



Priorities, needs and support as experienced by autistic people

Research paper - November 2023

brain in hand

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Priorities, needs, and support as experienced by autistic people

In 2022, Brain in Hand created a survey to be shared at the Autism Shows (a national event in three locations) and online via social media from July to October. 413 autistic people and 297 supporters of autistic people responded to the survey.

The purpose was to gain insights from autistic people and their supporters about their needs and experiences related to support. The survey highlights the inequalities faced by autistic people and provides more detail on their priorities, experiences, and needs.

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Guyatt, H., Swaine, Z., Knowles, L., Richards, C., Ward C., Desborough, J., Brain in Hand Ltd, (2023 November) Priorities, needs and support as experienced by autistic people.

Key take-aways

This section provides some key take aways from the survey, demonstrating priorities, needs, and support as experienced by autistic people and their supporters.

Mental health is a major concern for autistic people

- 66% need help managing overwhelm and health
- 48% need help managing emotions
- 57% ranked feeling safe as their top priority.

Autistic people are not getting support

- Only 27% had received professional support for their needs
- 89% of those receiving support found the process hard
- 54% of those not receiving support don't know what is available
- 31% of those not receiving support assume they are not eligible.

Younger (18-24) autistic people are worried about different things than older autistic people (45+)

- 75% of young people (compared to 49% of older people) ranked feeling safe as their top priority
- 58% of young people (compared to 40% of 45+ year olds) wanted help with socialising
- 38% of young people (compared to 18% of 45+ year olds) wanted help living independently
- 29% of young people (compared to 48% of 45+ year olds) wanted help managing health.

Older people are less likely to have received support than younger people

- Only 20% of people aged 45 and older had received support
- 75% of people aged 45 and older had never accessed any support service in their lifetime.

There are ways to reach autistic people and supporters with information

- 75% autistic people and 69% of supporters look to the internet for information
- Autistic people also rely on social media (47%) and other autistic people (44%)
- Supporters of autistic people also look to health services (56%) and charities (42%).

Impact statement

This section is a brief summary, in lay terms, of priorities, needs, and support as experienced by autistic people and their supporters. It states the purpose of the survey findings and how this study will help support positive change in the future.

Why is this an important issue?

Autistic people are not being adequately supported in society. Often unable to access what they need, they face significant health and life inequalities as a result. Improved understanding of the needs and experiences of autistic people and their supporters is essential in developing more appropriate and meaningful assistance.

What was the purpose of this study?

The purpose of this study was to gain insights from autistic people and their supporters about needs and experiences related to support.

What did the researchers do?

We conducted an online survey that could be accessed by visiting our stand at the Autism Shows in June 2022 or online through a Facebook link from July-October 2022. Our participants answered some questions about their personal information (e.g., age and gender), their needs, and their experience with support.

What were the results of the study?

The majority of autistic people are not receiving the support they need with areas of life that are important to them, primarily managing overwhelm, their health, and their emotions.

The needs and experiences of autistic people showed marked variation with the age and employment status of the participant. The younger autistic participants put more emphasis on the importance of 'feeling safe' and socialising and were more likely to have received professional support than older people.

Employed people focused more on feeling confident as a life priority and managing emotions than those who were unemployed.

People found the process of accessing support overwhelming. A lack of knowledge of what was available and how to access support were key barriers. Most people looked to the internet for information; autistic people also frequently referred to social media and other autistic people, and supporters made use of health services and charities.

What do these findings add to what was already known?

The findings support other research that highlights the inequalities faced by autistic people, adding to existing knowledge by providing more detailed insight into their experiences and needs. It also demonstrates how more specific demographic factors such as age can be important influences.

What are potential weaknesses in the study?

The sample was self-selected and not a randomised sample of the autistic population.

The demographic data provided by some of the participants suggests we captured the diversity and breadth of autistic people in terms of age and gender, but not in terms of ethnicity. We also could not ask any follow-up questions about our

participants' experiences because the survey was online.

How will these findings support positive change now or in the future?

Knowing more about the needs and experiences of autistic people can help those providing support make better decisions on what support is provided and how, and hopefully improve the outcomes for autistic people.

Structured abstract

Background

Autistic people face staggering health inequalities, with waiting lists for diagnosis growing under increased pressure on the NHS and staff shortages. This is having an impact on the support they are receiving, but it is unclear the extent of this problem and what autistic people are most concerned about. This study aimed to capture their needs and experience with support through a survey in which both autistic people and their supporters participated.

Methods

This survey was open to autistic adults and supporters of autistic people. It covered areas of life they wanted help with (for themselves or the person they supported), and the quality of professional support they had received, including barriers to support. Participants completed digital questionnaires available at the three Autism Shows and then remotely via Facebook over a 14 week period.

Results

A total of 413 autistic people and 297 supporters of autistic people participated in the survey. Sixty-nine percent of those that identified as autistic had been clinically diagnosed, with more than half having to wait at least a year (55%), and a third (34%) more than 2 years.

More than half of people recorded 'feeling safe' as the top priority (rising to 75% in the youngest age group) and 66% specifically mentioned 'managing overwhelm' and 'managing health' as key needs.

Younger respondents had higher needs related to socialising and living independently; employed respondents identified feeling confident and managing emotions as higher priorities than those not in employment. Only 27% of autistic participants said they had received support for the needs that they had identified, and most (89%) of them found the process hard.

Of those not able to access professional support, half stated this was because the process was complicated, they didn't know how to access support, or they didn't know what was available. There was a steady decline in the percentage receiving support with age. Twice as many 18-24 years olds (41%) said they had received professional support for their needs compared to those aged 45 years and older (20%).

Half of people aged 45 years and above had never accessed any support service in their lifetime. Internet search was the most frequently reported source of information by both autistic people (75%) and their supporters (69%). Supporters also frequently mentioned health services (56%) and charities (42%). For autistic people, social media (47%) and other autistic people (44%) were important sources of information.

Conclusion

Most people are not getting the support they need, but needs and experiences are not uniform, especially across different age groups. Listening to autistic people to gain a better understanding of what they want help with, and how to provide this support, could assist in focusing efforts and facilitating positive change.

Background

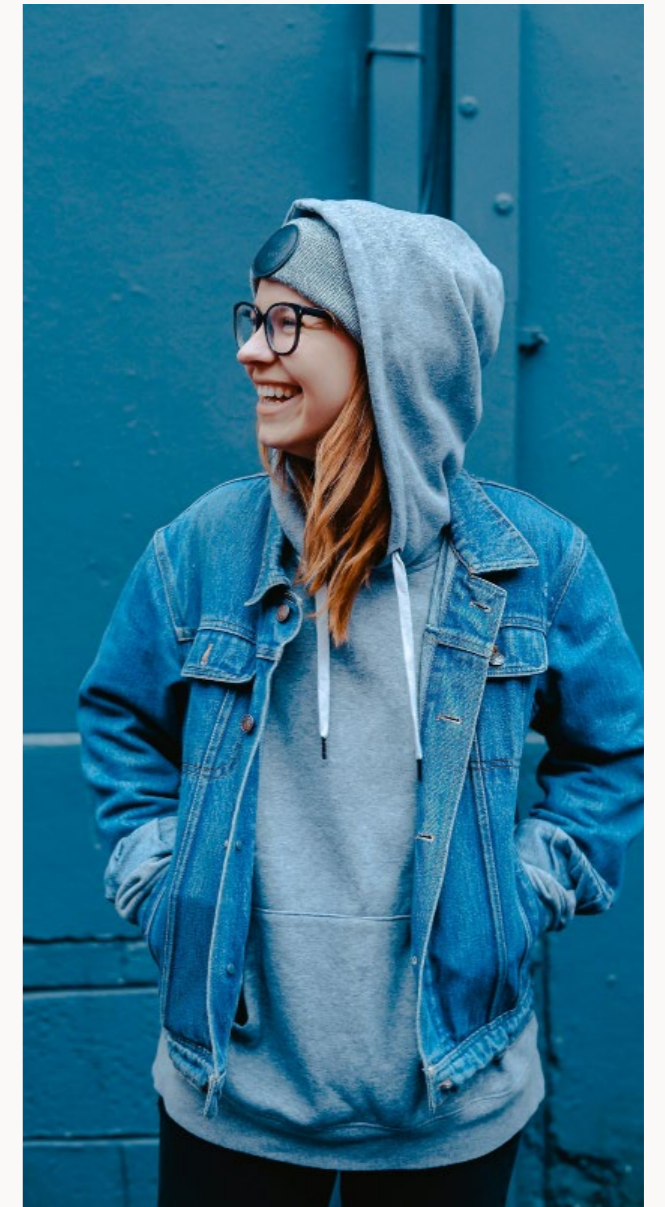
The aim of this study was to gain insights and understanding from autistic people and their supporters about their needs and experiences related to support.

Autistic people face major inequalities in their access to support services. One of the first barriers is an autism assessment. Despite commitments to get people assessed within a target 13 weeks, the latest NHS statistics suggest that most people wait much longer.

In June 2023, there were 143,119 patients with an open referral for suspected autism. Of these, 118,223 (83%) had a referral that had been open at least 13 weeks (NHS, 2023). The backlog is staggering and it will be near impossible to clear given current assessment rates. Even if a diagnosis is obtained, there is no guarantee that appropriate support will be provided. Post-diagnostic support has been identified as a significant area of concern for adults (Jones et al., 2014), parents supporting their children through the process (Crane et al., 2016), and professionals involved in diagnosing autism (Rogers et al., 2016).

With the increasing burden on the NHS, it is likely that adequate diagnostic and post-diagnostic services will become more difficult to access for autistic people. Understanding people's experience of support, the barriers they face and what their needs and priorities are will be crucial in establishing where resources need to be prioritised to avoid the widening of this health inequality gap.

This study looks to build on that understanding by listening to autistic people and their supporters on their needs and experience of support.



Methodology

This section describes how we conducted the survey, including the targeted participants and the questionnaire design.

Participants

This study was open to autistic adults and supporters of autistic people during the months of June-October in 2022. Participants completed digital questionnaires available at the three Autism Shows (10-11 June in Manchester, 17-18 June in London and 24-25 June in Birmingham) and then remotely via Facebook over a 14-week period. There was no screening for selection into the study – it was open to anyone who had been diagnosed as autistic or who thought they may be autistic and supporters of anyone who identified or had been clinically diagnosed as autistic.

Measures

The study used a bespoke questionnaire that was designed to capture the needs and priorities of autistic people, and their experience accessing support. Specifically, questions covered the priorities of autistic individuals and their supporters, areas of life they wanted help with for themselves or the person they supported, and the quality of professional support they had received, including barriers to support.

The survey also asked individuals about where they got helpful information, and the digital channels they preferred to use. Excluding demographic information (which covered age, gender, ethnicity, and employment), the survey consisted of 12 questions. All questions were closed and involved either a selection of one or more

responses from a drop-down menu or ranking of a list of items. None of the questions were mandatory: at any time, participants could skip a question and proceed to the next one.

Procedure

At the three Autism Shows, participants were invited to complete the survey using tablets provided by Brain in Hand. Following the shows, the survey was available online through Facebook.

The questionnaire took 15-20 minutes to complete, and participants were informed at the start that the information they provide would be shared externally to help inform on needs and support.

Data was provided anonymously, though people were given the option to provide contact information if they wanted to hear back on the findings or were interested in being part of other studies.

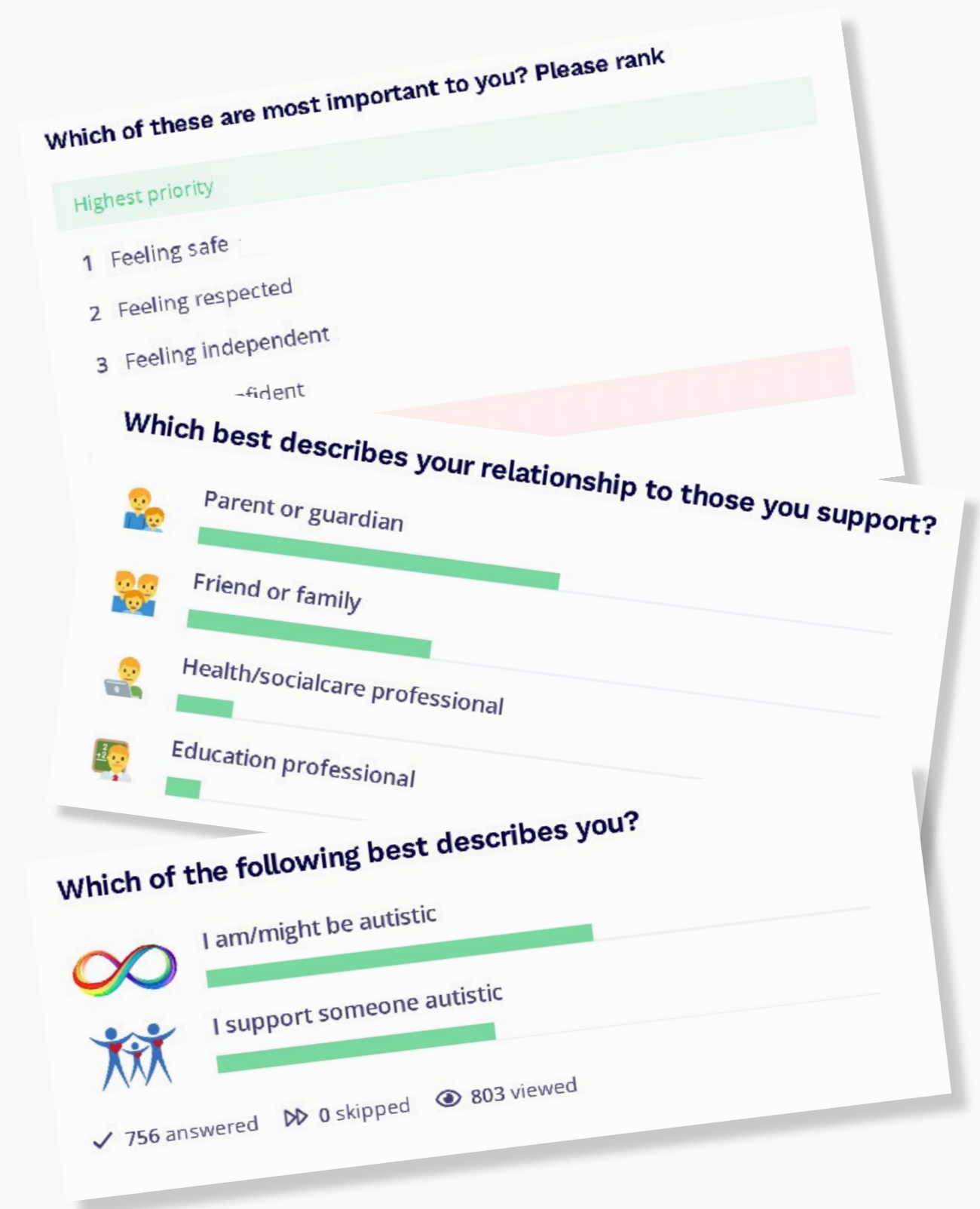
Questionnaire design

Following feedback from our Brain in Hand user community, we utilised a platform called [‘Give my View’](#) to develop a visual data collection tool that would be easier for autistic people to engage with.

Data analysis

Descriptive statistics were calculated using SPSS (IBM SPSS Statistics 29.0) and comparisons across sub-groups were tested for significance using Chi Squared, Mann-Whitney U, and Kruskal-Wallis H (IBM SPSS Statistics 29.0).

Metrics are provided for all autistic people surveyed, and for those with demographic data to demonstrate that this sub-sample is representative of the overall group, the findings are similar, and to therefore validate further analysis on this sub-group by the various demographic variables. The descriptive statistics in the text refer to the total sample unless specified otherwise.



Results

This section presents the survey findings, which explore sample demographics, diagnosis, professional support, and the priorities and experiences of autistic people and their supporters.

Sample demographics

A total of 413 autistic people and 297 supporters of autistic people participated in the survey.

The majority of the 710 participants were from the social media campaign (86%), with the London Autism Show (17-18 June), Manchester (10-11 June) and Birmingham (24-25 June) representing 6%, 4% and 4% respectively.

256 supporters shared their relationship with the person they support, 142 (55%) were a parent or guardian and 104 (41%) were family or a friend, with just 6 identifying as a health or social professional and 4 as an education professional.

Many (67%) of the 413 autistic people participating in the survey provided some demographic information related to age, gender, ethnicity or employment and **Table 1** and **Figure 1 (a)** and **(b)** summarise these characteristics.

Most of those surveyed were white British females, but from a diverse range of ages and employment situations. Two-thirds responding as an autistic person were female (67%), with 18% identifying as male and 12% as non-binary. Most also identified as White British (82%), with the remaining responses covering a range of ethnicities including African, Asian British, Black British, Chinese, Gypsy or Irish Traveller, Irish, Pakistani, White and Asian, White and Black African and White and Black Caribbean, with 20 noting a group 'other' than the list we provided.

Figure 1 (a). Autistic participant demographic data

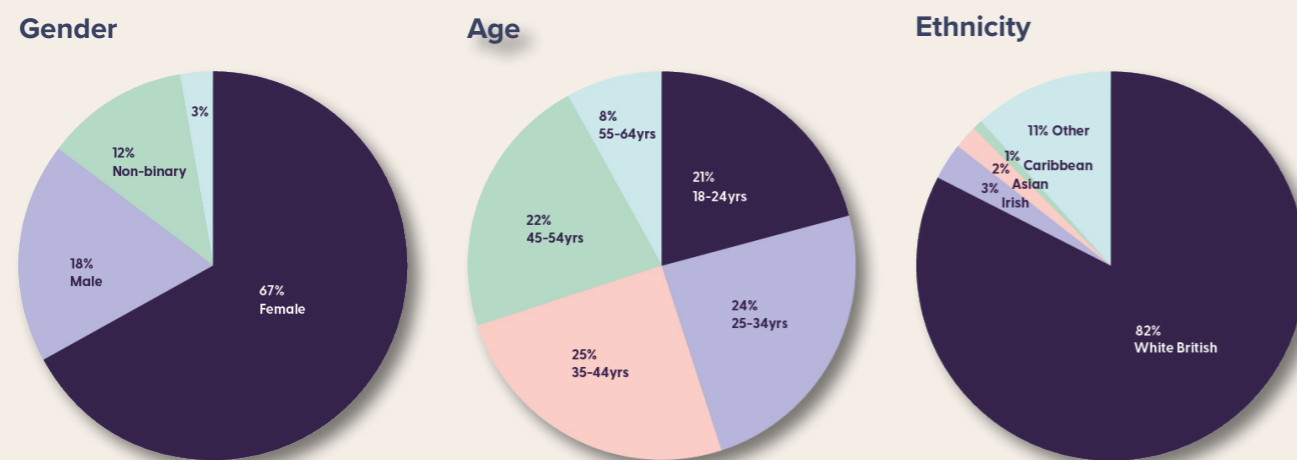
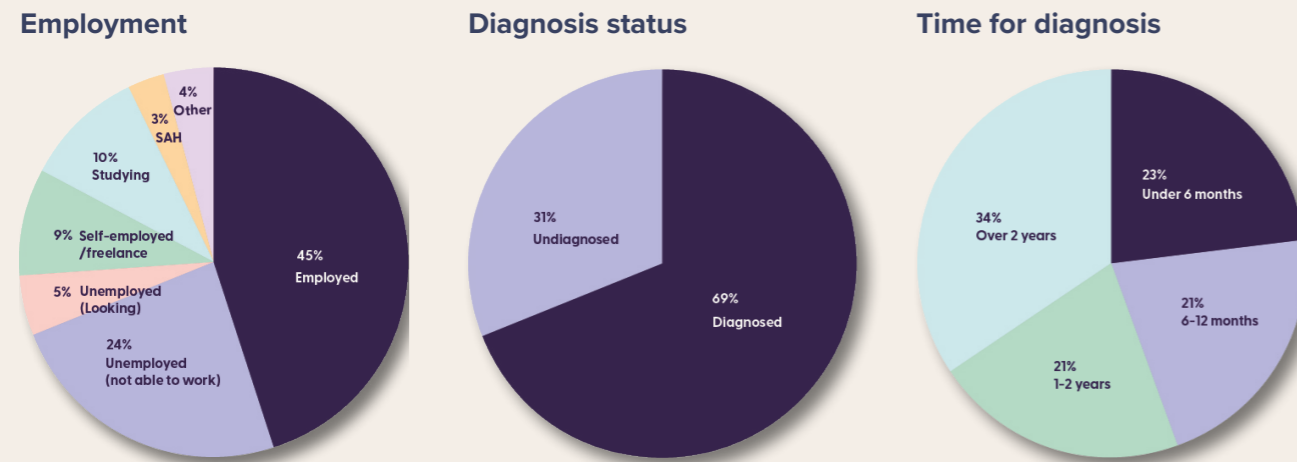


Table 1. Autistic participant demographic data

Variable	Category	N	%
These results are from those who provided information			
Gender (n=413)	Female	171	67%
	Male	47	18%
	Non-binary	30	12%
	Other	7	3%
	Prefer not to say (includes missing)	158	-
Age, years (n=413)	18-24	55	21%
	25-34	61	24%
	35-44	65	25%
	45-54	57	22%
	55-64	20	8%
	Prefer not to say (includes missing)	155	-
Ethnicity (n=413)	White British	203	82%
	Irish	8	3%
	White and Asian	6	2%
	White and Black Caribbean	3	1%
	Other categories	28	11%
	Prefer not to say (includes missing)	165	-
Employment (n=413)	Employed	114	45%
	Unemployed – not able to work	61	24%
	Unemployed – looking for work	12	5%
	Self-employed/freelance	22	9%
	Studying	26	10%
	Homemaker (Stay-At-Home SAH)	7	3%
	Other	9	4%
	Prefer not to say (includes missing)	162	-
Diagnosis status (n=258)	Diagnosed	177	69%
	Not diagnosed/ not applicable	81	31%
Time for diagnosis (n=177)	Under 6 months	40	23%
	6 - 12 months	38	21%
	1 - 2 years	38	21%
	Over 2 years	61	34%

Forty-five percent of those identifying as autistic reported that they were in employment and 10% were studying. Nearly a third (29%) stated they were unemployed, but only 5% were looking for work, the remaining 24% stating they are not able to work. There was a similar level of representation across each age group, though fewer in the 55-64 category and none 65 or older. Due to the small sample size in age group 55-64 years, for the purposes of the analysis by age, participants in this group were combined with those aged 45-54 to create a single '45 and older' group.

Figure 1 (b). Autistic participant demographic data



Older age groups were more likely to be employed, with 45% of the youngest age group being employed (15/33), 79% of 25-34 year olds (42/53), 66% of 35-44 year olds (37/56), and 63% of those aged 45 years and over (42/67) ($X^2(3, N = 209) = 10.464, p \leq .05$).

The small sample sizes of these sub-groups did not allow us to explore this 2-way disaggregation in key variables, but it should be noted that some of the trends by employment status may in fact be due to the age of the respondent.

Two-thirds of those identifying as autistic had been clinically diagnosed. Half of these had waited more than a year to get their diagnosis. Older people and those that were not in employment were more likely to have had to wait longer to receive a diagnosis.

Sixty-nine percent of those that identified as autistic had been clinically diagnosed. A formal clinical diagnosis was slightly lower in those that identified as non-binary (67%, 20/30) compared to females (69%, 118/170) and males (74%, 35/47).

There were no significant relationships between diagnosis status and employment or age. Of those that had been clinically diagnosed, more than half (56%) had to wait at least a year, and a third (34%) more than 2 years.

Those who identified as unemployed and those aged 45 years or over had some of the longest waiting times (47% and 43% respectively waiting more than 2 years). Waiting times were similar across the different gender groups.

Quantitative results - Life Priorities

The participants were asked to rank the relative importance of four sentiments – feeling confident, feeling independent, feeling respected, and feeling safe – where 1 was the most important and 4 the least important. Each person ranked these for themselves if they were answering as an autistic person or on behalf of the person that they support if they identified as a supporter. More than half of people recorded feeling safe as the top priority, with this rising to 75% in the youngest age group.

Table 2 and **Figures 2** (a) & (b) summarise the findings with respect to the question ‘which of these [feelings] are most important to you/to the person you support?’. A total of 397 autistic people (259 with demographic data) and 235 supporters answered this question. Feeling safe was ranked as the top priority by 57% of autistic people and 58% of supporters. The percentage that prioritised feeling confident, independent, or respected varied between 10 and 18%. Although the mean ranking of these three sentiments varied between participants responding as autistic or as a supporter, the only significant difference was recorded for ‘feeling confident’; this was ranked lower by autistic people than supporters ($U = 14089, p \leq .05$), usually in favour of ‘feeling independent’.

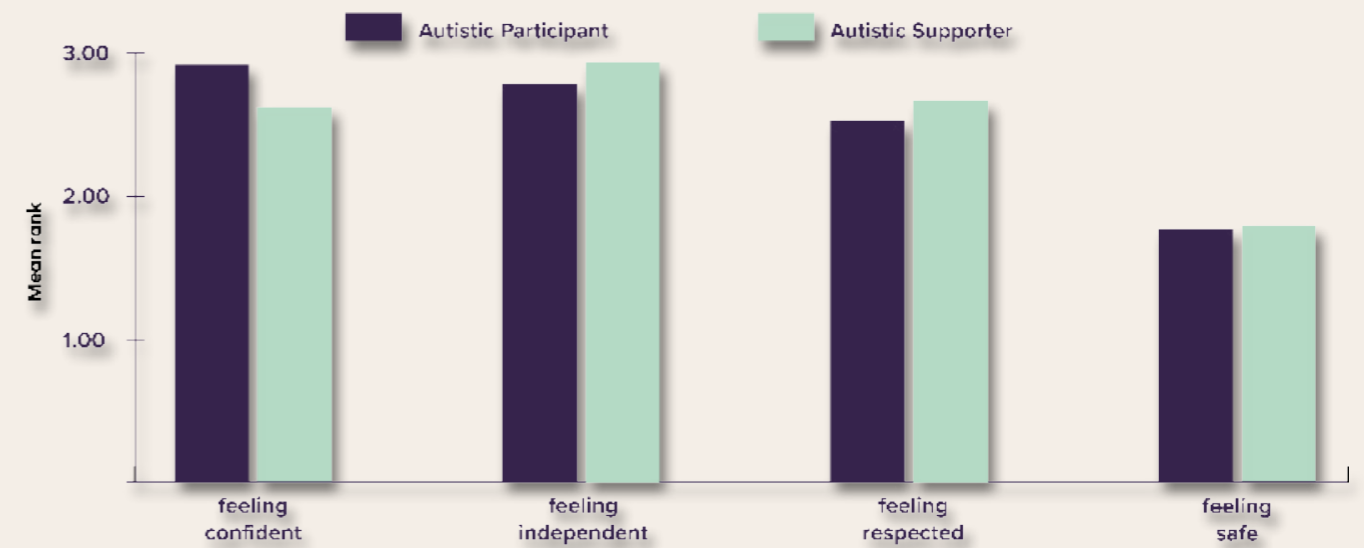
Importantly, the results from the demographic sub-sample were similar to the total sample of autistic participants, suggesting that further analysis by demographic variables of this sub-group is valid as a representative subsample of the total sample.

Table 2. Life Priorities: ‘which of these are most important to you/to the person you support?’

Variable	Autistic participant (all)		Autistic supporter		Autistic participant with any demographic data	
	Mean Rank (N=397)	% who ranked it 1st	Mean Rank (N=235)	% who ranked it 1st	Mean Rank (N=259)	% who ranked it 1st
Which of these are most important to you/to the person you support? Please rank (1 = most important, 4 = least important)						
Feeling confident	2.92*	10%	2.62	13%	2.99**	8%
Feeling independent	2.79	15%	2.94	13%	2.78	15%
Feeling respected	2.51	18%	2.67	16%	2.52	18%
Feeling safe	1.78	57%	1.76	58%	1.71	59%

*Significant to .01 level, when compared with supporters using Independent-Samples Mann-Whitney U Test
**Significant to .05 level, when compared with supporters using Independent-Samples Mann-Whitney U Test

Figure 2(a). Life Priorities: ‘which of these are most important to you/to the person you support (1=most important and 4=least important)?’



Life priorities varied by age, with feeling safe decreasing as a key sentiment and feeling confident and independent increasing with age. Employed autistic people also ranked feeling confident as a higher priority than those who were unemployed.

Figure 2 (b). Life Priorities: 'which of these are most important to you/to the person you support?'

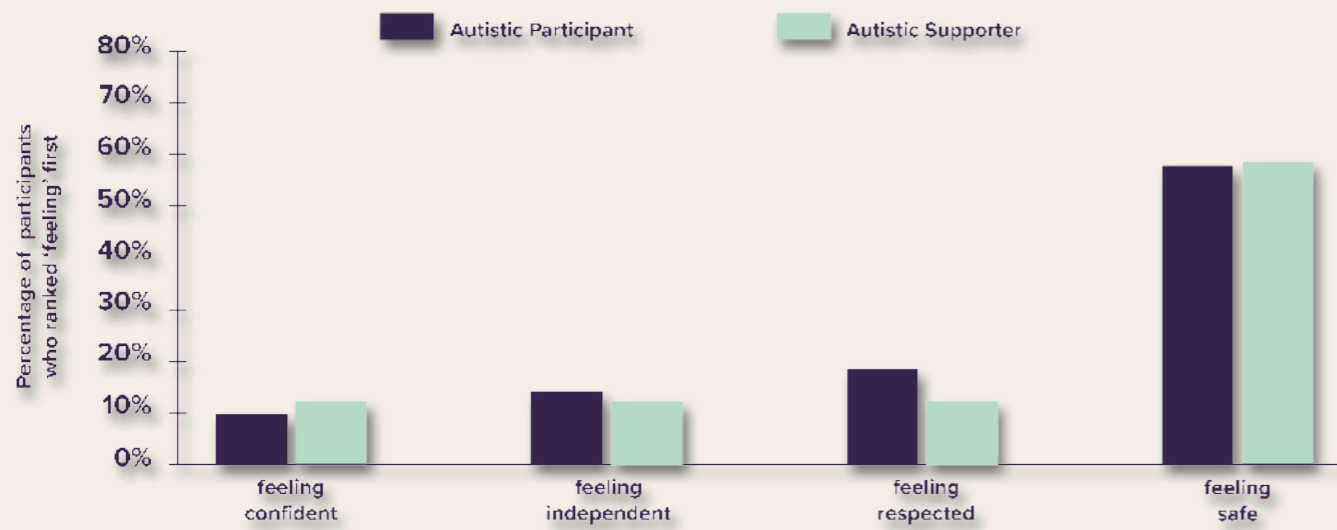


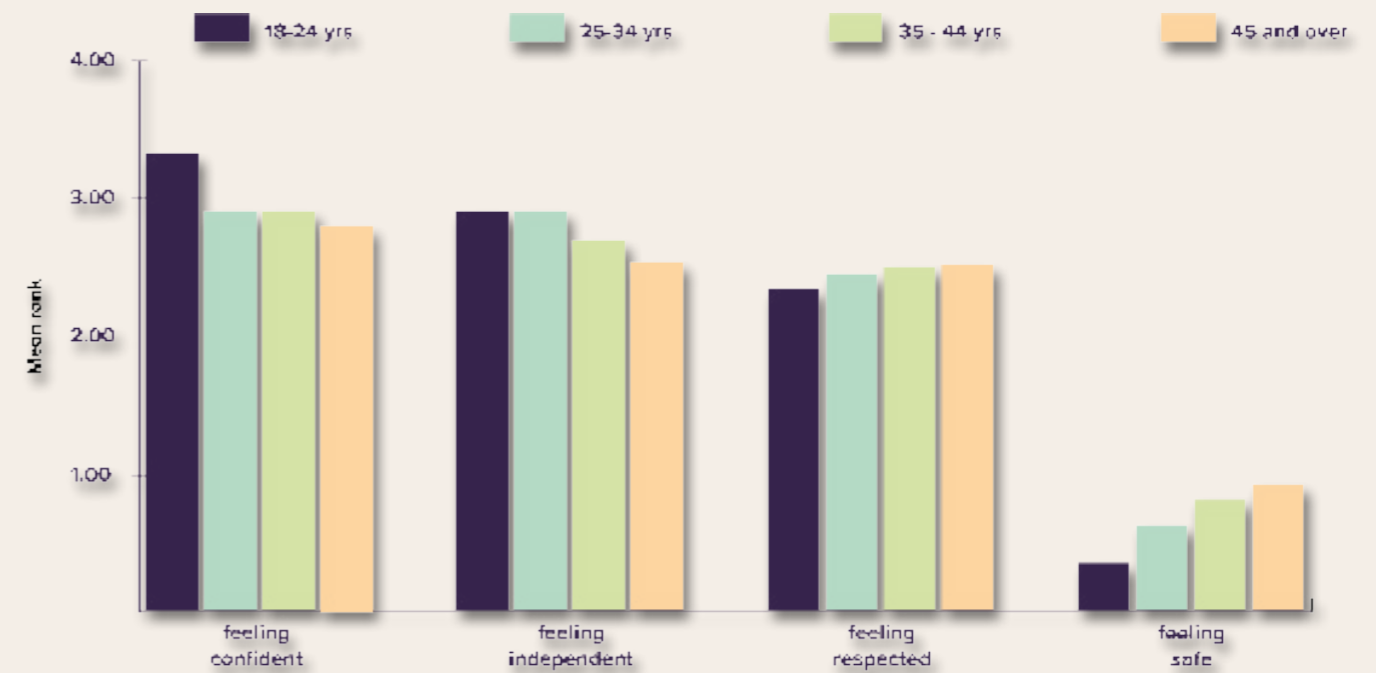
Table 3 and Figure 3 (a) and (b) summarise the main findings with respect to life priorities and changes by age. Both the percentage of people ranking different sentiments as a top priority and the average rank assigned show marked age trends. The ranking of 'feeling safe' varied significantly across age groups, becoming less important as age groups get older ($H(3) = 10.43, p \leq .05$). Feeling safe ranked first in 75% of the youngest age group (18-24 year olds) and 49% of the oldest age group (45 years and over). Conversely, feeling confident was ranked as the top priority by 14% of those aged 45 years or over and by none of the youngest age group, though this did not reach significance ($H(3) = 7.41, p > .05$). The change in the average rank by age-group (see Figure 3 (a)) also illustrates the different priorities given to feeling safe by age, decreases from an average rank of 1.38 for the 18 to 24 group to 1.93 for the oldest group.

Table 3. Life Priorities by age group

Variable	18-24yrs		25-34yrs		35-44yrs		45yrs +	
	Mean Rank (N=55)	% who ranked it 1st	Mean Rank (N=61)	% who ranked it 1st	Mean Rank (N=65)	% who ranked it 1st	Mean Rank (N=76)	% who ranked it 1st
Which of these are most important to you/to the person you support? Please rank (1 = most important, 4 = least important)								
Feeling confident	3.33	0% (0/55)	2.93	8% (5/61)	2.92	8% (5/65)	2.84	14% (11/76)
Feeling independent	2.93	11% (6/55)	2.93	11% (7/61)	2.71	18% (12/65)	2.58	18% (14/76)
Feeling respected	2.36	15% (8/55)	2.49	20% (12/61)	2.55	17% (11/65)	2.64	18% (14/76)
Feeling safe*	1.38	75% (41/55)	1.64	61% (37/61)	1.82	57% (37/65)	1.93	49% (37/76)

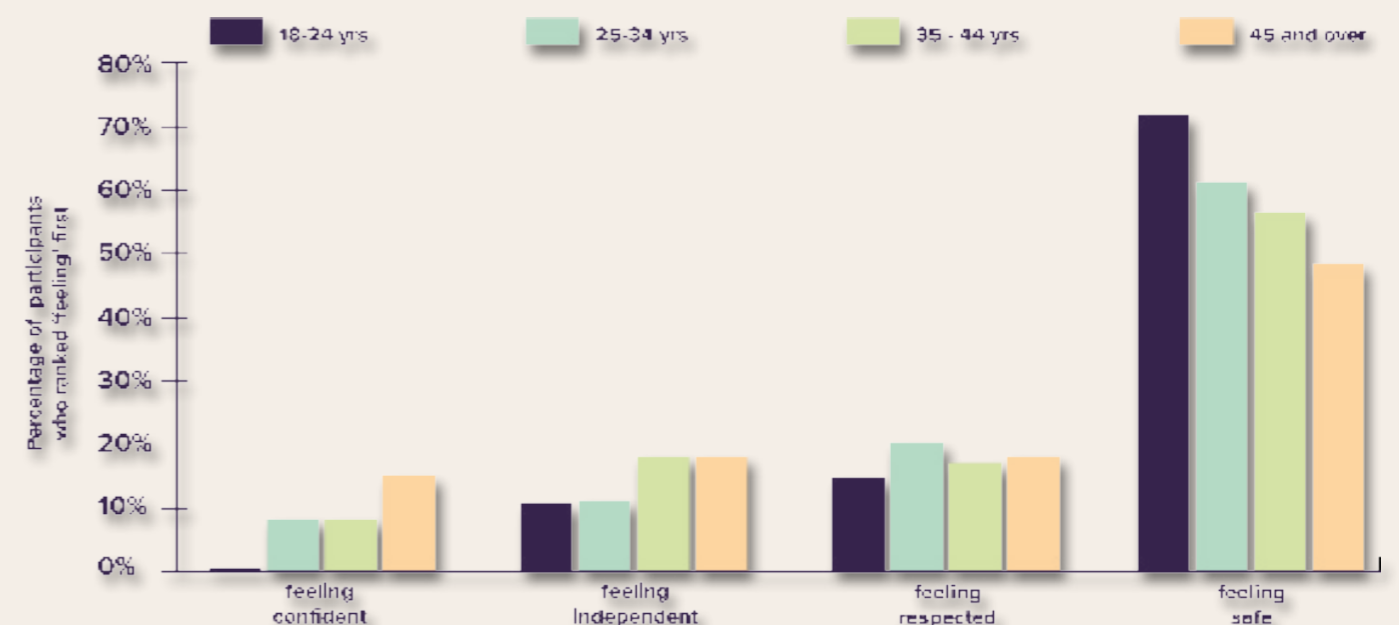
*Significant to .01 level, when comparing increasing age groups using Independent-Samples Kruskal-Wallis Test

Figure 3 (a). Changes in life priorities for autistic participants by age (1=most important and 4=least important)



There was no relationship between gender (male, female, non-binary) and any of the life priorities. However those who were employed ranked 'feeling confident' as more important than those who were not employed (average rank of 2.9 compared to 3.2) ($U = 4.55, p \leq .05$).

Figure 3 (b). Changes in life priorities for autistic participants by age



Quantitative results – Support needs

Participants were asked to select from a list of eight areas of life they or the people they support most needed help with. These were: living independently, looking after self, managing emotions, travel, managing health, study or work, socialising, and managing overwhelm. They were able to select up to 4 responses, though the average number of responses (median) was 3 (with only 30% of autistic people and 16% of supporters providing 4 responses).

Table 4 and **Figure 4** summarise the main findings for all autistic participants and all supporters alongside those who only provided demographic data. Importantly, the results from the demographic sub-sample were similar to the total sample of autistic participants, suggesting that further analysis by demographic variables of this sub-group is valid as a representative subsample of the total sample.

A total of 373 autistic people (256 with demographic data) and 254 supporters answered this question.

The most frequently mentioned area of life where support was most needed was managing overwhelm, reported by 66% of autistic people and 63% of supporters who responded to the question.

A similar percentage of autistic people mentioned managing health (66%), but this was only indicated as an important area of support by 22% of supporters ($X^2(1, N = 627) = 117.351, p \leq .01$).

This was the most significant divergence in opinion by the two groups of participants, though slight differences were also evident for other areas. Notably 48% of autistic people selected looking after myself/themself compared to 40% of supporters ($X^2(1, N = 627) = 4.006, p \leq .05$).

Socialising was selected more frequently by supporters (45% of autistic people and 58% of supporters) ($X^2(1, N = 627) = 11.009, p \leq .01$).

Only a fifth mentioned travel and less than a third 'living independently', and this was similar for both autistic participants and their supporters.

Most autistic people wanted help with managing overwhelm and their health, with fewer focusing on travel or living independently. Supporters of autistic people had divergent opinions with respect to managing health as an important area of life in which autistic people need support.

Table 4. Support needs

Variable	Autistic participant (all)		Autistic supporter		Autistic participant with any demographic data	
	N	%	N	%	N	%
Numbers are based on those who responded to each question with non-responders excluded						
Which areas of life do you feel you /those you support - need most help with? (total n)	373		254		256	
Living independently	100	27%	74	29%	72	28%
Looking after self ^{**/*}	180	48%	102	40%	136	53%
Managing emotions ^{**/**}	179	48%	147	58%	117	46%
Travel	67	18%	47	19%	53	21%
Managing health ^{**/**}	248	66%	57	22%	177	69%
Study or work	152	41%	108	43%	114	45%
Socialising ^{**/**}	167	45%	148	58%	108	42%
Managing overwhelm [*]	248	66%	159	63%	177	69%

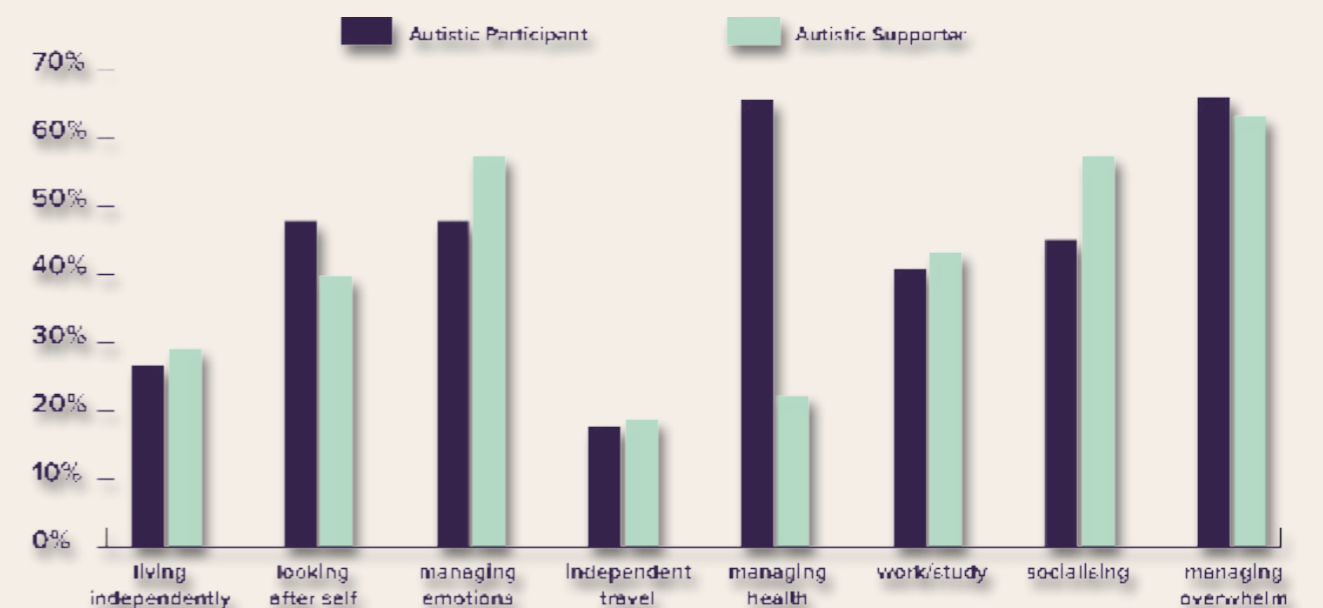
*Difference between autistic participants and supporters significant at .1 level, 2-tailed chi squared (all)

**Difference between autistic participants and supporters significant at .05 level, 2-tailed chi squared (all)

*Difference between autistic participants and supporters significant at .1 level, 2-tailed chi squared (w/ demographics)

**Difference between autistic participants and supporters significant at .05 level, 2-tailed chi squared (w/ demographics)

Figure 4. Support needs for autistic participants and autistic supporters



Support needs varied by demographics with younger people prioritising socialising and living independently more than older people and employed people focusing more on managing emotions than those who were unemployed.

Table 5 and **Figure 5** summarise the main findings with respect to life priorities of autistic participants by age and employment status. There were some trends related to age, with the younger age groups mentioning socialising more frequently than older ages (58% of 18-24 year olds compared with 36% of over 35s) ($X^2 (3, N = 258) = 9.555, p \leq .05$), and at a similar level to supporters of autistic people (see Table 4).

Similarly, living independently was mentioned more frequently by younger people compared to older ones (38% of 18-24 year olds versus 18% of over 44 year olds) ($X^2 (3, N = 258) = 6.640, p \leq .01$).

In contrast, managing health was more important to older than younger respondents, with this being mentioned by nearly half of those aged 45 years and above, but less than a third of those aged 18-24 years (29%). Those who were employed reported managing emotions significantly more frequently than people who were not employed, 51% compared with 37% ($X^2 (1, N = 209) = 4.007, p \leq .05$).

Conversely, those who were not employed identified travel as a need more frequently than employed participants (29% compared with 13%) ($X^2 (1, N = 209) = 8.450, p \leq .05$). There were no differences in identified needs by gender.

Table 5. Support needs by age and employment status

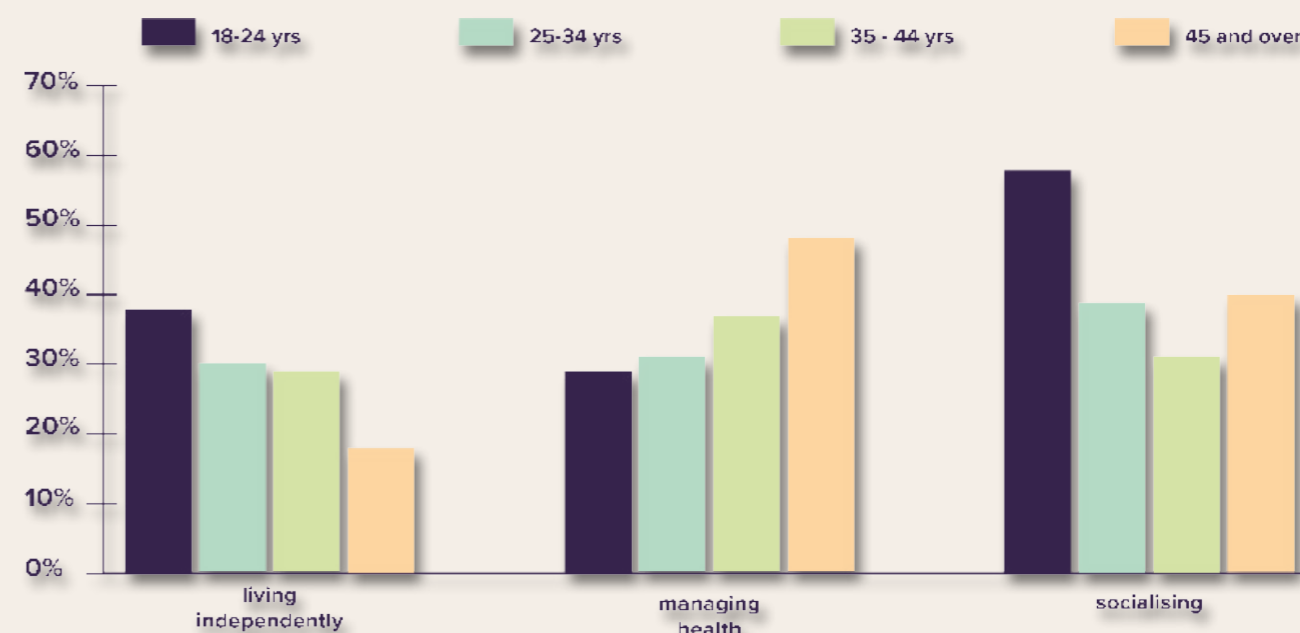
	Employed	Un-employed	18-24 yrs	25-34 yrs	35-44 yrs	45 yrs +
Which areas of life do - you feel you need most help with? (total sample size)	136	73	55	61	65	77
Living independently	24% (33)	34% (25)	38% (21)	30% (18)	29% (19)	18% (14)
Looking after self ^{**/*}	56% (76)	45% (33)	49% (27)	57% (35)	62% (40)	43% (33)
Managing emotions ^{**/**}	51% (70)	37% (27)	40% (22)	46% (28)	52% (34)	42% (32)
Travel	13% (17)	29% (21)	25% (14)	13% (8)	25% (16)	19% (15)
Managing health ^{**/**}	35% (48)	42% (31)	29% (16)	31% (19)	37% (24)	48% (37)
Study or work	44% (60)	44% (32)	36% (20)	39% (24)	52% (34)	45% (35)
Socialising ^{**/**}	37% (50)	48% (35)	58% (32)	39% (24)	31% (20)	40% (31)
Managing overwhelm [*]	69% (94)	68% (50)	66% (36)	72% (44)	75% (49)	60% (46)

*Difference across age groups significant at .1 level, 2-tailed chi squared

**Difference across age groups significant at .05 level, 2-tailed chi squared

**Difference between employed and unemployed significant at .05 level, 2-tailed chi squared

Figure 5. Changes in support needs related to living independently, managing health and socialising by age



Quantitative results – Professional support

Participants were asked about the professional support they had received through a series of questions. They were first asked whether they had received professional support for their needs, then, depending on their response, either how hard this had been and why or the reasons they had not received support. Importantly, the results from the demographic sub-sample were similar to the total sample of autistic participants, suggesting further analysis by demographic variables of this sub-group is valid as a representative subsample of the total sample.

Most autistic people are not having their needs met through professional support. Even for those that have accessed support, most found the process hard as it was too complicated, overwhelming and took too long. For those not accessing support, knowledge on what was available and how to access it were also key barriers, and nearly a third of autistic people thought that they would not be eligible.

27% Only 27% of autistic participants said they had received support for the needs that they had identified.



Table 6 and Figure 6 summarise the findings related to accessing support and experience of professional support. A total of 365 autistic people (252 with demographics) and 230 supporters answered this question. Only 27% of autistic participants said they had received support for the needs that they had identified, with 60% stating a definite no, and 13% being unsure.

For those that had received support, most (89%) found the process hard (a score of 50 or lower on a 100 point rating scale) with half of the respondents noting that the process is overwhelming, complicated and too lengthy.

For those not able to access professional support, at least half mentioned that this was because the process was complicated or because they didn't know what was available or how to access support. Nearly a third of autistic people (31%) thought that they would not be eligible.

This perception around eligibility did not seem to be related to whether someone was clinically diagnosed (37% who responded to this question) or not (35%).

Similarly, knowledge on what is available and how to access it did not differ between those who had been diagnosed or not.

Supporters of autistic people provided some feedback that was different from that reported by autistic participants.

For example, a higher percentage of supporters of autistic people stated that the autistic person had received professional support (47% compared to 27%, $X^2(1, N = 595) = 24.18, p \leq .01$).

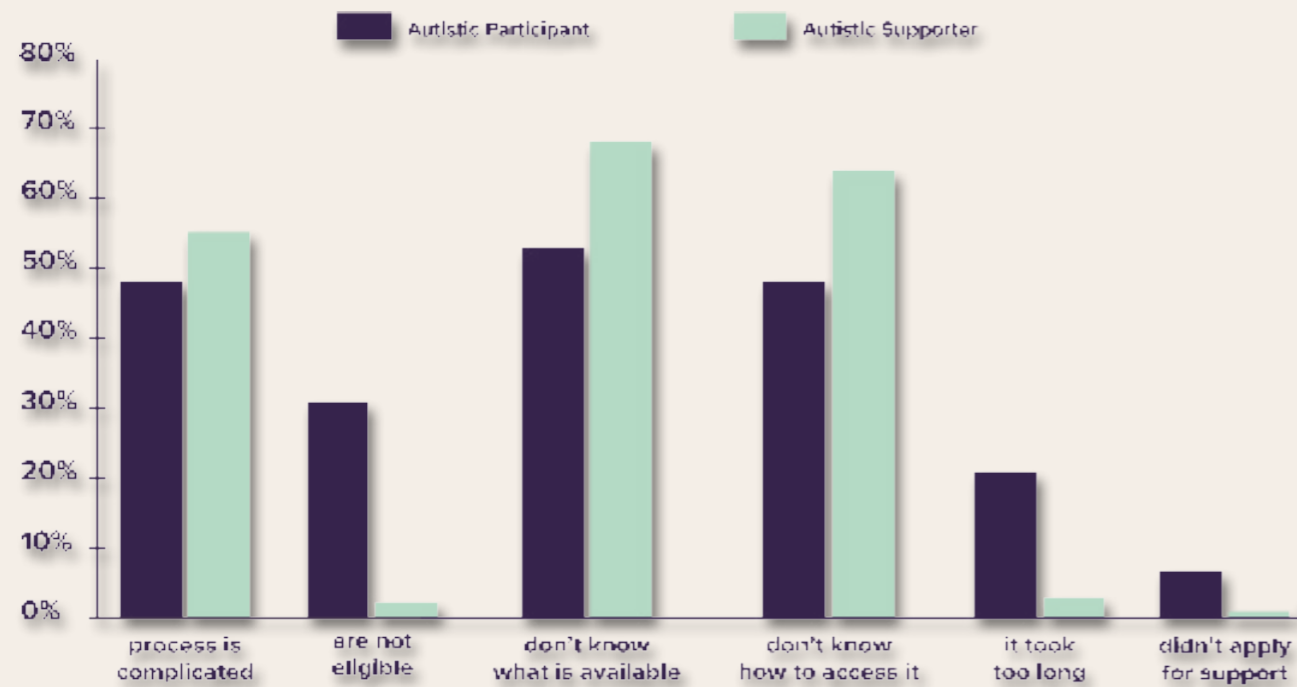
They also had differing opinions on some of the reasons why the process is hard, with only 22% mentioning the process was overwhelming compared to 48% of autistic participants $X^2(1, N = 162) = 12.63, p \leq .01$.

For those who had not received services, supporters reported not being eligible (2% compared to 31%, $X^2(1, N = 312) = 34.027, p \leq .01$) and it taking too long (4% compared to 21%, $X^2(1, N = 312) = 15.023, p \leq .01$) significantly less frequently than autistic people.

Table 6. Experience with accessing professional support

Variable	Autistic participant (all)		Autistic supporter (all)		Autistic participant with demographic data	
	N	%	N	%	N	%
Numbers are based upon those who responded to each question with non-responders excluded)						
Have you/they received support for this? (total n)	365		230		252	
Yes	98	27%	107	47%	73	29%
No	220	60%	117	51%	149	59%
Not sure	47	13%	6	3%	30	12%
Have you/they received support for this? (total n)	97		106		73	
For those that had received professional support for these areas, what percentage scored it as hard and why (a score of 50/100 or lower)	86	89%	88	83%	67	92%
Why was it hard? (total n)	83		79		66	
The process is complicated	48	58%	59	75%	38	58%
The process is overwhelming	40	48%	17	22%	33	50%
It took too long	43	52%	48	61%	33	50%
Not enough information	16	19%	18	23%	14	21%
Those that had not received support (total n)	214		117		149	
For those that had not received support, what percentage scored it as hard (a score of 50/100 or lower)	212	99%	112	96%	148	99%
What are the main reasons you/they have not received support?	209		103		144	
The process is complicated	101	48%	57	55%	69	48%
I am/ they are not eligible	64	31%	2	2%	52	36%
I don't know what is available	112	54%	70	68%	74	51%
I don't know how to access it	101	48%	66	64%	72	50%
It took too long	43	21%	4	4%	36	25%
I didn't apply for support	14	7%	1	1%	10	7%

Figure 6. The main reasons autistic people and their supporters say they have not received support



Older autistic people were less likely to have received support, but also less likely to have found the process complicated.

Table 7 and Figure 7 summarise the main findings with respect to professional support access by autistic participants and age.

Autistic individuals' experiences with professional support were highly age-dependent, with a steady decline in the percentage receiving support with age.

Twice as many 18-24 years olds (41%) said they had received professional support for their needs compared to those aged 45 years (20%) ($X^2(1, N = 131) = 7.079, p \leq .05$). The higher levels in younger age groups align with the findings from autistic supporters.

However, unlike the supporters, close to half of autistic people across the age-groups noted that one of the reasons it was so hard to access support was because it was overwhelming.

Those in the middle age groups also noted that

they felt there was not enough information, with a peak of 29% to 44% among those ages between 25 and 44.

Among those who had not received support, only the 'process is complicated' markedly differed by age, with younger groups endorsing this at a higher rate.

All autistic ages surveyed

48%

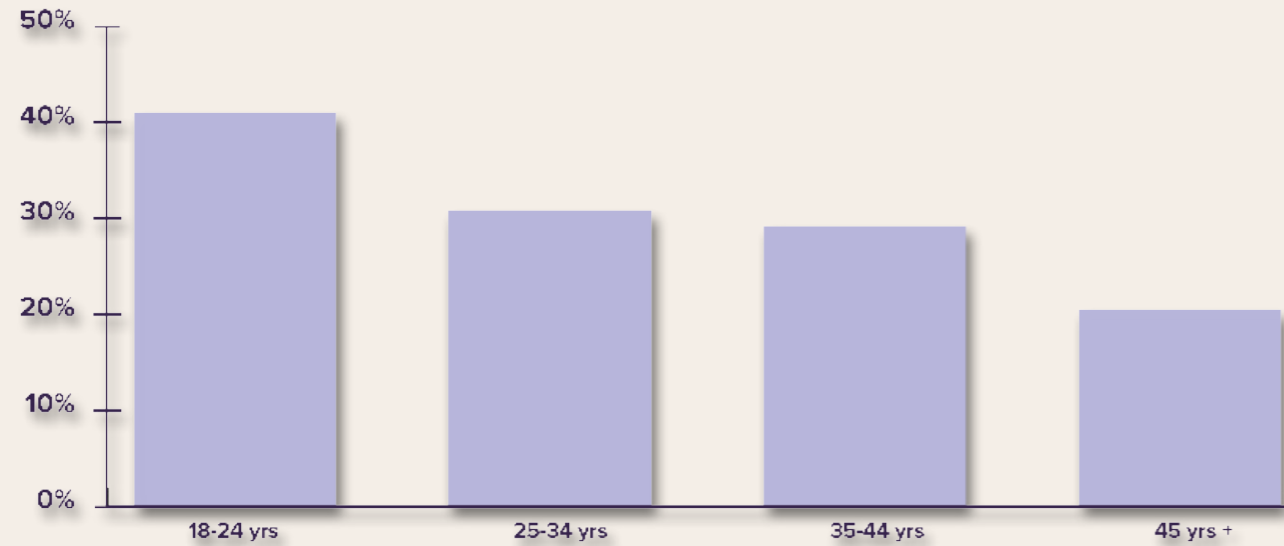
found the process of accessing professional support overwhelming

Table 7. Experience with accessing professional support by age

Variable	18-24yrs		25-34yrs		35-44yrs		45yrs +	
	N	%	N	%	N	%	N	%
Numbers are based upon those who responded to each question with non-responders excluded								
Have you/they received support for this? (total n)	54		61		59		77	
Yes	22	41%	19	31%	17	29%	15	20%
No	21	39%	34	56%	35	59%	58	75%
No sure	11	20%	8	13%	7	12%	4	5%
Those who received professional help (total n)	22		19		17		15	
For those that had received professional support for these areas, what percentage scored it as hard and why (a score of 50/100 or lower)	22	100%	17	90%	16	94%	12	80%
Why was it so hard?	21		17		16		12	
The process is complicated	14	67%	9	53%	9	56%	6	50%
The process is overwhelming	11	52%	8	47%	7	44%	7	58%
It took too long	12	57%	7	41%	7	44%	7	58%
Not enough information	2	10%	5	29%	7	44%	0	0%
Those that had not received support (total n)	21		34		35		58	
For those that had received professional support for these areas, what percentage scored it as hard and why (a score of 50/100 or lower)	21	100%	33	97%	35	100%	58	100%
What are the main reasons you/they have not received support	21		32		35		55	
The process is complicated	11	52%	22	69%	12	34%	24	44%
I am/ they are not eligible	7	33%	11	34%	13	37%	20	36%
I don't know what is available	10	48%	15	47%	21	60%	27	49%
I don't know how to access it	10	48%	16	50%	22	63%	23	42%
It took too long	9	43%	9	28%	5	14%	13	24%
I didn't apply for support	1	5%	3	9%	1	3%	4	7%

When comparing support by gender, non-binary individuals were nearly twice as likely to receive support (47%, 14 out of 30) compared with females (27%, 45 out of 167) or males (25%, 11 out of 44). Comparing support by employment status, 34% of employed individuals (44 out of 131) had received support, while only 19% of those not employed (14 out of 72) had received support ($X^2(1, N = 203) = 4.554, p \leq .05$).

Figure 7. Autistic peoples receipt of support for their needs by age



Quantitative results – Access of services

Participants were asked if they or the people they support had ever received support from a list of seven different services that covered health (NHS mental health services and mental health crisis services), social care (social services) and other government support (Disabled Student Allowance, Employment support, Education, Health and Care Plan (EHCP), and financial support). A total of 413 autistic participants answered this question, 136 who had specified employed status and 73 unemployed.

Nearly a third of autistic people had never accessed any of these services, but of those that had, the levels of coverage were low. The highest was in NHS mental health services, which a third had accessed in their lifetime.

Table 8 and Figure 8 summarise the main findings with respect to access of services by autistic participants overall, and by employment status. Generally, the percentage of autistic people accessing these seven key services were low, and 30% had never accessed any of them in their lifetime.

The most common service was NHS mental health services at 31%, followed by mental health crisis support, which had been accessed by 15% of survey participants. The results from the demographic sub-sample were mostly similar to the total sample of autistic participants, aside from a slightly higher percentage accessing NHS mental health services.

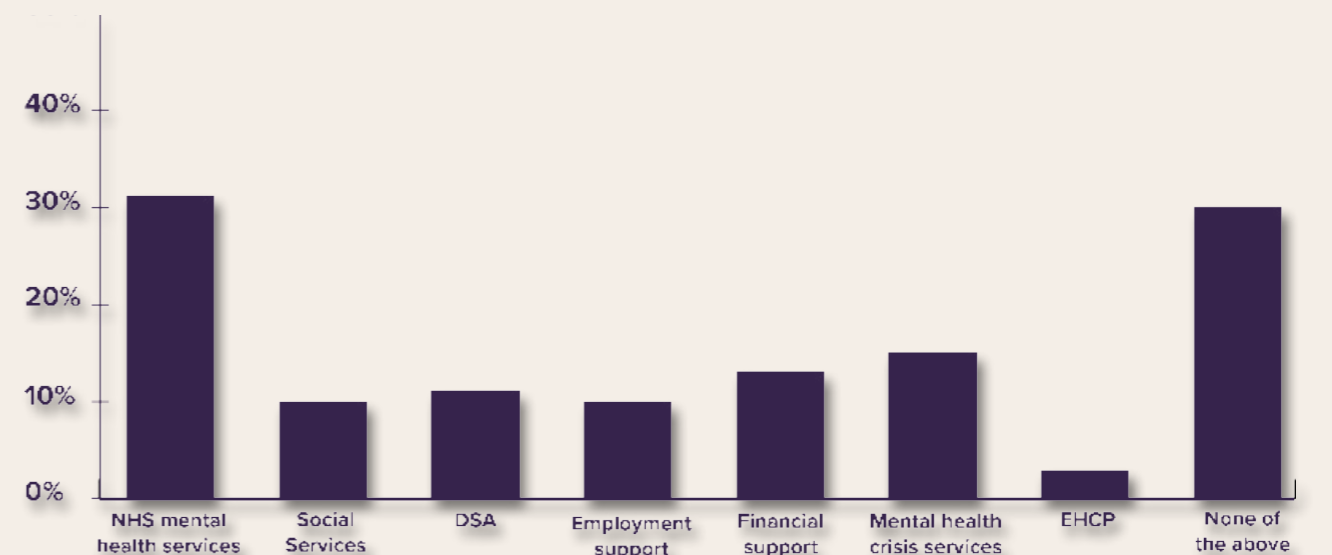
The majority of autistic people in our survey (77%) had just accessed just 1 or 2 services. Of the 201 autistic people who identified receipt of specific services, 46% had accessed just one service, and 31% two services. The maximum number of services received was 4 out of the 7 available options and this accounted for only 9% of respondents.

Table 8. Access of services by autistic participants, overall, and by employment status

Variable	Autistic participant (all)		Autistic participants with demographic data		Employed		Unemployed	
	N	%	N	%	N	%	N	%
Numbers are based upon those who responded to each question with non-responders excluded)								
Have you received/are you receiving any support from the following?	413		260		136		73	
NHS mental health services	127	31%	101	39%	57	42%	27	37%
Social services**	41	10%	30	12%	5	4%	17	23%
Disabled student allowance	46	11%	35	13%	16	12%	6	8%
Employment support	40	10%	32	12%	20	15%	7	10%
Financial support**	54	13%	38	15%	10	7%	20	27%
Mental health crisis services**	60	15%	47	18%	20	15%	19	26%
EHCP (education health care plan)**	11	3%	8	3%	7	5%	0	0%
None of the above	123	30%	91	35%	50	37%	20	27%

*Difference between autistic participants and supporters significant at .1 level, 2-tailed chi squared (all)
 **Difference between autistic participants and supporters significant at .05 level, 2-tailed chi squared (all)

Figure 8. Access of services by autistic participants over their lifetime



Employed autistic people were more likely never to have accessed social service support, financial support and support from a mental health crisis team than those who were unemployed.

As shown by Table 8 access to services varied significantly by employment status. Those who were employed were less likely to receive support from social services (4% versus 23%) ($X^2(1, N = 209) = 19.398, p \leq .05$), financial support (7.4% compared with 27%) ($X^2(1, N = 209) = 15.524, p \leq .05$), and support from a mental health crisis team (15% versus 26%) ($X^2(1, N = 209) = 4.011, p \leq .05$). They were more likely to be in receipt of an EHCP (Education, Health and Care Plan) (5% versus 0%), ($X^2(1, N = 209) = 3.888, p \leq .05$).

Table 9 and **Figure 9** summarise the main findings with respect to access of services by age of autistic participants. **There are clear trends of reduced access with increasing age.**

Half of those aged 45 and older stated they had never received support from any of the seven services, compared to 18% of 18-24 years olds and 31% of those in the middle age groups ($X^2(3, N = 258) = 15.810, p \leq .05$). This decrease in access by age was also reflected in most of the individual services, particularly with NHS mental health services where 21% of those aged 45 years and older had accessed this support compared to 51% of 18-24 year olds ($X^2(3, N = 258) = 16.083, p \leq .05$).

Older autistic people are less likely to have accessed services than younger adults with half of people aged 45 years and above never having accessed any service in their lifetime.

Non-binary individuals were more likely to receive Disabled Students' Allowance (30%) than females (12%) or males (6.4%) ($X^2(2, N = 248) = 9.803, p \leq .05$) and less likely to be receiving no support from the services listed (17%) compared with females (39%) and males (32%) ($X^2(2, N = 248) = 5.936, p \leq .1$).

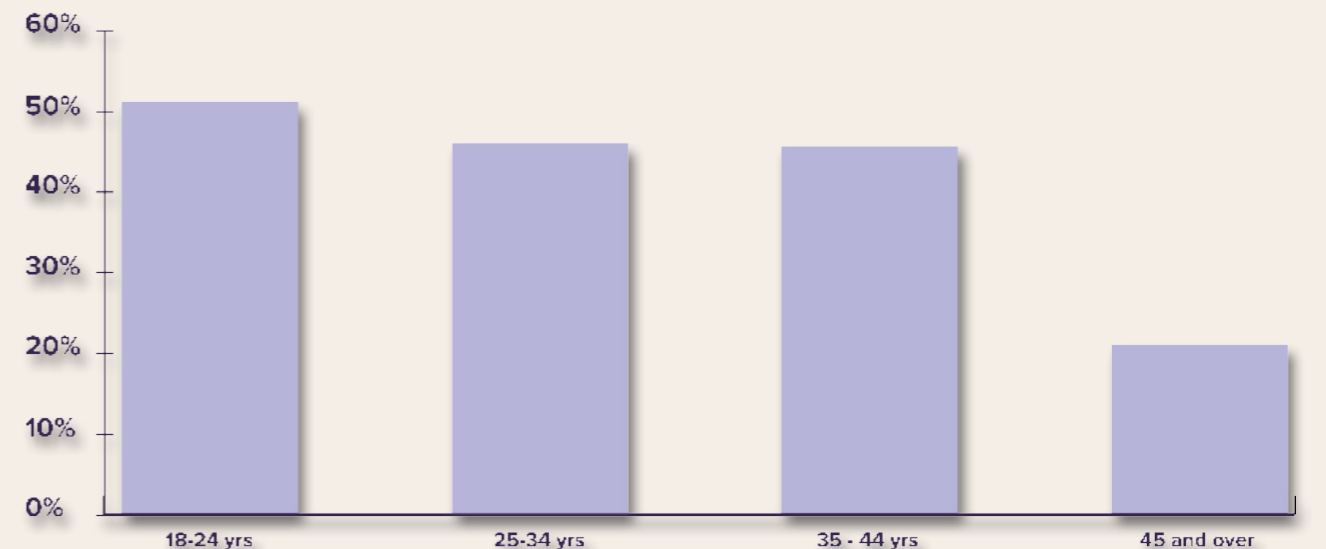
Table 9. Access of services by autistic participants, overall

Variable	18-24yrs		25-34yrs		35-44yrs		45yrs +	
	N	%	N	%	N	%	N	%
Numbers are based upon those who responded to each question with non-responders excluded)								
Have you received/are you receiving any support from the following?	55		61		65		77	
NHS mental health services**	28	51%	28	46%	29	45%	16	21%
Social services	11	20%	4	7%	7	11%	8	10%
Disabled student allowance**	17	31%	11	18%	4	6%	3	4%
Employment support	4	7%	11	18%	8	12%	9	12%
Financial support	8	15%	9	15%	12	18%	9	12%
Mental health crisis services**	4	7%	2	3%	1	2%	1	1%
EHCP (education health care plan)	14	25%	9	15%	13	20%	11	14%
None of the above**	10	18%	19	31%	21	32%	39	51%

**Difference between autistic participants and supporters significant at .05 level, 2-tailed chi squared (all)

51% of 18 - 24 year olds have accessed NHS mental health support, compared to 21% of over 45 year olds.

Figure 9. Access of NHS mental health services by age



Quantitative results – Sources of Information

Participants were asked where they look for information or help for themselves or those they support from a list of 9 different sources (social media, friends, professional peers, other autistic people, family, social services, health services, internet searches, and charities).

The results from the demographic sub-sample were similar to the total sample of autistic participants, suggesting that further analysis by demographic variables of this sub-group is valid as a representative subsample of the total sample.

Most autistic people and their supporters look to the internet for information, but social media and other autistic people are also important for autistic people, as are charities and health services to supporters.

Table 10 and **Figure 10** summarise the findings related to sources of information for support. A total of 360 autistic people (258 with demographics) and 257 supporters answered this question. Internet search was the most frequently reported source of information by both autistic people (75%) and their supporters (69%). Supporters also frequently mentioned health services (56%) and charities (42%), significantly more frequently than autistic people at 43% and 28% respectively). For autistic people, social media (reported by 47%) and other autistic people (44%) were important sources of information. Even though supporters mentioned health services more than autistic people, this was still an important source of information for autistic people comparable in number with ‘other autistic people’.

There were some differences in access to information by age, employment status, and gender. Among autistic people there was a trend for 35-44 year olds to rely on friends more than the younger or older age groups (21%) compared with between 8% and 14% for the other age groups ($X^2(3, N = 258) = 6.608, p \leq .1$). The youngest age group was also less likely to rely on charities (18%), compared with between 29% and 41% among the older age groups ($X^2(3, N = 258) = 7.274, p \leq .1$). Gender was also related to seeking information from charities. While only 25% of females and 30% of non-binary people used charities for information, 45% of males reported using charities ($X^2(2, N = 248) = 6.778, p \leq .05$).

Table 10. Main sources of information

Variable	Autistic participants (all)		Supporters		Autistic participants with demographic data	
	N	%	N	%	N	%
Numbers are based upon those who responded to each question with non-responders excluded						
Where do you look for information or help/ for those you support?	360		257		258	
Social media**	168	47%	95	37%	124	48%
Friends**	45	13%	57	22%	36	14%
Professional peers	n/a	n/a	87	34%	n/a	n/a
Other autistic people	157	44%	n/a	n/a	121	47%
Family	70	19%	53	21%	45	17%
Social Services**/**	49	14%	54	21%	38	15%
Health Services**/*	155	43%	144	56%	117	45%
Internet search*	271	75%	178	69%	201	78%
Charities**/**	101	28%	109	42%	77	30%

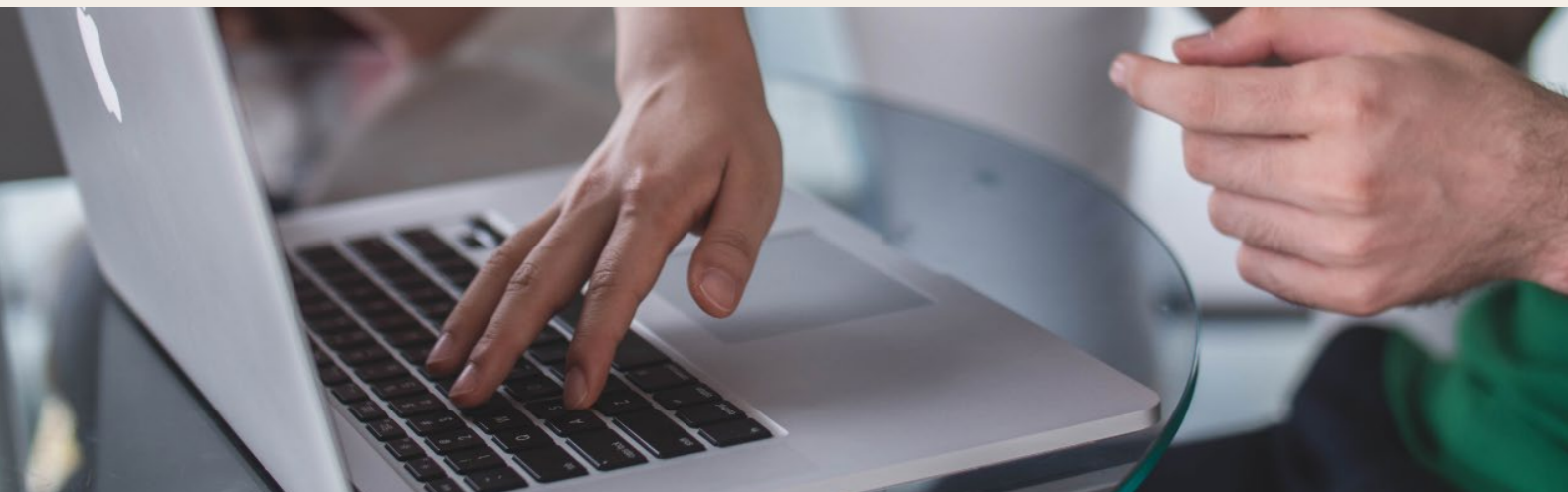
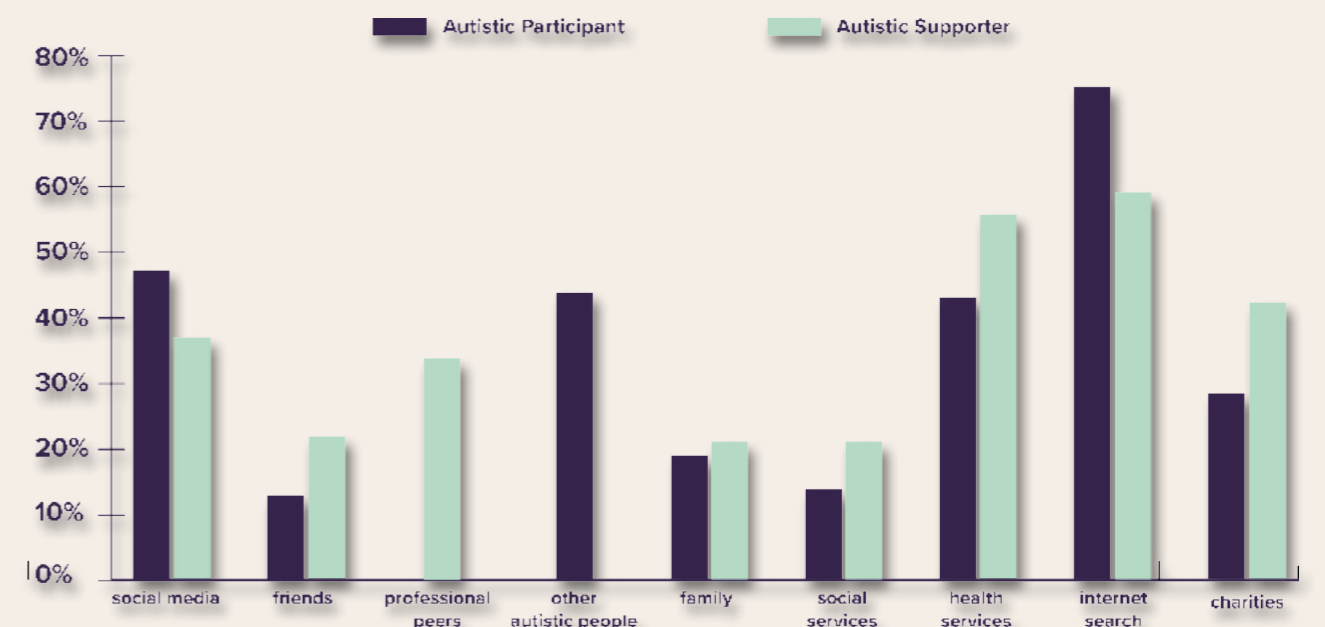
*Difference between autistic participants and supporters significant at .1 level, 2-tailed chi squared (all)

**Difference between autistic participants and supporters significant at .05 level, 2-tailed chi squared (all)

*Difference between autistic participants and supporters significant at .1 level, 2-tailed chi squared (w/ demographics)

**Difference between autistic participants and supporters significant at .05 level, 2-tailed chi squared (w/ demographics)

Figure 10. Main sources of information for autistic people and their supporters



Discussion

This section aims to review the findings of the survey and put them in context of the overall research. The clear message is autistic people's needs are not being met. Accessing support is difficult, with experiences varying depending on age and employment status.

This study confirms other reports and anecdotal information that the needs of autistic people are not being met, with few receiving the professional support they need and few accessing the public services that should have been put in place to support them. But it goes further in highlighting specifically what those needs are and the problems with accessing professional support, illustrating that these can vary depending on the age of the person and their employment status.

What did we find out in terms of priorities and needs?

An overwhelming finding with respect to life priorities was the importance of feeling safe over the other three options of feeling confident, respected, or independent. Nearly 60% of people ranked this as their number one priority, and three-quarters of people had it as one of their top 2 priorities.

The concept of 'feeling safe' is open to interpretation but most definitions utilise terms such as 'self-assured', 'feeling secure and protected', and 'free from harm both emotionally and physically' no matter the environment or situation.

Unpicking exactly what people were interpreting as 'feeling safe' would have been an interesting question to explore qualitatively; unfortunately, one of the limitations of the study was that all questions were closed.

This finding is also linked to the question related to needs, where 66% of autistic people reported that managing overwhelm is one of the top four areas of life they need help with, along with managing health (66%), managing emotions (48%) and looking after themselves (48%).

Were they getting help for these?

Similar to a survey conducted a few years ago (Camm-Crosbie et al., 2019), our study showed that more than half of people had not received any professional support for their self-identified needs. Furthermore, nearly all those surveyed who had not received support reported that the process was too hard, they lacked knowledge on what was available and how to access it, and that a key barrier was that it was complicated. Interestingly, nearly a third of autistic people thought that they would not be eligible.

This perception around eligibility did not seem to be related to whether someone was clinically diagnosed or not. Only 27% of autistic participants said they had received support for the needs that they had identified, and most also found the process hard, noting that it was complicated, overwhelming, and took too long. In terms of the types of services people had accessed, NHS mental health services was mentioned most often (31%), followed by mental health crisis services (15%).

The other services, which included social services, employment support, financial support, and DSA, had each been accessed by fewer than 14%. The majority of autistic respondents had accessed just 1 or 2 services.

What does this mean for autistic people?

A recent study highlighted the negative impacts of not receiving adequate support on the well-being of autistic people, being associated with feelings of disempowerment, perceived burdensomeness on family and friends, and social exclusion and isolation (Camm-Crosbie et al., 2019). Building on evidence from previous work, it was suggested that the absence of, or inappropriate, support may itself be a risk factor for increased rates of suicide: 71% of autistic adults were noted to score above the psychiatric cut off for suicide risk (Cassidy et al., 2018).

More recent analysis by the same author suggests elevated autistic traits are significantly over-represented in those who die by suicide (Cassidy et al., 2022).

The qualitative data from the Camm-Crosbie study reinforces some of the findings of this current study, where many people found the process of asking for support lacked transparency and felt daunting and complex.

On the other hand, those that do receive adequate support can have their lives transformed, with employment and education opportunities opening up. This suggests that, if support is done properly, poor quality of life and premature death by suicide are potentially avoidable (Camm-Crosbie et al., 2019).

In our study, the fact that 75% of autistic people aged 18-24 years put feeling safe as their top priority should be a major concern.

What could be done to improve the situation?

Previous studies have pointed to the need to improve the knowledge of those working in mental health settings around what it means to be autistic (Raja, 2014) and to establish specific mental health pathways for autistic people (Crane et al., 2018).

The findings of this current study suggest the process of accessing support needs to be made more transparent and less complex. Surprisingly, having a diagnosis did not seem to improve people's knowledge on what is available or how to access it. Half of those who had not received support didn't know what was available or didn't know how to access it, and a third thought they were not eligible. Access to accurate information needs to be improved and our study provided some insights as to where autistic people and their supporters go to get advice.

Understanding where autistic people are getting advice from could help providers target information more appropriately.

Most people rely on the internet, though charities and health services are important sources of information for supporters - as are social media and other autistic people for autistic respondents.

Safety - physical and emotional - came across as the most overwhelming concern for autistic people.

Less than a third of people are getting the support they need and most find the process of getting support complex and overwhelming.

The lack of adequate support is a risk factor in escalating the negative outcomes for autistic people.

This supports other research that found autistic people prefer interacting with other autistic people, and experience close social affiliation with them (Crompton et al., 2020; Morrison et al., 2020).

Did the age of the survey participant affect the findings?

It is only recently that surveys and research are considering older autistic people as a distinct group whose experience of being autistic may differ from younger people. A study in **The Lancet** highlighted the substantial diagnostic gap in adults compared to children

and young people in England, with an estimated 9 in 10 autistic adults aged 50 years and over being undiagnosed (O’Nions et al., 2023).

Many autistic adults could have missed out on a diagnosis as children when less was known about autism, and would have reached adulthood without a diagnosis despite significant challenges in their daily lives, (Lai and Baron-Cohen, 2015).

Our study highlighted that although rates of clinical diagnosis were similar across age groups, older people experienced longer waiting times, with 43% of those aged 45 years and over waiting for more than 2 years.

Simplifying processes, sharing information using appropriate channels and increasing transparency are all within the gift of providers and could have a significant impact on improving accessibility of services to autistic people.

If the current growth in NHS waiting lists persists, over 236,000 people will wait for autism assessments by September 2024

(<https://digital.nhs.uk/data-and-information/publications/statistical/autism-statistics>)

This age group also experienced the lowest levels of support, only a fifth had received any professional support for their needs and half had never accessed support services in their lifetime.

The priorities of autistic people also changed with age, younger people prioritising socialising and living independently more than older people, who instead put greater emphasis on managing health.

The age of an autistic person is an important determinant not only of their experience of support but also of their needs, and this should be considered in both research activities and service provision.

What other demographics were shown to have an impact on the responses provided?

There has been a great deal of discussion recently around females being mis- and under-diagnosed and the implications for the support (or lack thereof) they have received and the impact on their wellbeing as a result (Atherton et al., 2021; Bargiela et al., 2016).

A recent study in Canada analysed data from over 400,000 people (of which nearly 75,000 were autistic), found that autistic females had an 83% increased risk of self-harm compared with non-autistic individuals, and that this was 47% for autistic males (Lai et al., 2023). Most of the respondents to our survey were female (67%), which is a common trend for online surveys (Wu et al., 2022).

We did not find marked differences between males and females, possibly due to the small numbers of males participating (only 18% of those responding, 47 autistic men). We also had 30 autistic people who identified as non-binary, who tended to report higher levels of access to support than the other respondents.

The survey also asked about the respondents’ employment status, and although there were associations between age and employment which may have been driving some of the differences observed, employed people tended to focus more on feeling confident as a life priority and managing emotions than those who were unem-

ployed.

Of the 73 people who noted they were unemployed, 84% stated they were unable to work. It would have been interesting to probe into why this is the case and whether better support would change this situation. Although employment may not be right for all neurodivergent people, a study by NAS (2016) indicated that most autistic people wanted to be in employment; 77% who are currently unemployed wanted to work, and 4 in 10 of those working part-time wanted to work more hours. Half of those surveyed identified the biggest factors they needed to help them into work as support, understanding, or acceptance.

We also asked the respondents about their ethnicity, with most identifying as white. There is evidence of ethnic disparities in the diagnosis of autism, with BAME children being diagnosed later and at a lower rate when compared to white children (Roman-Urrestarazu et al., 2021), possibly as a result of lower awareness in these communities.

A persons background, identity and personal circumstances are important considerations in understanding needs and experience. Researchers should aim to look at ways of capturing this information and gathering insights across these diverse demographics.

Conclusions

The data is concerning, demonstrating that a significant number of people are unable to access support for their needs. A better understanding of the difficulties in accessing support and more investment in appropriate support is urgently needed.

A significant proportion of people who need help are not receiving it. Based on the feedback from this survey, a lot could be done to improve this by providing better information on what support is available, how to access it, and making the process less complicated and overwhelming.

The fact that most autistic people remain concerned about their safety, overwhelm and their health is a shameful reflection on how public services are failing to provide accessible and appropriate support to fulfil their needs. As we look for solutions to better support autistic people, it is important to capture demographics and other contextual information as aspects of an individual, such as age and employment status seem to have a profound impact on needs and experience with support. Other personal attributes such as ethnicity and socioeconomic status will likely be important variables to consider in future research.

References

Atherton, G., Edisbury, E., Piovesan, A., & Cross, L. (2021). Autism through the ages: A mixed methods approach to understanding how age and age of diagnosis affect quality of life. *Journal of Autism and Developmental Disorders*, 1-16.

Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype. *Journal of autism and developmental disorders*, 46, 3281-3294.

Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism*, 23(6), 1431-1441.

Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults. *Molecular Autism*, 9, 1-14.

Cassidy, S., Au-Yeung, S., Robertson, A., Cogger-Ward, H., Richards, G., Allison, C., ... & Baron-Cohen, S. (2022). Autism and autistic traits in those who died by suicide in England. *The British Journal of Psychiatry*, 221(5), 683-691.

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, 20(2), 153-162.

Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., & Hill, E. L. (2018). Autism diagnosis in the United Kingdom: Perspectives of autistic adults, parents and professionals. *Journal of autism and developmental disorders*, 48, 3761-3772.

Crompton, C. J., Ropar, D., Evans-Williams, C. V., Flynn, E. G., & Fletcher-Watson, S. (2020). Autistic peer-to-peer information transfer is highly effective. *Autism*, 24(7), 1704-1712.

Jones, L., Goddard, L., Hill, E. L., Henry, L. A., & Crane, L. (2014). Experiences of receiving a diagnosis of autism spectrum disorder: A survey of adults in the United Kingdom. *Journal of autism and developmental disorders*, 44, 3033-3044.

Lai, M. C., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry*, 2(11), 1013-1027.

Lai, M. C., Saunders, N. R., Huang, A., Artani, A., Wilton, A. S., Zaheer, J., ... & Lunskey, Y. (2023). Self-harm events and suicide deaths among autistic individuals in Ontario, Canada. *JAMA network open*, 6(8), e2327415-e2327415.

Morrison, K. E., DeBrabander, K. M., Jones, D. R., Faso, D. J., Ackerman, R. A., & Sasson, N. J. (2020). Outcomes of real-world social interaction for autistic adults paired with autistic compared to typically developing partners. *Autism*, 24(5), 1067-1080.

National Autistic Society (NAS) (2016). I'm not unemployable, I'm autistic. The autism employment gap. Accessed 1st November

NHS (2023). Autism statistics, July 2022 to July 2023. <https://digital.nhs.uk/data-and-information/publications/statistical/autism-statistics/july-2022-to-june-2023#highlights>

O’Nions, E., Petersen, I., Buckman, J. E., Charlton, R., Cooper, C., Corbett, A., ... & Stott, J. (2023). Autism in England: assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data. *The Lancet Regional Health–Europe*, 29.

Raja, M. (2014). Suicide risk in adults with Asperger’s syndrome. *The Lancet Psychiatry*, 1(2), 99-101.

Rogers, C. L., Goddard, L., Hill, E. L., Henry, L. A., & Crane, L. (2016). Experiences of diagnosing autism spectrum disorder: A survey of professionals in the United Kingdom. *Autism*, 20(7), 820-831.

Roman-Urrestarazu, A., van Kessel, R., Allison, C., Matthews, F. E., Brayne, C., & Baron-Cohen, S. (2021). Association of race/ethnicity and social disadvantage with autism prevalence in 7 million school children in England. *JAMA pediatrics*, 175(6), e210054-e210054.

Wu, M. J., Zhao, K., & Fils-Aime, F. (2022). Response rates of online surveys in published research: A meta-analysis. *Computers in Human Behavior Reports*, 7, 100206.

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