have a good support system in place but could see the value for others in times of overwhelm.

"I have a good support network, but I work with a lot of people who don't have that."

"For some this can be the difference between having support during sensory/emotional overload and it being resolved, or that going on to then have a massive impact."

The participant felt the most valuable aspects of the on-demand support service would be to provide reassurance that someone was there 24/7 and it would be useful before, during and after crisis situations.

However, they felt that there could be some barriers to people accessing this service such as not wanting to feel they are wasting the services time and thinking someone else may need it more.

Case study 2: A Brain in Hand user

We spoke to a user at the show who was there in the capacity of a professional, and identified as autistic and ADHD, both without diagnosis. They said they use the Brain in Hand response service for support with overwhelm while parenting alone.

“When I have been overwhelmed at home with the kids and when everything just gets too much.”

When asked about what they would expect the on-demand support service to provide for them, they chose the following four, out of eight options:

- Someone to listen as I talk through a problem
- Someone to help me understand the problem I am experiencing
- Reassurance that I can contact someone at any time of the day or night
- Signposting to relevant support services

When asked what having access to a support service like this means for them, they said:

“Feeling like I’ve got back-up when I’m on my own. Having that support and security blanket.”

Despite being a Brain in Hand user, they still expressed they experience barriers to use which included, not knowing the person I was going to speak to and having to explain a situation I was finding difficult. They also found not wanting to feel they are wasting the services time and thinking someone else may need it more to be barriers, which we have highlighted to be barriers most felt by ADHD participants and least felt by participants who did not identify as autistic and/ or ADHD (other).

Case study 3: A Supporter: They do not identify with either autism or ADHD.

This participant was at the show in the capacity of a professional and a supporter. They spoke from the point of view of themselves professionally supporting people. They worked in residential care. They had not heard of Brain in Hand before the autism show.

“Yeah individuals we support who are ready to move from residential to supported living or are independent enough to benefit from a service like this.”

They felt that the on-demand support system offered by Brain in Hand could be useful for people they support who are ready to move from residential care to supported living. They felt that a service like this would be good for gaining some independence back.

“From a residential point of view, it’s having someone else’s perspective, for an individual who has been supported it gives some independence back.”

They felt that the service should provide all that was listed, but the priorities were: someone to listen as I [the user] talks through a problem, someone to help me understand the problem I [the user] is experiencing and someone to provide advice on what to do when I [the user] face a problem.

As for barriers, they felt that not knowing the person I [the user] was going to speak to and having to explain a situation I [the user] was finding difficult were most likely to prevent someone from using the service.

Case study 4: Autistic and ADHD participant

This participant is a user of Brain in Hand, they were at the autism show as a supporter, who is also diagnosed with autism and ADHD. When asked to think of a time recently where they might have used the service they discussed a time where they couldn't find several things they were looking for, when struggling with lots of tasks to do and after a trip to the supermarket that took longer than expected. They find it useful having someone to go over what they need to do and talk through the steps.

"I think the symbol of the life ring is good to explain it, I like knowing the option is there."

They also gave interesting insights, mentioning the design of the life ring and how they like knowing it is there if needed. The participant shared that in moments of overwhelm when a user requests support, the responder could speak to an autistic person about their special interests. They shared that this would help the autistic person calm down, meaning the responder can support the user more effectively with the challenge they were experiencing. By doing so, the participant felt this would be a good strategy for responders to help users find solutions.

"Special interests means the person can easily talk about it so when you talk about the problem at hand it's almost like you can get to the solution better."

When asked about their expectations of the service they felt that all option given should be provided, but their priorities were around someone to listen as they talk through a problem, for advice on what to do when they face a problem, and motivation to get things done.

Despite being a Brain in Hand user, they still felt they experienced barriers to use such as: not wanting to feel they are wasting the services time, thinking someone else may need it more, and not knowing if the reason they want to use it is the reason they should use it. Interestingly the first two options stated here were two that were picked up in the study as being chosen the most by neurodivergent people and the least by neurotypical people.

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Annex

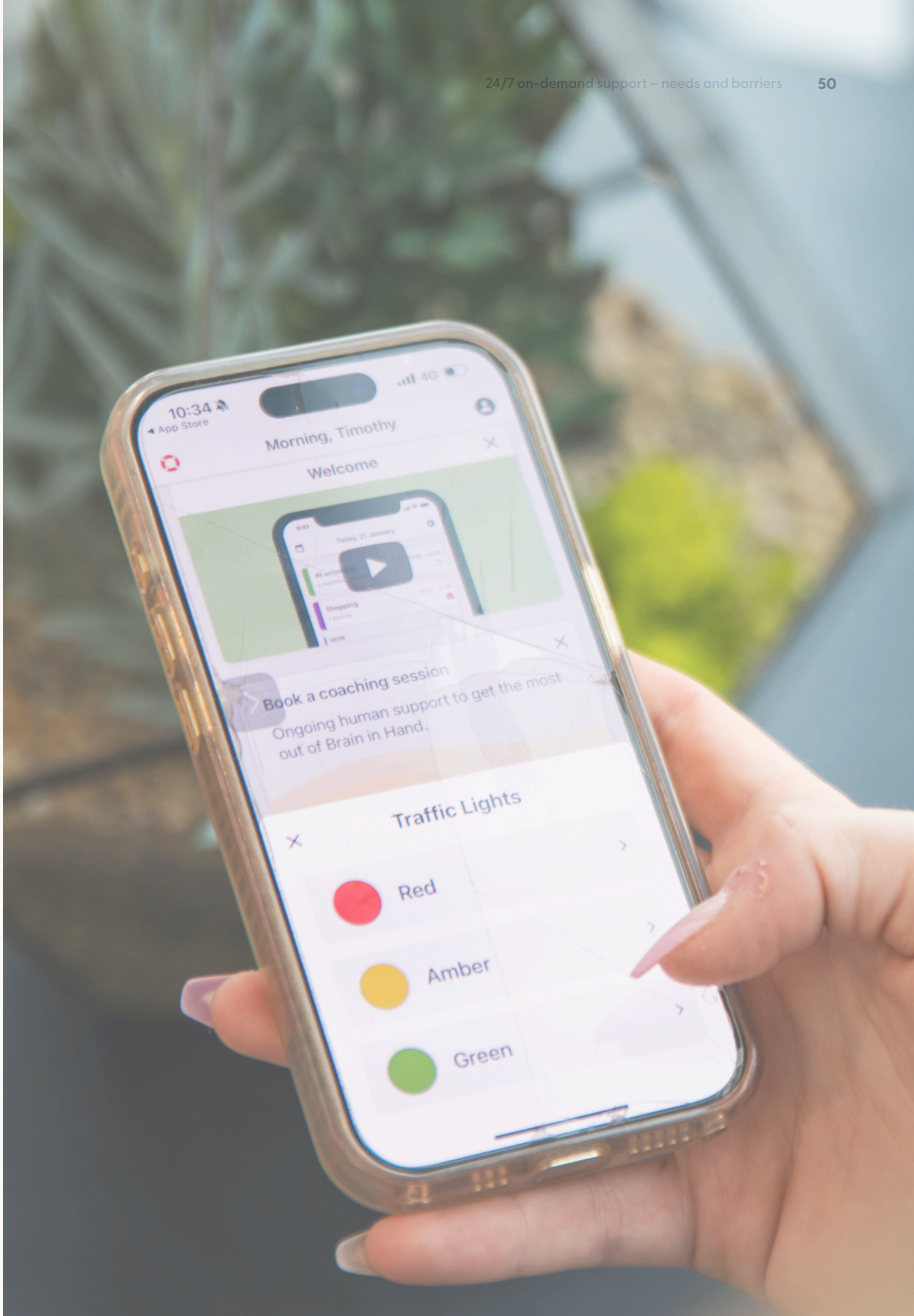
Annex 1: Overall selections for what participants would expect an on-demand service to provide.

Options	Count	Percentage (n=107)
Someone to listen as I talk through a problem	90	84%
Someone to help me understand the problem I am experiencing	78	73%
Someone to provide advice on what to do when I face a problem	77	72%
Understanding and managing my emotions	76	71%
Someone to support me with crisis situations	74	69%
Motivation to get things done	72	67%
Reassurance that I can contact someone at any time day or night	70	65%
Signposting to relevant support services	68	64%
Other	14	13%

Annex

Annex 2: Overall selections for what participants expect would be barriers to accessing the on-demand service.

Options	Count	Percentage (n=99)
Not knowing what to expect/ unfamiliar	53	54%
Not knowing the person I was going to speak to	49	49%
Having to explain a situation I was finding difficult	48	48%
Having to wait up to 30 minutes	47	47%
I don't want to feel like I'm wasting the services time	44	44%
Worrying they may not be able to help	40	40%
Previous negative experiences with support services	39	39%
I think someone else may need it more	38	38%
I don't know if the reason I want to use it, is the reason I should use it	36	36%
Other	29	29%



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