



The impact of the mental health inequalities experienced by autistic adults

Research paper - December 2023

brain in hand

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The impact of the mental health inequalities experienced by autistic adults

In October 2023, Brain in Hand (a health tech company that supports neurodivergent people and people managing anxiety-related health conditions) conducted an online survey to gather insights from the autistic community on mental health, anxiety, waiting lists, and support offered.

It was shared on social media channels over a four-day period and 575 responses were received.

The survey highlights the impact of the mental health inequalities experienced by autistic adults across the UK. It demonstrates the changing diagnosis landscape, the disparities in health care support, and the negative impact on autistic people's lives. We hope that these powerful statistics on the level of mental health difficulties and associated risks of harm can help lobby for more effective support, especially when combined with the data that shows positive change is possible if appropriate support is provided.

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Data & referencing: Research Team, Brain in Hand 2023

Guyatt, H., Ward, C., Fielden, T., Brain in Hand Ltd, (2023 December) The impact of the mental health inequalities experienced by autistic adults

Key take-aways

This section provides key take-aways from that survey, which demonstrated the changing diagnosis landscape, the disparities in health care support, and the negative impact on autistic people's lives.

The diagnosis landscape is changing.

23% of those with a clinical diagnosis had paid for this privately.

11% of people were not looking to get an autism diagnosis (this rose to 21% in those aged 55 and over).

There are disparities between NHS and private health care support.

Those with a **NHS clinical diagnosis** had to wait for longer than those who got a private diagnosis, with only **9%** getting their **NHS diagnosis within 13 weeks** compared to **28%** of those that **paid privately**.

Those with a private diagnosis were more likely to be offered support that met their needs (**41%** of those offered, or 11 out of 27) compared to those offered support following NHS diagnosis (**18%** or 20 out of 113) - **this was significant**.

Most autistic people are not receiving the support they need.

70% said they had **never been offered professional support**.

Only **6%** had received support that **met their needs**.

Autistic people's mental health is on the decline.

58% of people say their **mental health had worsened** over the past year.

62% of people say their **anxiety had worsened**, and only **1.4%** stated they did not have anxiety.

This is negatively impacting on autistic people's lives.

93% of people said their mental health was impacting on life.

Of these, **28% had thoughts of self-harm (26% of all surveyed)** - this was highest in young people (40% of 18-24 year olds, 38% in all surveyed in that age group) compared to 12% of those 55 years and over (11% in all surveyed).

Of these, **46% felt isolated (43% of all surveyed)** but this was notably lower in those that had a private diagnosis – **32% (29% in all surveyed)** and those that had received professional support that met their needs – **30% (24% in all surveyed)**.

But positive change is possible with the right support.

Nearly half of people who received support that met their needs had their mental health increase.

38% of those who received professional support that met their needs had their anxiety decrease.



Impact statement

This section is a brief summary, in lay terms, of the current mental health inequalities experienced by autistic people that were found in this study. It states the purpose of this survey and how these findings will help support positive change in the future.

Why is this an important issue?

The increase in waiting times for assessment, combined with poor post-diagnosis support reported by the autistic community, is having a profound effect on their mental health. Effective lobbying for change requires evidence on the scale of the problem and the impact it is having on people's lives.

What was the purpose of this study?

To investigate the mental health of autistic people in the current climate of long NHS waiting times for diagnosis and reports that people are not getting the support they need.

What did the researchers do?

We conducted an online survey to gather insights from the autistic community on mental health, anxiety, waiting lists, and support offered. It was shared on social media channels over a four-day period.

What were the results of the study?

We received 575 responses from a range of age groups across the UK. Most people stated that they had not received any professional support and only a few who had received support said that it met their needs.

More than half of people reported that their mental health or anxiety had got worse over the past 12 months, with 93% stating that their mental health was impacting on life. Nearly half of these experiencing an impact reported feeling isolated and more than a quarter had thoughts of self-harm. This was most problematic for young people, with 40% noting that one of the main ways their mental health was impacting on their life was through thoughts of self-harm.

There were indications, however, that if people received appropriate support, their mental health could be improved. The data also suggested that professional support received after a private diagnosis was both more appropriate and led to fewer people feeling isolated than support post NHS diagnosis. Of the 65% of people who had a diagnosis, nearly a quarter had paid privately for this.

What do these findings add to what was already known?

The findings support other research that highlights the lack of support being provided to autistic people. They also add to what is already known by providing some concerning statistics related to worsening mental health and anxiety, feelings of isolation, and thoughts of self-harm.

Importantly, these findings also suggest that positive change is possible if the right support is provided.

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 geographical location, but not in terms of gender, with few males responding to the survey.

We also did not ask about ethnicity. We also could not ask any follow-up questions about our participants' experiences because the survey was online.

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

Powerful statistics on the level of mental health difficulties and associated risks of harm can help lobby for more effective support, especially when combined with the data that shows positive change is possible if appropriate support is provided.

Structured abstract

The continued pressure on the NHS is widening the health inequality gap for autistic people to levels which are likely to result in concerning levels of poor mental health, lower quality of life, and premature death. The scale of the problem is unclear, and this study aimed to gather evidence on the extent to which autistic people are being underserved and the impact of this on their mental health.

Methods

This survey was promoted across social media channels and open to autistic adults over a four day period in October 2023. It covered their experience with diagnosis and professional support received, and asked about their mental health and how it was impacting on their lives.

Results

A total of 575 people responded to the survey. People continued to report long waiting times for a clinical diagnosis, with only 9% of those going through the NHS having their diagnosis within the NHS 13-week target window compared to 28% of those paying privately.

Those with a private diagnosis were also more likely to be offered support that met their needs (41% of the 27 offered support) than those offered support following a NHS diagnosis (18%).

Levels of support were generally poor, with 70% of respondents stating they had never been offered professional support and only 6% receiving support that met their needs. Mental health was reported to have worsened over the past year for 58% of people, and 93% stated their mental health was impacting on life.

Of those with negative impacts, 28% had thoughts of self-harm, and 46% felt isolated. Nearly half of those who had received support that met their needs had seen their mental health get better over the past year.

Conclusion

Autistic people are not receiving the support they need, and their mental health is on the decline, with concerning impacts on thoughts of self-harm and feelings of isolation. The data suggest that positive change is possible if the right support is provided, but currently, those going through the NHS are faring worse than those going for a private diagnosis.

Background

The aim of this study was to gain insights into how autistic people's mental health is changing and the impact it is having on their lives.

Despite the government's ambition to tackle the health inequalities being faced by autistic people (HM Government, 2021), the high numbers still waiting for an assessment (NHS, 2023) and reports of increased rates of self-harm and suicide (Blanchard et al, 2021) question whether enough investment is being made.

Last year, Brain in Hand (BiH) offered participation in a survey to autistic people and their supporters to gather insights into their needs and experience with support. The findings supported other research that suggests people are not getting the support they need with managing anxiety, overwhelm, and their health needs (Camm-Crosbie et al., 2019). People reported that accessing support was hard, and public services are failing autistic people, especially older adults who report the lowest levels of support (Guyatt et al., 2023).

The impact of this lack of support on the mental health of autistic people is likely to be huge. A recent analysis of data spanning over 30 years (1989-2019) suggests reductions in life expectancies for autistic adults of more than 6 years, with the authors concluding that these may be underestimates given the high rates of under-diagnosis (O'Nions et al., 2023). As diagnosis waiting times and access to support have probably at best stagnated, and more likely worsened, analysis of more recent data could indicate an even greater divide.

This study looks to build our understanding of what people are currently experiencing in terms of support and what impact this has had on their mental health over the past year.



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 over a four-day period in October 2023. The online survey was promoted across social media channels (including paid ads) and participants completed a short questionnaire on Microsoft Forms. There was no screening for selection into the study – it was open to anyone who had been diagnosed with autism or who thought they may be autistic.

Measures

The study used a bespoke questionnaire that was designed to capture the insights from the autistic community on mental health, anxiety, waiting lists, and support offered. Excluding demographic information (which covered age, gender, and geographical location), the survey consisted of 7 questions, all closed. These covered diagnosis status, time to diagnosis, professional support received, changes in mental health and anxiety over the past 12 months, and whether mental health was impacting on life and how. All questions were mandatory (with a 'prefer not to say' option for the gender demographic question).

Procedure

The social media platforms and paid ads shared a link to the survey, which participants were able to use to complete the questions.

The questionnaire took 5 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.

People responding to the survey or viewing the invitation to participate were able to leave feedback in the comments section of the social media channel. Some of this feedback is included in this paper as it provides relevant contextual and lived experience information to support the findings of the research.

Questionnaire design

The questionnaire was designed in a closed format; each question was multiple-choice, with the list of options tested to ensure they covered all possible responses an individual may want to make. The format of the questionnaire meant this was a quick survey to complete while yielding rich and insightful information.

Data analysis

Descriptive statistics were calculated using SPSS (IBM SPSS Statistics 29.0) and comparisons across sub-groups were tested using a chi-square test.

Results

This section presents the survey findings which explore sample demographics, diagnosis, professional support, mental health and anxiety over the past 12 months, and the impacts of mental health on life.

Sample demographics

A total of 575 people responded to the survey. We asked three demographic questions with drop-down menus (Which region are you located in; Please specify your age-group and Please specify your gender) at the end of the survey to better understand our sample and look for any differences in the findings by age and gender.

We got representation from across all the regions of the UK, and a few people who did not reside in the UK (1%). Most respondents were from the Midlands (18%), South East (16%), North West (13%), South West (12%) and North East and Yorkshire (12%).

We got good representation across all age groups. However, only 14 respondents were aged 65 or over; for the purposes of age-related analysis, we have here combined the 55-64 age group with the 65+ group.

Most of the respondents were female (66%), with only 19% respondents identifying as male and 12% as non-binary. We had a small proportion who chose the option for 'other' (9 people) or 'prefer not to say' (7 people).

Geographical representation

Non UK	1%
Midlands	18%
South East	16%
North West	13%
South West	12%
North East	12%
Yorkshire	12%
Other	16%



Diagnosis

We asked the question *'Which of the following best describes your situation?'*, providing 5 options related to diagnosis status for people to choose from (see Table 1).

A fifth were on the NHS waiting list and less than 3% were planning to go privately to get an assessment. Interestingly, 11% said they were not going to seek an assessment.

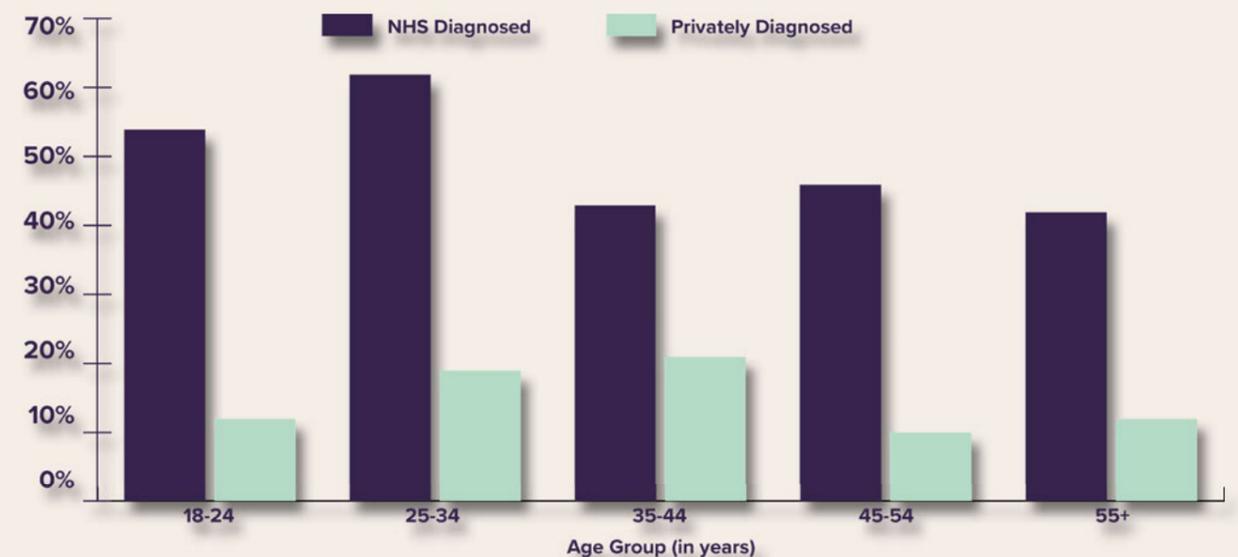
Two-thirds of people (65%) reported having a clinical diagnosis, though 23% of these had paid privately rather than going through the NHS.

Table 1 and Figure 1 illustrate the findings with respect to diagnosis status and changes by age.

Table 1. The relationship between diagnosis status and age.

Age group	18-24 (n=151)	25-34 (n=125)	35-44 (n=105)	45-54 (n=110)	55+ (n=84)	All ages (575)
I'm autistic, clinically diagnosed (NHS)	53.6% (81)	61.6% (77)	42.9% (45)	45.5% (50)	41.7% (35)	50.1% (288)
I'm autistic, clinically diagnosed (Paid privately)	11.9% (18)	19.2% (24)	21.0% (22)	10.0% (11)	11.9% (10)	14.8% (85)
I'm on the waiting list for an autism assessment (NHS)	23.2% (35)	12.0% (15)	24.8% (26)	24.5% (27)	23.8% (20)	21.4% (123)
I'm planning to pay privately for an autism assessment	3.3% (5)	2.4% (3)	1.9% (2)	3.6% (4)	1.2% (1)	2.6% (15)
I'm self-diagnosed autistic, not seeking an autism assessment	7.9% (12)	4.8% (6)	9.5% (10)	16.4% (18)	21.4% (18)	11.1% (64)

Figure 1. NHS and private clinical diagnosis by age



There were differences in diagnosis by age, with younger people more likely to have a clinical diagnosis either by NHS or privately paid, and older people more likely not to be seeking an autism assessment. (see Figure 1)

For example, in those aged 55 and over (84 people), only 42% (35) had a NHS clinical diagnosis, 12% (10) had paid privately, and 21% (18 people) were not seeking an autism assessment.

Slightly fewer females (63%, 239 out of 382) and non-binary people 64%, (45 out of 70) were

clinically diagnosed than men 72%, (77 out of 107). Participants were asked to indicate how long they had to wait or have been waiting to get an autism assessment from a list of < 3 months, 3 months to 1 year, 1 to 2 years, 2 to 3 years, or more than 3 years.

The findings in relation to diagnosis and waiting time is shown in Table 2, with Figure 2 illustrating the difference in relation to whether a person received a diagnosis through the NHS or privately.

Those assessed via the NHS had to wait for much longer than those who went to private providers with only 9% of people getting a NHS assessment within the 13 week target and 60% having to wait for more than a year (Table 2).

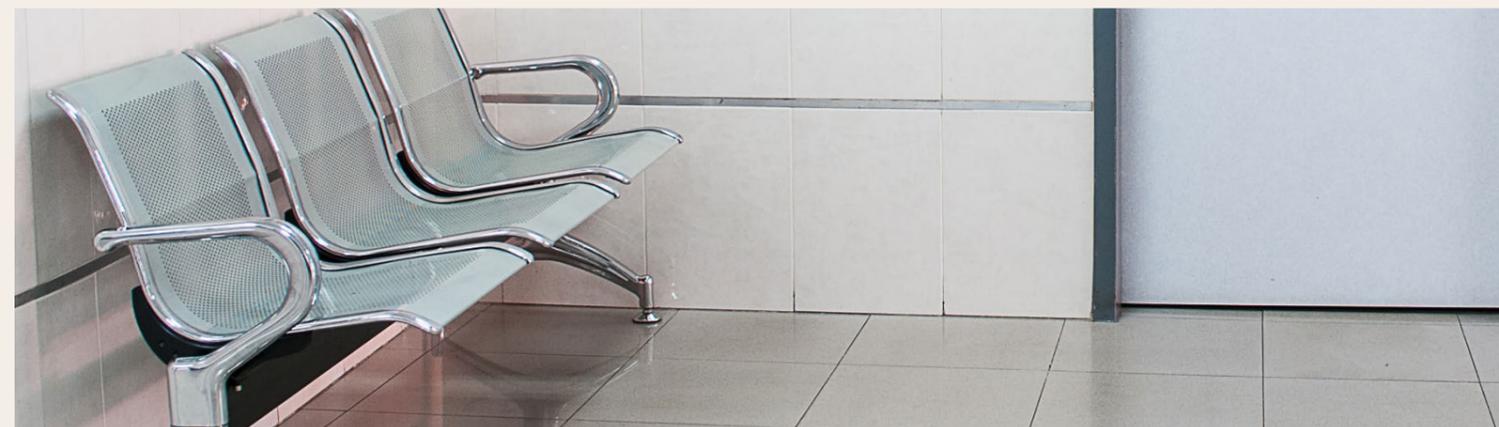
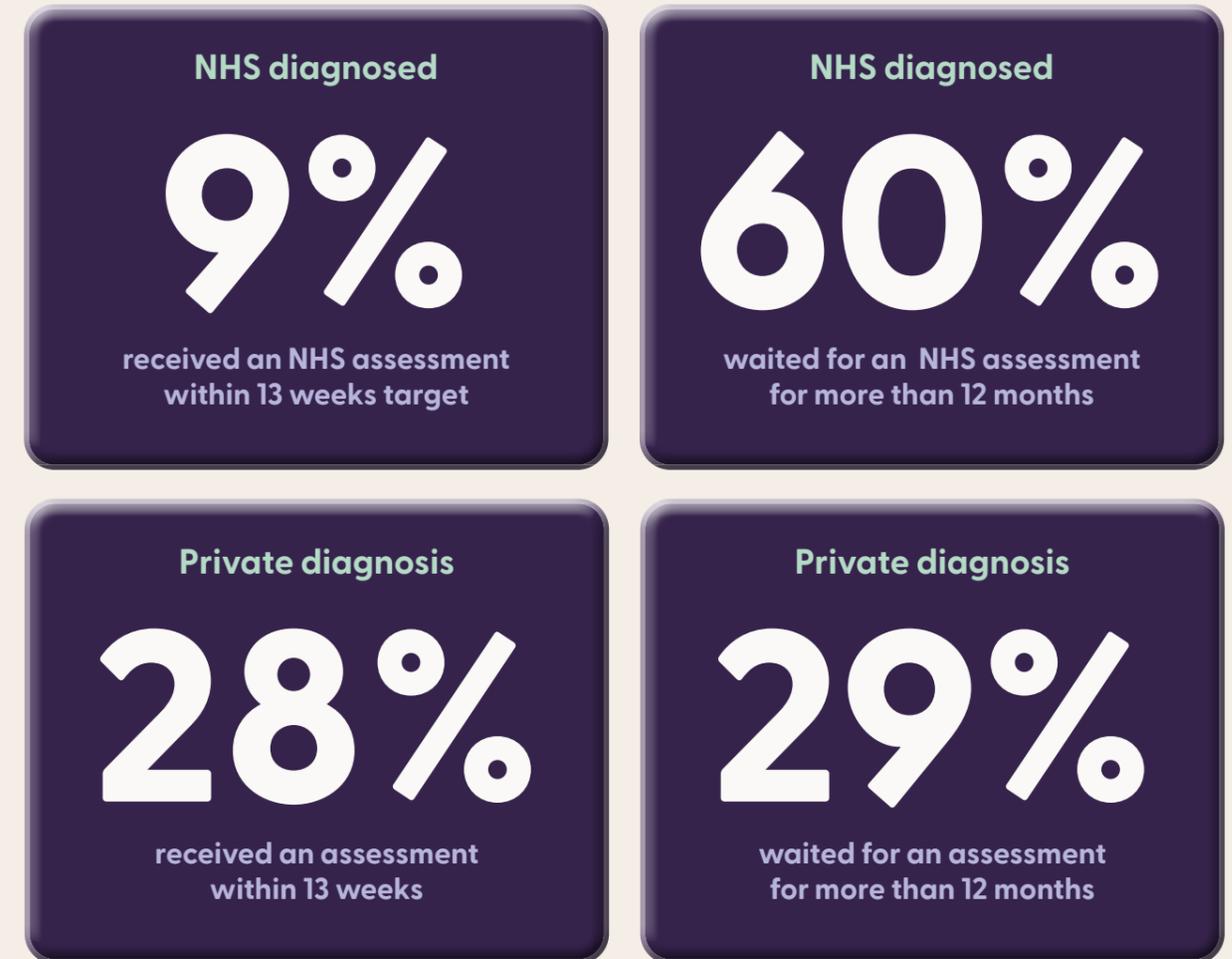
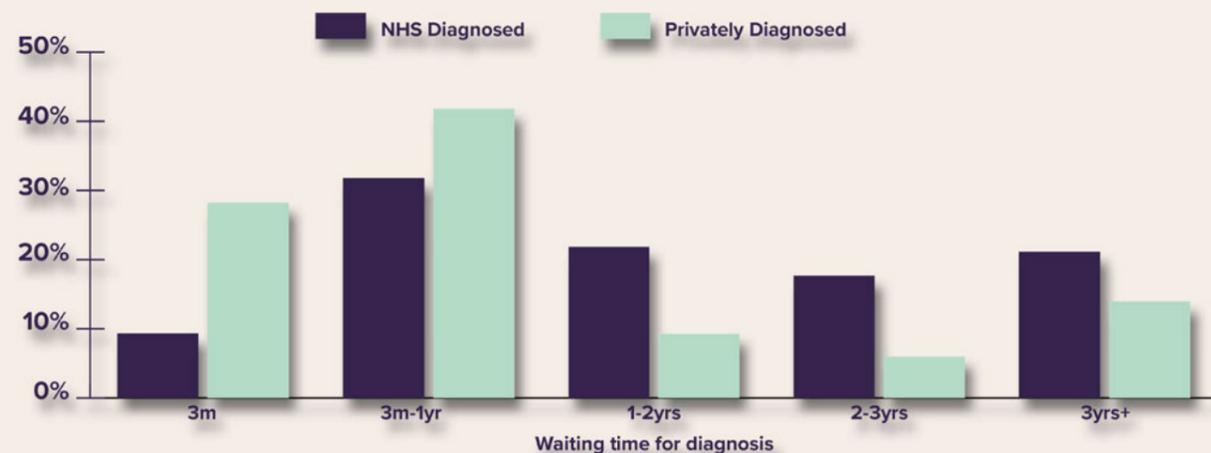
By comparison, of those diagnosed privately, 28% were assessed within 13 weeks and 19% waited for more than a year. These differences were significant at the 5% level ($X^2(1, N = 373) = 22.00, p < 0.00001$ for comparisons within 13 week target and $X^2(1, N = 373) = 24.77, p < 0.00001$ for comparisons of waiting at least a year.

There were no obvious trends in waiting times by age or gender.

Table 2. The differences in waiting times by private and NHS diagnosis

Time taken to get diagnosis						
Diagnosis	< 3 m	3m-1yr	1-2 yr	2-3 yr	3+ yrs	Total
NHS diagnosed	8.7% (25)	31.3% (90)	21.5% (62)	17% (49)	21.5% (62)	288
Privately diagnosed	28.2% (24)	42.4% (36)	9.4% (8)	5.9% (5)	14.1% (12)	85
All those diagnosed (NHS and private)	13.1% (49)	33.8% (126)	18.8% (70)	14.5% (54)	19.8% (74)	373
On the NHS waiting list	13.0% (16)	24.4% (30)	28.5% (35)	20.3% (25)	13.8% (17)	123
On waiting list or diagnosed	13.1% (65)	31.5% (156)	21.2% (105)	15.9% (79)	18.3% (91)	496

Figure 2. NHS and private clinical diagnosis by waiting time for a diagnosis



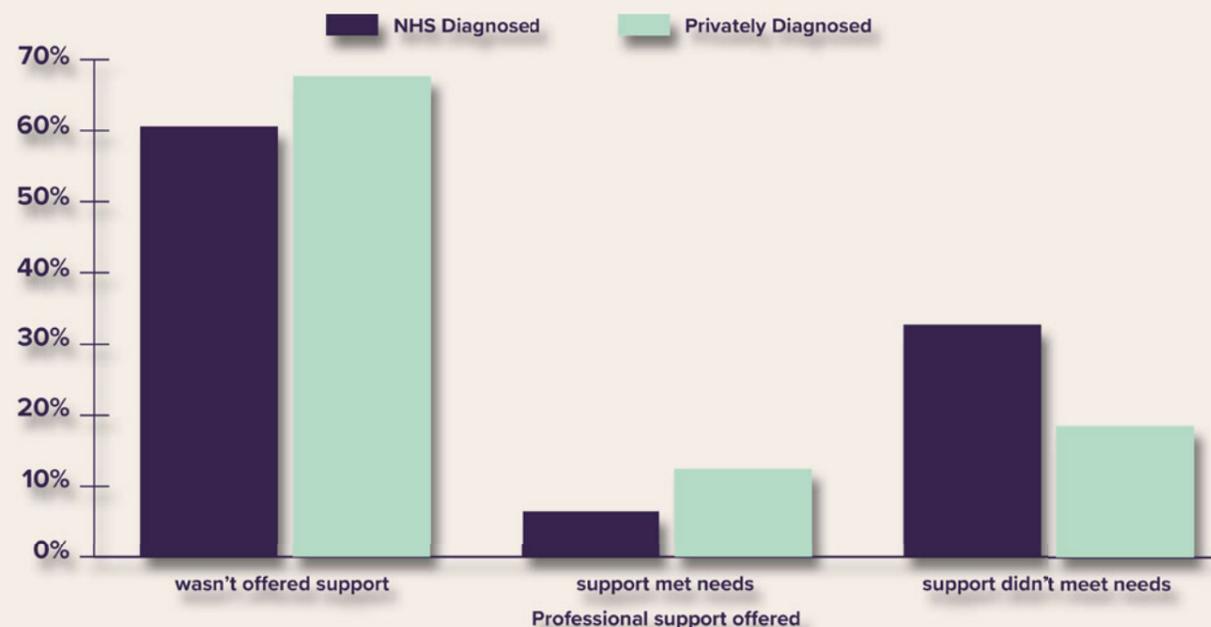
Professional support

Survey participants were asked if they had been offered professional support. More than two thirds of respondents (70%) said they had never been offered professional support. Furthermore, only 20% of those that were offered support received support that met their needs - **only 6%** of all respondents. (see Table 3).

Table 3. The relationship between diagnosis status and professional support

Have you been offered professional support?			
Diagnosis status	No, I wasn't offered support	Yes, and it met my needs	Yes, but it didn't meet my needs
I'm autistic, clinically diagnosed (NHS)	60.8% (175)	6.9% (20)	32.3% (93)
I'm autistic, clinically diagnosed (Paid privately)	68.2% (58)	12.9% (11)	18.8% (16)
I'm on the waiting list for an autism assessment (NHS)	85.4% (105)	2.4% (3)	12.2% (15)
I'm planning to pay privately for an autism assessment	80.0% (12)	0.0% (0)	20.0% (3)
I'm self-diagnosed autistic, not seeking an autism assessment	84.4% (54)	0.0% (0)	15.6% (10)
All responses	70.3% (404)	5.9% (34)	23.8% (137)

Figure 3. NHS and private clinical diagnosis by professional support offered



A person's diagnosis status had an impact both on their likelihood of receiving any support and on whether it met their needs. As expected, people with a clinical diagnosis were more likely to have been offered support – but this percentage was still low at just 38%. Interestingly, although slightly fewer were offered support after a private diagnosis – 32% – they were more likely to be offered support that met their needs (see Figure 3).

41% (11/27) of those offered support with a private diagnosis said it met their needs compared to only 18% (20/113) offered support with a NHS diagnosis. This difference was significant at the 5% level ($X^2(1, N = 140) = 6.711, p = 0.0096$). Older people and females were less likely to be offered professional support, but support that met needs was low and similar across all sub-groups: 75% of females (285 out of 382) and 81% of people aged 55 years and over (68/84) had not been offered support.

Mental health over the past 12 months

Participants were asked specifically whether their mental health (psychological, emotional and social wellbeing) had got better, worse, or stayed

the same over the past 12 months. 58% of people said their mental health had worsened, 29% stayed the same, and 13% improved (see Table 4).

People on NHS waiting lists were more likely to have worsening mental health (68%, 84 out of 123) than those with a clinical diagnosis (NHS or private) (54%, 203 out of 373). This difference was significant at the 5% level ($X^2(1, N = 496) = 7.297, p = 0.0069$).

Younger people were more likely to have worsening mental health than older age groups. In those aged 18-24 years, 64% (96 out of 151) reported worsening mental health compared to 50% (42 out of 84) in those aged 55 years and older. These differences were significant at the 5% level ($X^2(1, N = 235) = 4.104, p = 0.0428$).

There was no significant difference by gender, though people who identified as non-binary had slightly higher levels of worsening mental health (61%, 43 out of 70) than people identifying as female (56%, 214 out of 382) or male (56%, 60 out of 107).

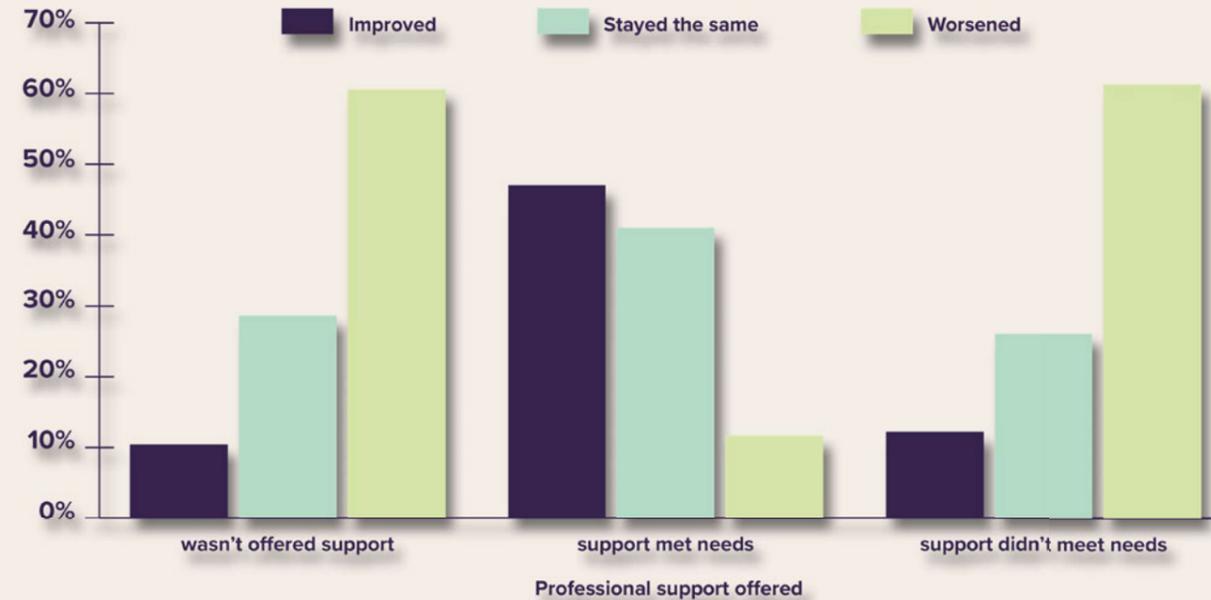
Table 4. The relationship between mental health and professional support

Have you been offered professional support?				
In the last 12 months, has your mental health... (psychological, emotional and social wellbeing)	No, I wasn't offered support	Yes, and it met my needs	Yes, but it didn't meet my needs	All responses
Improved	10.4% (42)	47.1% (16)	12.4% (17)	13.0% (75)
Stayed the same	29.2% (118)	41.2% (14)	26.3% (36)	29.2% (168)
Worsened	60.4% (244)	11.8% (4)	61.3% (84)	57.7% (332)

Nearly half of people that received support that met their needs had their mental health improve in the past 12 months (47%, 16 out of 34). This suggests that positive change is possible when people receive appropriate support. In contrast,

only a small percentage saw their mental health improve if they had not been offered support (10%, 42 out of 404) or had received support that did not meet their needs (12%, 17 out of 137) (see Figure 4).

Figure 4. Mental health over the past 12 months in relation to professional support offered



Anxiety over the past 12 months

Survey participants were asked specifically whether their anxiety (feeling of unease, worry, or fear) had got better, worse, or stayed the same over the past 12 months.

62% of people said their anxiety had worsened, 28% stayed the same, and 8% improved (see Table 5). Only 1.4% stated they did not have anxiety.

People on NHS waiting list were more likely to have worsening mental health (73%, 90 out of 123) than those with a clinical diagnosis (NHS or private) (58%, 216 out of 373). These differences were significant at the 5% level ($X^2(1, N = 496) = 9.117, p = 0.0025$).

Younger people were more likely to have worsening anxiety than older age groups. In those aged 18-24 years, 68% (102 out of 151) reported worsening mental health compared to 60% (50 out of 84) in those aged 55 years and older. This was not significant at the 5% level.

There was no significant difference by gender, though people who identified as non-binary had slightly higher levels of worsening anxiety (69%, 48 out of 70) than people identifying as female (62%, 235 out of 382) or male (60%, 64 out of 107).



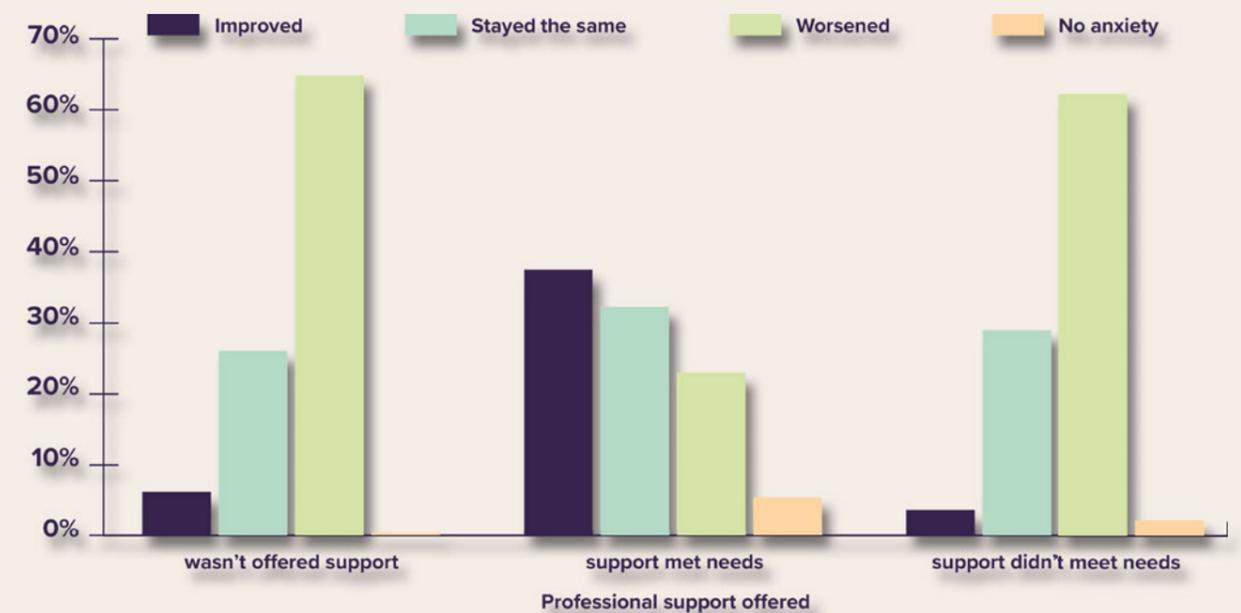
Table 5. The relationship between anxiety and professional support

Have you been offered professional support?				
In the last 12 months, has your anxiety... (feeling of unease, worry or fear)	No, I wasn't offered support	Yes, and it met my needs	Yes, but it didn't meet my needs	All responses
Improved	6.9% (28)	38.2% (13)	4.4% (6)	8.2% (47)
Stayed the same	27.2% (110)	32.4% (11)	29.2% (40)	28% (161)
Worsened	65.3% (264)	23.5% (8)	63.5% (87)	62.4% (359)
I don't have anxiety	0.5% (2)	5.9% (2)	2.9% (4)	1.4% (8)

A significant percentage of people that received support that met their needs had their anxiety improve in the past 12 months (38%, 13 out of 34).

This suggests that positive change is possible when people receive appropriate support. In contrast, only a small percentage saw their anxiety improve if they had not been offered support (7%, 28 out of 404) or had support that did not meet their needs (4%, 6 out of 137) (see Figure 5).

Figure 5. Anxiety over the past 12 months in relation to professional support offered



A significant percentage of people that received support that met their needs had their anxiety improve.

Mental health negatively impacting life

Survey participants were asked ‘Has your mental health negatively impacted your life in the past 12 months?’ and an overwhelming 93% responded that it had.

A follow up question to this was ‘How has your mental health **MOST** impacted your life in the past 12 months?’ The respondent was permitted to select a maximum of 2 choices from the

following list: I am struggling with work or studies; I feel unable to pursue my interests and passions; I have thoughts of self-harm; I feel isolated; or in another way.

The findings are summarised in **Table 6** and **Figure 6** in relation to how people’s mental health has changed over the past year.

Table 6. Mental health and its impact on people’s lives

How has your mental health MOST impacted your life in the past 12 months?						
Mental health changes over past 12 months	Mental health is affecting me	I have thoughts of self-harm	I feel isolated	I feel unable to pursue my interests and passions	I struggle with work or studies	Struggling in another way
Improved	77% (58/75)	25.9% (15)	37.9% (22)	44.8% (26)	53.4% (31)	13.8% (8)
Stayed the same	88% (147/168)	15.6% (23)	42.9% (63)	42.2% (62)	49.0% (72)	21.8% (32)
Worsened	98% (327/332)	34.6% (113)	49.2% (161)	34.3% (112)	53.2% (174)	14.4% (47)
All (affected)	100% (532/532)	28.4% (151)	46.2% (246)	37.6% (200)	52.1% (277)	16.4% (87)
All (surveyed)	93% (532/575)	26.2% (151/575)	42.8% (246/575)	34.8% (200/575)	48.2% (277/575)	15.1% (87/575)

Mental health impact

28%

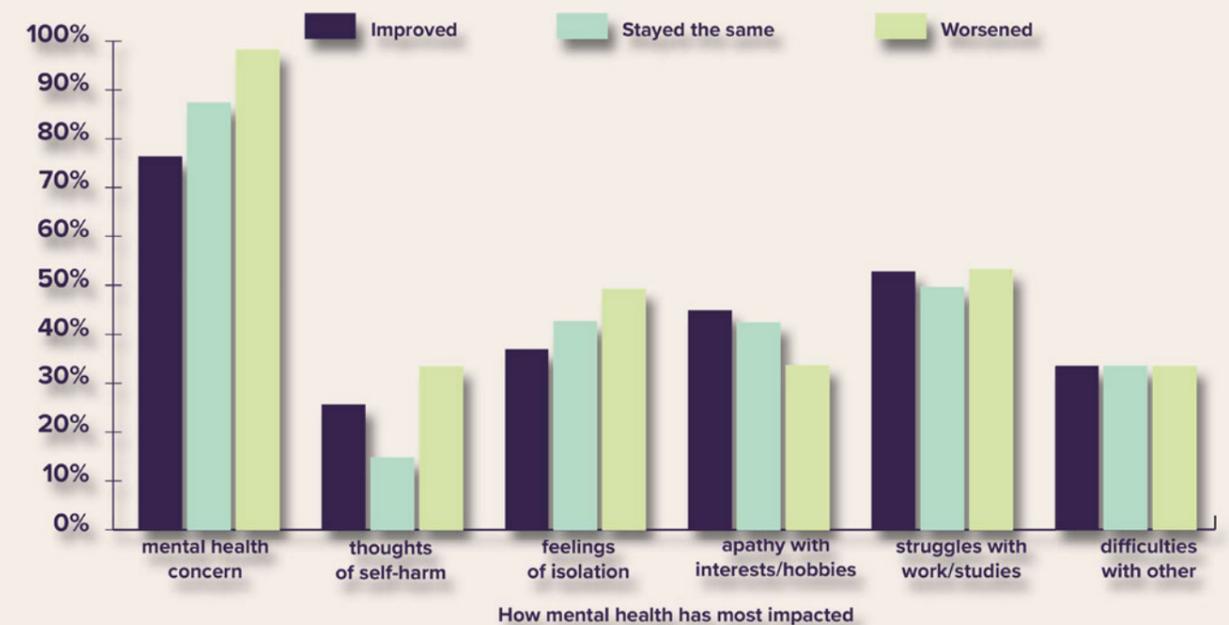
had thoughts of self-harm

Mental health impact

46%

felt isolated

Figure 6. How mental health has impacted life in relation to changes in mental health over past 12 months



Of those having their mental health impact their lives, 28% had thoughts of self-harm (26% of all surveyed).

This was highest in young people (40%, or 57/144, of 18-24-year-olds who said mental health had impacted their lives, and 38%, or 57/151, of all 18-24-year-old respondents) compared to 12% (9 out of 77) of those 55 years and over (11% in all surveyed, 9 out of 84). It was also highest in non-binary people (38%, 25 out of 66) compared to females (27%, 97 out of 353) and males (27%, 26 out of 97). Thoughts of self-harm were lowest in those not seeking an assessment (19%, 11 out of 57, 17% in all surveyed) compared to other groups, noting that older respondents were less likely to be seeking an assessment.

Of those having their mental health impact their lives, 46% felt isolated (43% of all surveyed). This was notably lower in those that had a private diagnosis at 32% (25 out of 78) (29%, 25 out of 85, in all surveyed) and those that had received professional support that met their needs at 30% (8 out of 27) (24%, 8 out of 34, in all surveyed).

A high percentage of people planning to pay for a private diagnosis reported feeling isolated (57%, 8 out of 14 for those reporting mental health was impacting on their lives) (53% for all surveyed, 8 out of 15).

Of those having their mental health impact their lives, 38% felt unable to pursue their interests and passions (35% of all surveyed) and 52% said they were struggling with work or studies (48% of all surveyed). The youngest age group (18-24 years) were more likely to mention struggles with work or studies (59%, 85 out of 144), whereas the oldest age group (55 and over) focused more on being unable to pursue interest and passions (48%, 37 out of 77).

Of those who said their mental health or anxiety had worsened, 98% stated their mental health impacted their lives, but 77% of those that said it had improved were also experiencing a negative impact of mental health on their lives. For example, of the 75 people reporting an improvement in their mental health, 15 (20%) had thoughts of self-harm and 22 (29%) felt isolated.

52%

Mental health impact

felt they were struggling with work or studies (48% of all surveyed).

Narratives & feedback

People provided feedback about the survey or on their experience with support in the comments boxes on the social media platforms where the survey was shared. Several key themes emerged.

Firstly the lack of access to support was a key issue, with people providing examples of how they had found support difficult to obtain. There was a particular focus on the difficulties for adults.

The feedback also provided some insights into why this was a problem: people were often seen as 'too high-functioning' to need support, exhibited behaviours that did not align with preconceived notions of what autistic people look like, or found it was simply assumed that **if you make it into adulthood you must be okay**.

"There is no support for adults. The NHS seems to think if you've made it to adulthood you're fine."

"Happy 18th your child is dropped by CAMHS and you're expected to help them cope with adulthood. There is no transition. Re arranging medication becomes a nightmare. No how are they doing nothing. Just a wave as you are pushed out of the proverbial door."

"As a 'high functioning' adult there is zero support. I struggle with many things especially work and running a household. I am not entitled to pip but I have to pay for cleaners and every work email I send has to be checked"

"People have no chance of getting support for autism. It is either outdated stereotyping from NHS professionals that say things like "you

cannot be autistic because you can talk" or "you can make eye contact". The other option is you can choose to pay thousands for a private assessment for it to be rejected by the NHS. There are so many barriers in being heard and it affects accessing health care because you're not understood and you're told you'll just need anti-depressants. It's all that's on offer"

Secondly, as alluded to above, examples were provided of inappropriate treatment such as anti-depressants and CBT, which may not work for everyone, and can in fact sometimes make things worse.

"My daughter was diagnosed age 21. It took us 17 years to get anyone to listen to us as a family no support from anywhere before diagnosis. Had a couple of years of going to a local adult learning disability clinic, then once diagnosed, was discharged same day"

"I've not got an official diagnosis, and I'm not on a waiting list for an assessment because it's so hard to keep asking to be referred... So it's not that I don't want an assessment, it's that it's too hard to even get on the waiting list"

"Mental health services in NHS Lanarkshire are failing my son. Not appropriate for autism. Discharged from CPN service because he can't do CBT as it makes him worse. That is apparently all the CPN offer despite SIGN guidelines stating CBT should be adjusted for Autism! He has tried CBT in the past so he knows it's not for him."

And thirdly, a sense that autistic adults are being ignored by not only support systems but also researchers.

"Autistic people constantly get ignored, overlooked and talked over, despite the fact that we are the ones with direct lived experiences. It's fantastic to see an organisation that actually wants to listen to us"

"Autistic adults (and adhd adults) are pretty much invisible. No research, no support. If you think about it, we're actually in a huge majority as autistic people spend far more of their lives as adults than children. You would imagine we all magically vanished at adulthood from looking at research!!!"

There were also some suggestions on how the survey could be improved, with options for free text or a 'none of these' option as some people felt that they didn't always fit into the response options available or wanted to better explain their situation.

The most obvious case was when people were asked to describe their diagnosis/assessment situation, where people noted that for some they wanted a diagnosis but could not get on the NHS waiting list nor afford to go privately.

"An option on the first question that would be useful is one that says: 'am self diagnosed but have been refused a diagnosis at assessment'. Which is me. I put the bottom option which is the only self diagnosed one, but says not looking for an assessment. I'd love a proper second opinion, even a private one that I can't afford, because I know that I am inside the spectrum to a point where it seriously interferes with my life. Which is the diagnostic level. When I was told that when they said I didn't have autism, I said, 'If it didn't affect my life I would never have asked for an assessment.' Why would I for goodness sake?"

"I'm glad someone is asking these questions. I do feel that the form lacked one option...I've not got an official diagnosis, and I'm not on a waiting list for an assessment because it's so hard to keep asking to be referred. So it's not that I don't want an assessment, it's that it's too hard to even get on the waiting list"

There was also a suggestion to have a question clarifying when they were diagnosed. As diagnosis times have changed markedly to gain a good understanding of current waiting times it would be useful to filter or analyse by time since diagnosis.

"It might be helpful to have a question about when the respondent was diagnosed. I didn't have a long wait to be diagnosed but that was 20 years ago and a lot has changed."

"Autistic people constantly get ignored, overlooked and talked over, despite the fact that we are the ones with direct lived experiences. It's fantastic to see an organisation that actually wants to listen to us"

Discussion

This section aims to review the findings of the survey and put them in context of the overall research. Autistic adults are not getting the support they need, resulting in a significant decline in their mental health.

The main findings of this survey are that autistic adults are not getting the support they need, with significant declines in people's mental health over the past 12 months that can have concerning impacts on their lives.

There was also the suggestion of a discrepancy in the quality of care being provided through the NHS and privately, with those going private more likely to receive a faster diagnosis and more likely to be offered support appropriate to their needs. For those that do receive appropriate support, there was also an indication that this can improve their mental health and anxiety, but the reality is that, given the current support being provided, for most people the situation is getting worse.

What further insights were there on access to diagnosis?

Our survey of autistic people in 2022 found that 69% had been clinically diagnosed, with more than half having to wait at least a year (56%), and a third (34%) more than 2 years (Guyatt et al., 2023).

The survey in 2023 yielded similar findings, with 65% clinically diagnosed, 53% waiting at least a year, and 34% more than 2 years.

This suggests that nothing has improved since last year despite commitments to reduce waiting times.

The 2023 survey also provided us with additional insights that we did not have last year related to private diagnosis.

A private diagnosis for autism costs in the region of £2,000, which is a significant outlay. Increased UK online searches (+900% year on year Dec2022/Dec2023 UK) for private diagnosis and clinics offering these services (also now noting waiting lists) suggest more and more people are going down this route.

Our survey found that nearly a quarter of those clinically diagnosed had paid for a diagnosis, though only 10% of those looking to get a diagnosis were planning to pay privately.

People paying for a diagnosis had to wait a much shorter time than those diagnosed through the NHS, with 28% of those paying privately having their diagnosis within the NHS 13 week target window compared to only 9% of those assessed through the NHS.

Age was an important determinant in people's experience and expectations around diagnosis. Older people were less likely to have a clinical diagnosis and more likely not to be seeking an autism assessment than younger ages.

Although fewer women and non-binary people were clinically diagnosed than men, the differences were not significant. This suggests that the gender gap in diagnosis may be closing,

People are seeking out private diagnoses, with indications that post-diagnosis support through this route could be more appropriate to their needs.

though the self-selecting sample surveyed may have impacted these findings.

What did we learn about professional support?

Our survey of autistic people in 2022 found that less than a third (27%) of autistic people reported that they had received professional support to meet their needs. Our survey in 2023 found that only 6% had been offered professional help that met their needs (Guyatt et al., 2023).

Although exact wording of the questions differs slightly between the 2022 and 2023 surveys, the low number of people receiving professional support appropriate to their needs is alarming and implies a downward trend, with 70% being offered no professional support at all.

The data also showed that those who were offered support after a private diagnosis were more likely to receive support appropriate to their needs (41%) than those receiving a NHS diagnosis (18%). This is suggestive of a wide gap between the quality of support being provided post-diagnosis in the NHS compared to the private sector.

Although professional support was less likely to be provided to females and older people, the high percentages of those receiving inappropriate support meant that this was then similar across all demographics.

Few autistic people are receiving the support they need, and the situation seems to be getting worse.

Autistic people's mental health is on the decline, but there is the potential to reverse this trend if appropriate support is provided.

What does this mean for mental health and anxiety?

More than half of people reported that their mental health (58%) or anxiety (62%) had worsened over the past 12 months.

Those on an NHS waiting list were more likely to report a worsening in mental health or anxiety than those who had an NHS clinical diagnosis.

Conversely, nearly half of those that had received support that met their needs reported that their mental health or anxiety had improved.

This suggests there is an opportunity to turn things around if appropriate professional support is provided.

This is supported by other studies, which have reported that autistic people who receive adequate support can have their lives transformed, with employment and education opportunities opening up for them as a result (Camm-Crosbie et al., 2019). However, for the majority of people, appropriate support is not forthcoming and mental health is on the decline.

Although a worsening of mental health was highest in the youngest age group, at least 50% of respondents in every gender and age group reported that things were getting worse, indicating that it is a universal problem.

Autistic people's mental health is on the decline, but there is the potential to reverse this trend if appropriate support is provided.

What does this mean for the quality of life of autistic people?

An overwhelming 93% of people surveyed said their mental health was impacting on their lives. For many this was in very significant ways, with a quarter having thoughts of self-harm (increasing to 40% in 18-24 year olds) and nearly half feeling isolated.

There is robust evidence on the negative impacts of isolation on quality of life, with some studies indicating that it is also associated with an increased risk for early mortality (Holt-Lunstad et al., 2015; Motillon-Toudic et al., 2022).

Higher risks of premature mortality and poor quality of life metrics for autistic people are not new (Cassidy et al., 2022; Newell et al., 2023), but the findings of this current survey suggest that their worsening mental health is impacting on their lives to an even greater degree than before.

What would we like to know more about?

Our survey in 2022 provided some insights into what people were most concerned about, their priorities, and their needs. For most this related to safety, physical and emotional, managing emotions, anxiety, and health. In both surveys we learnt that people were not getting the support appropriate for their needs, but what we did not explore is what appropriate support looks like.

Some of the narratives suggested support that was inappropriate for some people, such as anti-depressants and CBT, but it is not clear what does work.

Facilitating access to an Annual Health Check may support in addressing some of the health inequalities, but more research is needed in understanding needs and appropriate support (Sharpe et al., 2019). It would also be illustrative to further explore the observation in this survey that a private diagnosis may lead to more appropriate support post-diagnosis.

Autistic people's worsening mental health is having a significant impact on their lives, putting people at risk of serious harm.

Conclusions

This shocking data heralds a potentially catastrophic tsunami of negative outcomes for autistic people. Society and the public sector must act now to provide the support that autistic people need.

More research is required to better understand what good, appropriate support that meets autistic people's needs looks like. We must acknowledge that there is no one-size-fits-all answer and explore practical and innovative solutions to get this support delivered to those who need it. The use of digital media campaigns to allow self-referral for digital support tools, for example, is an innovative approach we have proven to be feasible and effective. Developing practical solutions like these, in consultation and co-production with autistic people, should be a priority for service providers and policymakers.



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