

Autism Survey 2023 Results



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We are currently reviewing our Adult Autism Strategy and Action Plan 2019-2022. We want our revised strategy to be aligned with the National Strategy for Autistic Children, Young People and Adults (2021-2026) which extended the scope of the strategy to include children and young people for the first time. The six areas set out in the strategy by the Government that would make a difference in the lives of autistic people and their families are:

1. Improving understanding and acceptance of autism within society.
2. Improving autistic children and young people's access to education and supporting the move from childhood to adulthood.
3. Supporting more autistic people into employment
4. Tackling health and care inequalities for autistic people
5. Building the right support in the community and supporting people receiving inpatient
6. Improving support within the criminal and youth justice systems

To be better equipped to write the draft strategy the West Berkshire Adult Autism Partnership carried out an online survey to seek the views of autistic people, parent/carers, and family members. The survey was open for a period of 6 weeks from 5th June 2023 to 19th July 2023. We received a total of 144 responses from the survey (some responses were incomplete).

The responses have been arranged according to questions in the survey linked to the 6 priority areas.

Priority 1

Improving understanding and acceptance of autism within society.

We felt a starting point would be to find out about peoples experience of getting a diagnosis, waiting times and support after being diagnosed.

Q5. Have you got a formal Autism diagnosis?

134 people responded to this question.

91 (67.91%) responded 'Yes'

5 (3.73%) responded 'No' I don't have a formal diagnosis, but I am being assessed

19 (14.18%) responded 'No' I don't have a formal diagnosis I am waiting to be assessed

19 (14.18%) responded No I don't have a formal diagnosis, but I believe I am on the Autistic Spectrum

It took me 3 years and 6 months only happened because of Richard Benyon.

ADHD diagnosis.

I have been reading about it and following YouTube channels of Autistic people such as Autism from the Inside by Paul Micallef, and I found out I have had signs of Asperger's since childhood.

Currently the waiting list is 3 years

Consultant Psychiatrist has recommended autism assessment for me following ADHD diagnosis.

I self-diagnosed.

I have co-morbid diagnoses of attention deficit disorder and Anxiety.

I didn't get my diagnosis until Autumn 1999 when I was 14. It wasn't until then that I finally was given a Learning Support Assistant at school. Before that my mum had to fight hard to get me a diagnosis.

Assessment requested through doctor but not response yet. Been a trying thing to do.

I had a late diagnosis in 2017 at the age of 36.

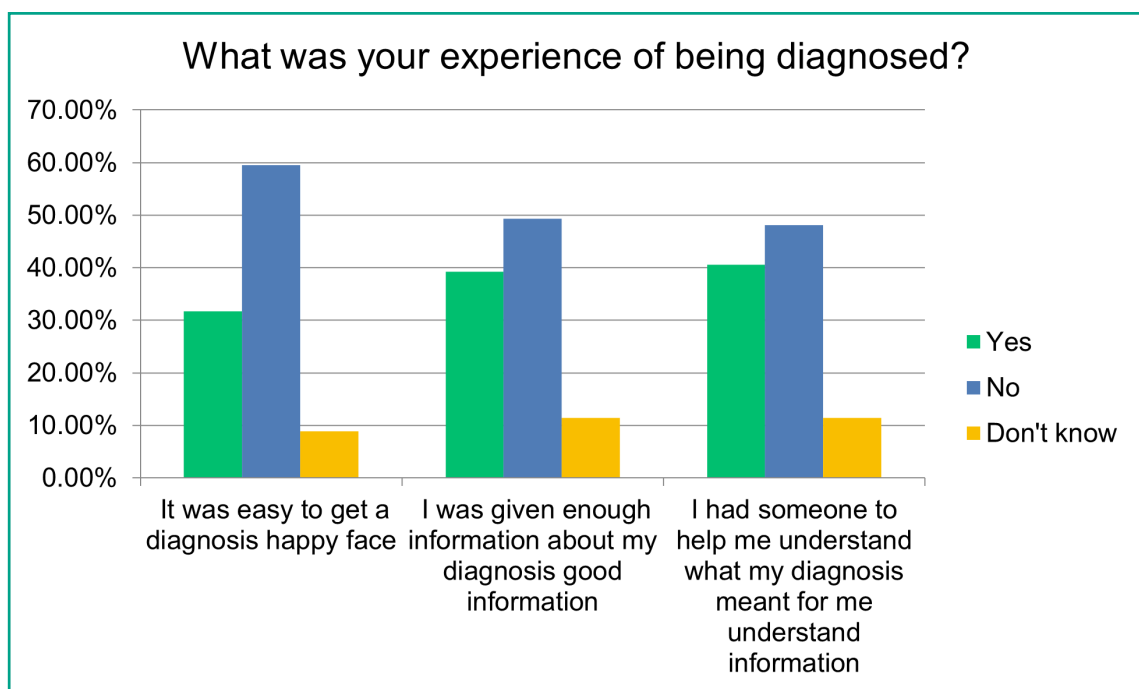
Only recently though - a couple of years ago.

Drs and paediatric consultant have confirmed son is on the spectrum.

A child psychiatrist recommended an autism assessment, and we are all comfortable with this as a working diagnosis.

Q7. What was your experience of being diagnosed?

80 people answered this question.



Additional comments on experience of being diagnosed are outlined below:

Feel glad that I now know why I am the way I am after so long feeling like I don't fit in this world.

You just get dumped after initial assessment, there's a little help but not much to help you cope with life afterwards.

I didn't get the help I needed after I was diagnosed.

The "Being Me" course was useful, but I needed, and still do need a lot more help with the follow up. What being autistic means more specifically.

Had to wait over 3 years for appointment to get diagnosed.

The waiting list is longer than 2 years. That's longer than any job contract I had ever had at the time so I would have moved out of the area by the time I reached the top of the waiting list. Fortunately, I could find the £1500 required for a private assessment and the GP surgery helped me find someone to do the assessment and accepted the private diagnosis.

I was diagnosed after a meeting with a support worker from Swan who wanted to help me get through domestic abuse.

It took ages to get a public health care diagnosis, so I had to go private.

It was relatively easy to get a referral and diagnosis, but I feel as though that was only because my son had previously been diagnosed.

Not that I can think of, I don't really know how the diagnosis went as I was only about two at the time.

I was diagnosed aged 15 in 2003. At this time Autism was rarely heard of. The diagnosis process was mostly my parents talking and me being asked a couple of questions.

I was fast-tracked for my diagnosis because I was a student at Cambridge University, and they had an autism research clinic. I know that my experience is not the norm in this regard

It was a relief to finally understand why I'd been struggling all my life.

As I was only 3 at the time when I got my diagnosis, I can only get this information from my mother as I do not have much memory from it.

As I was only 3 at the time, I only have the experience that my mother has told me regarding this issue. From what my mother has told me, it was both easy and difficult to get a diagnosis at the same time.

You're given your diagnosis but only really get a basic course on autism afterwards, and no counselling post diagnosis is available - this would be very important as there is a grieving process to go through as you realise you will never be better and never be normal. You are left floundering to make your own way.

As my mum was in charge of getting my diagnosis, I don't really have much knowledge of what went on at the time.

Was 10 so wasn't fully told / understood the situation.

I was diagnosed when I was 7. My mum had to do it all through the GP. I was originally referred to OT who referred me for an Autism diagnosis. I was diagnosed with Aspergers.

The common point of entry gateway or whatever it's called, initially 'diagnosed' me from the piece of paper my GP sent in and said that I just needed Talking Therapies, not an assessment. They had not met or spoken to me, or even bothered to speak to my GP, but decided that they could diagnose me from a few written sentences requesting an assessment. How arrogant, incompetent, unjust and unprofessional is that?! Quite unbelievable. And wrong, so wrong.

Post diagnosis support

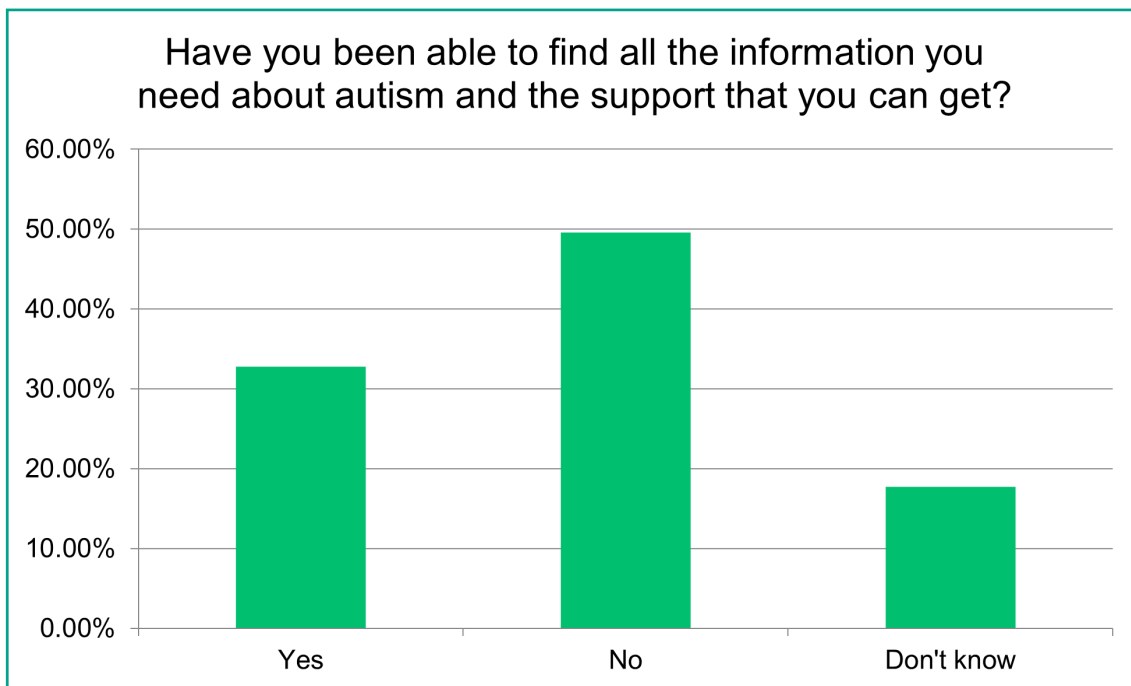
Q9. Have you been able to find all the information you need about autism and the support that you can get?

113 people responded to this question.

37 (32.74%) responded 'yes'

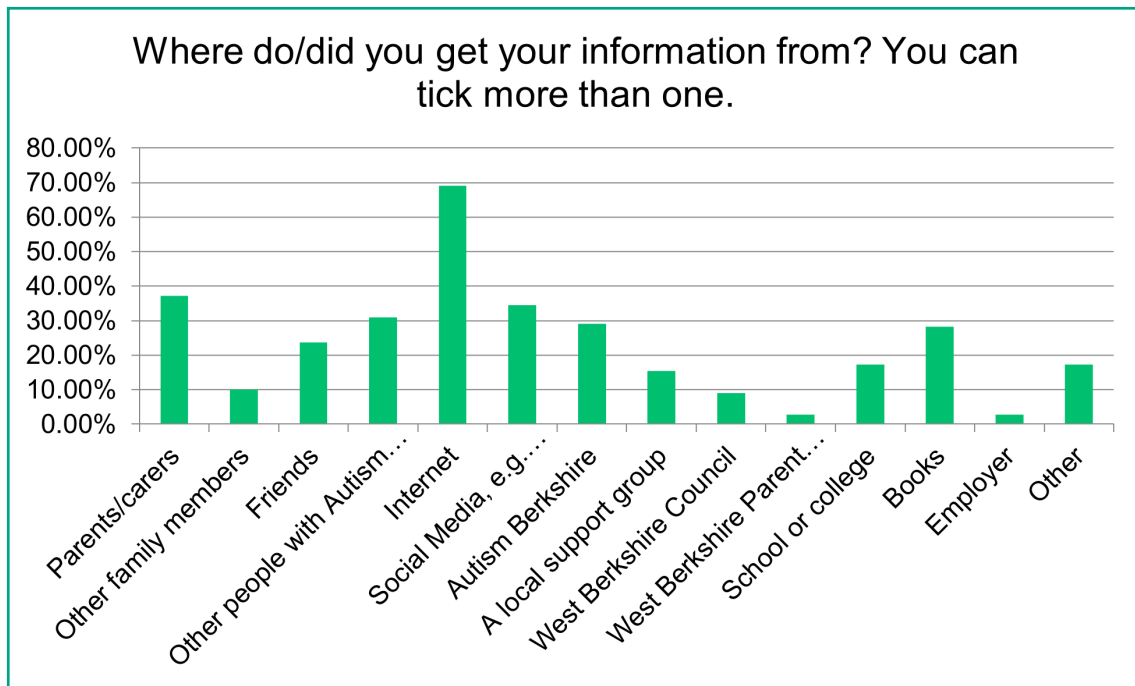
56 (49.56%) responded 'No'

20 (17.70%) responded 'Don't know'.



Q10. Where did you get your information from?

107 people answered this question



Priority 2

Improving autistic children and young people's access to education and supporting the move from childhood to adulthood.

Q13. What do you think would make it better for autistic children and young people in school or college?

45 people answered this question.

If they got the money given to support them spent on them, and we're going treated better.

Additional resources and/or lessons on what autism is, the different effects it can have on your life, and various different strategies on how to reduce various autism related issues.

More awareness by teachers, if a student is clearly struggling with normal teaching methods or seems to always be daydreaming etc, teachers need to stop assuming that they aren't trying hard enough and criticising, and instead pick up on the signs if they can and let the parents know or try to offer support.

More tolerance for everything.

Resources. A less structured learning criteria that isn't as focused on academic outcomes.

If teachers actually understood what autism is. I am a man, but I do think that autism at school is an even harder experience for girls and women, as adults have different expectations for how girls and women should behave. I also needed more quiet space at school than most children. I struggled with really simple things sometimes, like how loudly a clock ticked during exams.

I would say that there ought to be teachers that are better funded and trained to understand neurodivergence and deal with students in a more tactful and helpful way rather than traditional means which don't always work. More support can also mean more help for students struggling with workloads and homework.

Not to be bullied.

People to understand that you don't need to have a wheelchair to have a disability.

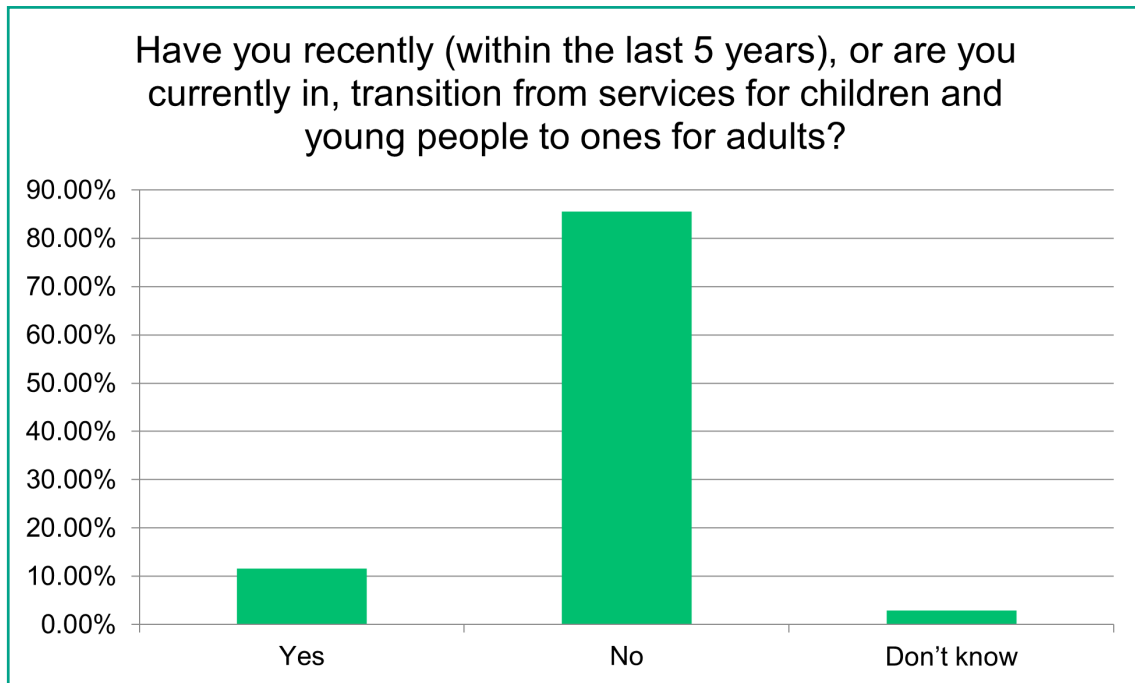
Staff that understand their needs and that not every autistic person is the same.

I would say that there ought to be teachers that are better funded and trained to understand neurodivergence and deal with students in a more tactful and helpful way rather than traditional means which don't always work. More support can also mean more help for students struggling with workloads and homework.

I think teachers ought to be better funded and trained to recognize when a student is struggling and to offer more support in schoolwork rather than just letting them get on with it.

Q21 Have you recently (within the last 5 years), or are you currently in, transition from services for children and young people to ones for adults?

104 people answered this question.



Q22. Do you think the information you get about transition is clear and accessible?

11 people answered this question.

1 (9.09%) responded 'Yes'

9 (81.82%) responded 'No'

1 (9.09%) responded 'Don't know'.

Q23. Were you involved in planning your transition?

10 people answered this question.

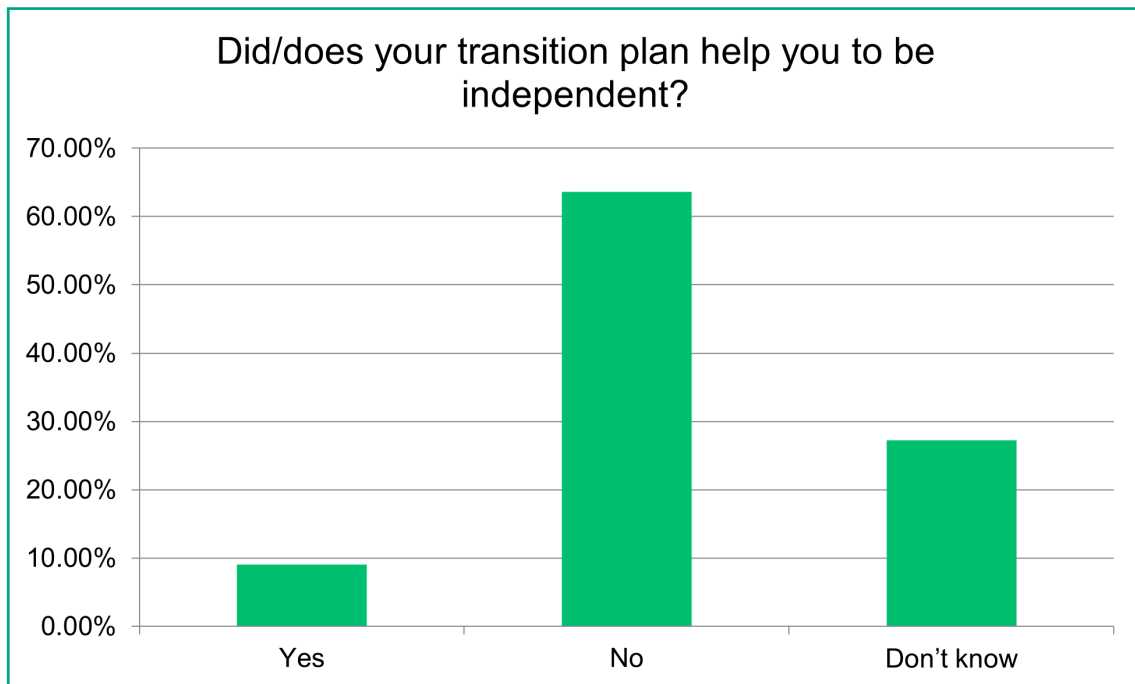
3(30%) responded 'Yes'

6(60%) responded 'No'

1(10%) responded 'Don't know'.

Q24. Did/does your transition plan help you to be independent?

11 people answered this question.



Q25. Did/does your transition plan give you choice and control over your support?

11 people answered this question.

2 (18.18%) responded 'Yes'

6 (54.55%) responded 'No'

3 (27.27%) responded 'Don't know'.

Priority 3

Supporting more autistic people into employment.

Q14. Have you ever had a job, including volunteering?

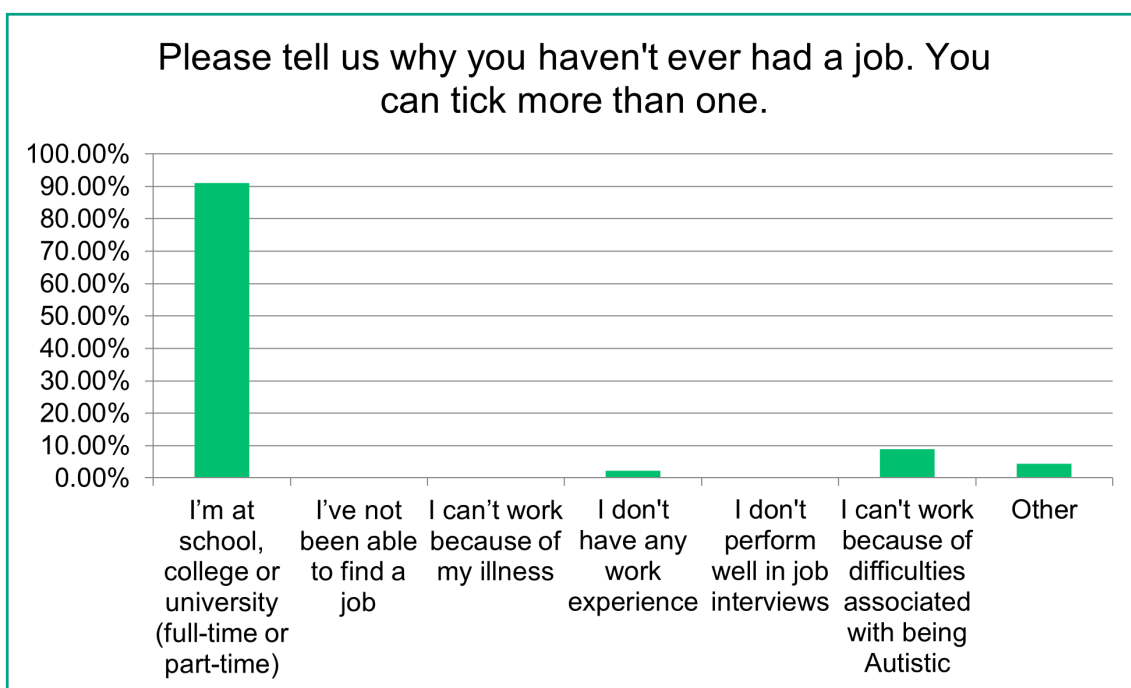
111 people answered this question.

67 (60.36%) responded 'Yes'

44 (39.64 %) responded 'No'

Q15. Please tell us why you haven't ever had a job. You can tick more than one.

45 people responded to this question



Additional responses are outlined below.

Registered to a mainstream school, unable to attend due to unmet needs. No full-time educational provision provided despite level 1 and level 2 complaints raised.

Hasn't been in school for a year because LA refuse specialist provision even though mainstream can't meet need.

Although my son has not been able to access his school for over a year.

But I will get a job when I'm old enough as my mum is a Job Coach.

Q16. What type of jobs have you had? You can tick more than one.

61 people answered this question.

18 responded 'Business administration and management, e.g. office manager, administrative assistant'.

6 responded 'Financial services, e.g. bank manager, accounts assistant'.

7 responded 'IT and computer science, e.g. IT support technician, web developer'.

4 responded 'Environmental and agricultural, e.g. farmer, landscape gardener'.

4 responded 'Science and mathematics, e.g. chemist, statistician'.

4 responded 'Building and construction, e.g. architect, bricklayer'.

4 responded 'Art, craft, and design, e.g. artist, photographer'.

1 responded 'Hair and beauty, e.g. hairdresser, beauty therapist'.

13 responded 'Education, e.g. teacher, teaching assistant'.

4 responded 'Health care, e.g. GP, physiotherapist'.

8 responded 'Hospitality and tourism, e.g. hotel receptionist, restaurant server'.

22 responded 'Retail and customer service, e.g. customer service advisor, store manager'.

1 responded 'Transport and logistics, e.g. train driver, postal worker'.

1 responded 'Manufacturing, e.g. production manager, sewing machinist'.

0 Law e.g. Solicitor

0 Marketing and Advertising

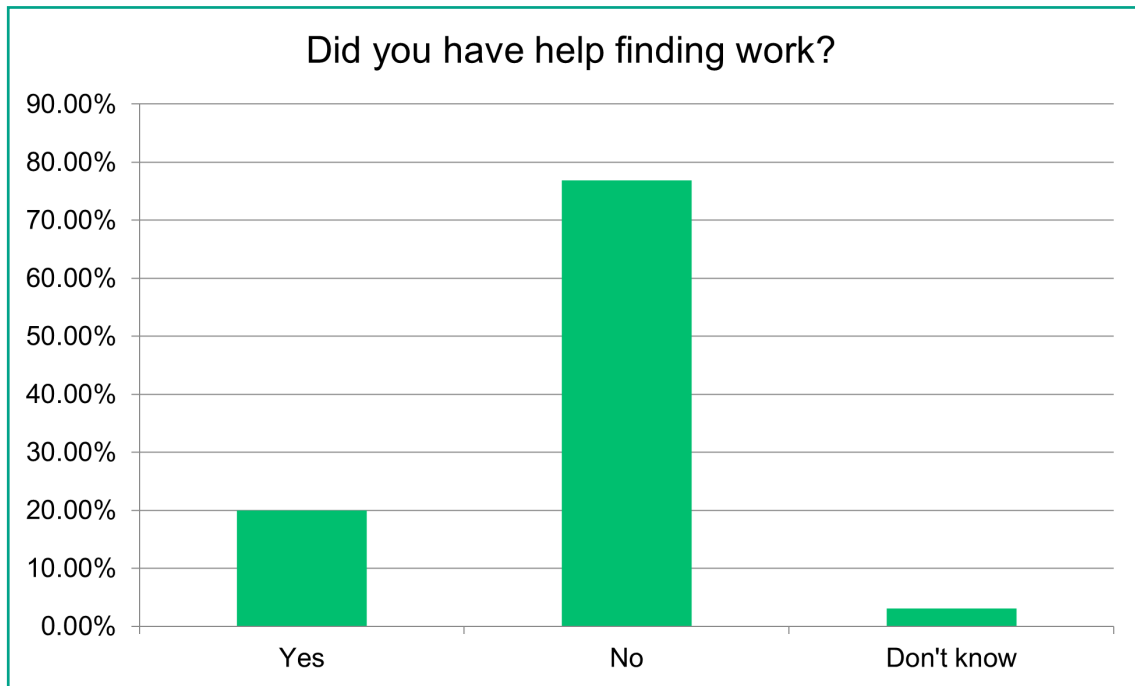
25 responded 'Other (please specify)'

25 people who selected 'other' provided the following responses.

- Factory
- Library service
- Care Assistants, Support Workers
- Self Employed Writer
- Professional Actor and Musician
- Health and Social Care, Charity
- Car Parking Assistant
- Research Assistant
- Student Ambassador at University
- Charity sector and Local government -housing and homelessness
- NHS Healthcare Assistant and yard assistant with horses
- Health and Safety
- Workshop presenter for Autism Berkshire and volunteer for West Berkshire Mencap
- Charity shop
- 1 week volunteering in a charity shop in Year 10 and 1 week in an IT company while at college
- Library work
- Postal Assistant
- Chartered engineer
- Waitress
- Librarian
- Recruiter, Trainer
- Warehouse

Q17. Did you have help finding work?

65 people answered this question.



Q18. Who helped you find work? You can tick more than one.

12 people answered this question.

8 (66.67%) responded 'Parents/carers Parents'

1 (8.33%) responded 'Other family members'

3 (25.00%) responded ' Friends'

0 (none) Autism Berkshire

0 (none) A Local Support Group

0 (none) Job Centre

2 (16.67%) West Berkshire Council

1 (8.33%) School or College

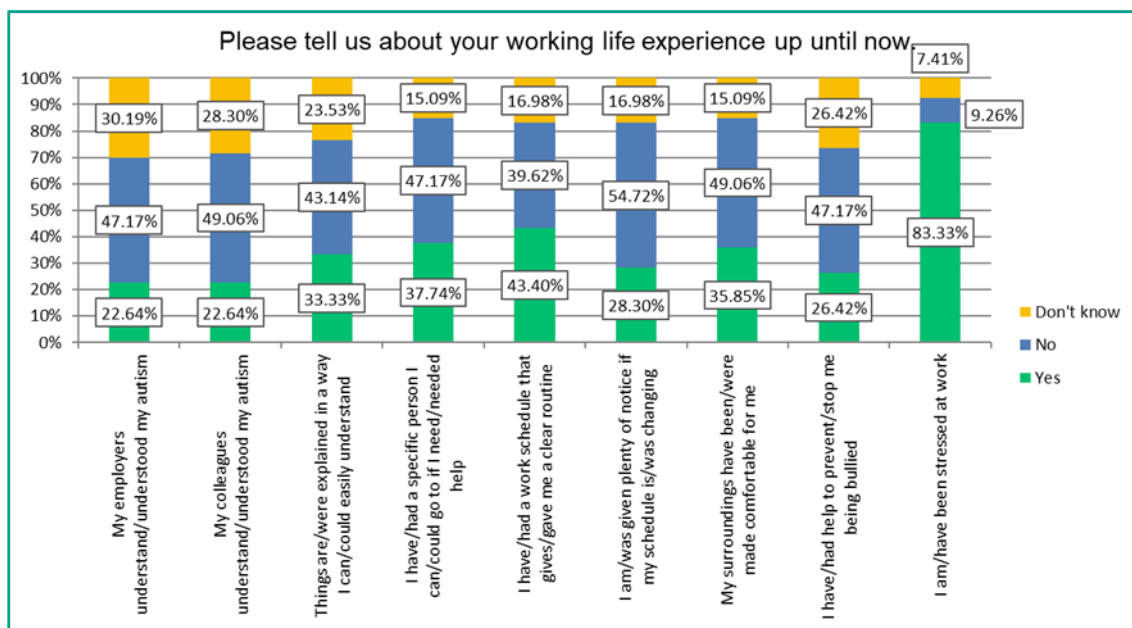
Additional comments

I did 'One Day A Week' Work Experience in the Postal Team at West Berkshire Council for over a year and had a Part-Time role created for me at another council office.

Also managed to find work myself too.

Q19. Please tell us about your working life experience up until now.

56 people answered this question.



Below are responses to the statements.

My employers understand/understood my autism.

12 (22.64%) responded 'Yes'
 25 (47.17%) responded 'No'
 16 (30.19%) responded 'don't know'.

My colleagues understand/understood my autism.

12 (22.64%) responded 'Yes'
 26 (49.06%) responded 'No'
 15 (28.30%) responded 'Don't know'.

Things are/were explained in a way I can/could easily understand.

17(33.33%) responded 'Yes'
 22(43.14%) responded 'No'
 12(23.53%) responded 'Don't know'.

I have/had a specific person I can/could go to if I need/needed help.

20 (37.74%) responded 'Yes'
 25 (47.17%) responded 'No'

I have/had a work schedule that gives/gave me a clear routine.

23(43.40%) responded 'Yes'
 21(39.62%) responded 'No'
 9(16.98%) responded 'Don't Know'.

I am/was given plenty of notice if my schedule is/was changing.

15(28.30%) responded 'Yes'
 29 (54.72%) responded 'No'
 9(16.98%) responded 'Don't know'.

My surroundings have been/were made comfortable for me.

19(35.85%) responded 'Yes'
26 (49.06%) responded 'No'
8(15.09%) responded 'don't know'.

I have/had help to prevent/stop me being bullied.

14(26.42%) responded 'Yes'
25 (47.17%) responded 'No'
14(26.42%) responded 'Don't know'.

I am/have been stressed at work.

45(83.33%) responded 'Yes'
5(9.26%) responded 'No'
4(7.41%) responded 'don't know'.

Q20. Is there anything else you'd like to tell us about your experience of working life?

35 people answered this question.

Below are some of the experiences that people shared

I haven't had a formal diagnosis yet so have not been able to talk to any of my employers over the past 30 years about my needs.

It's been very challenging and exhausting for me.

I've been on a waiting list for diagnosis since 2020 until then I didn't know that I was on the spectrum. When I found out my current employer has a diversity policy and so I told them. Probably a mistake at the time because for about a year I was treated by certain colleagues as if I had a learning disability and put into a performance improvement programme (might be unrelated). Things have got better but mainly because they've realised all the benefits my brain pattern brings to the job (e.g. focus, pattern recognition etc).

I chose to be a freelancer because it is easier for me to plan my day and manage my time, and most importantly to communicate. I have problem communicating through phone or face to face. Therefore, communicating through email and messaging is ideal for me, helps to communicate clearly, as it gives me the chance to think clearly both in conveying my message and in perceiving others. Unfortunately, most employers and companies prefer phone calls, meetings, or face-to-face communication which is mentally draining for me most of the time.

Due to a burnout, I have been assessed as unfit to work and unfit to look for work.

No one at work knew I was autistic so I didn't receive any help but that was fine.

The jobcentre needs to follow through with their ideas for back to work buddy support.

I don't always want to disclose that I have autism, because it doesn't always feel safe to do so. I mask a lot, so it can be hard because I look fine and do well at work, but underneath I find most days incredibly stressful.

It's difficult to answer these questions because I wasn't diagnosed until age 30 so I couldn't access reasonable adjustments.

Going through diagnosis and as a female not displaying classic symptoms, I have found work extremely difficult.

Everyday is a struggle.

40 year self-employed.

It's been difficult.

I didn't have my diagnosis while I was working. It was very difficult.

For most of my working life, I didn't know I was autistic. When I found out, it was difficult to know what I needed to help me because I'd always had to cope before without help.

Have experienced hostility in the past and unsupportive managers but currently quite positive although I still get judgemental expressions occasionally.

People are not generally accepting of people who are different. People pay lip service to diversity only.

No.

I was bullied out of work.

I only received my diagnosis after working for >20 years. Getting a diagnosis helped me to be much kinder to myself about my perceived weaknesses.

The manager I had between 2020 & 2022 dismissed my Autism in my Appraisal in 2021 and didn't want to listen to a single word I had to say which I found Deeply Hurtful.

Just that I wish it were easier to find a job that has an annual salary of way more than £12k. Sadly, nobody who offers better-paid jobs seems to want to take me on.

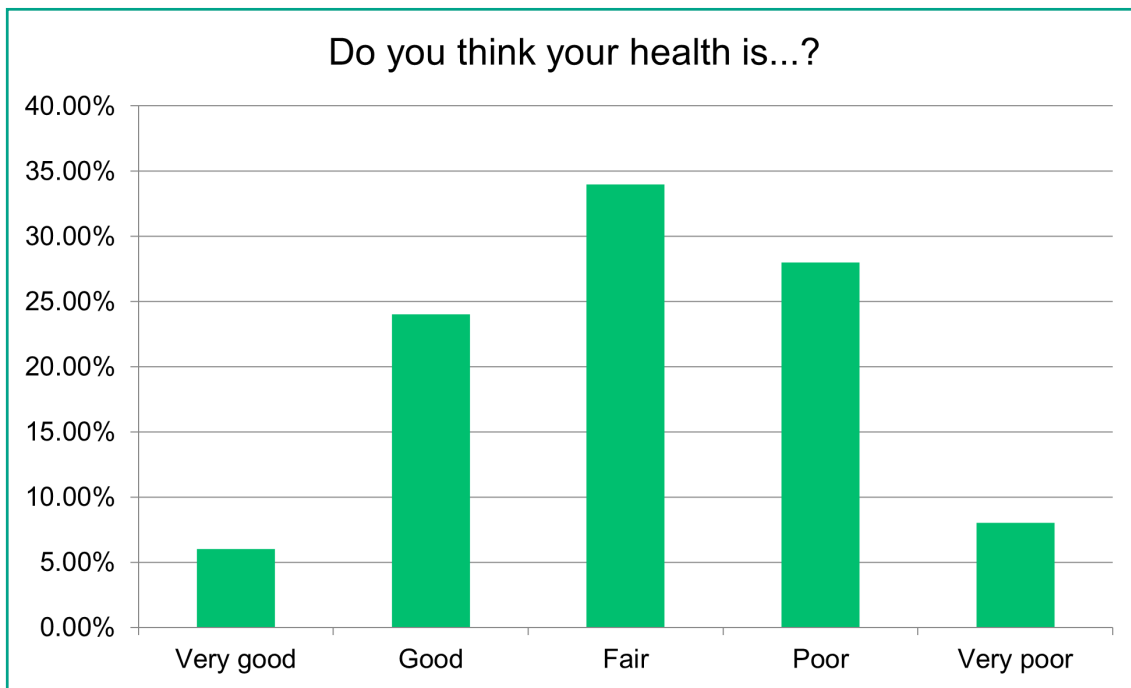
Only in the last year have I had an understanding working environment with support. I have been bullied & actively pushed out in the past.

My employment in a clothes shop in Newbury only lasted 3 weeks due to a severe lack of understanding of Autism. I now work for an Autism and Learning disability charity called Talkback UK. I have been working for them for 2 and a half years. They have an amazing understanding of Autism and are willing to learn from and involve autistic staff members in all aspects of the charity and their work. They are the best thing to have ever happened to me.

Priority 4

Tackling health and care inequalities for autistic people

Q35. Do you think your health is?



Q36. Is there anything you want to tell us about your health?

50 people answered this question.

Below are some of the comments from people who answered this question.

Have bpd triggered by traumas.

I have had a big relapse in an eating disorder.

Chronic arthritis.

Some diet and exercise classes that are suitable would be great, lot of exercise classes are too loud for me.

No.

I have suffered from anxiety and depression since the age of about 15 and I think this has been exacerbated by having Autism.

Sometimes I need to talk to a skilled psychologist, and I prefer the communication to be just through messaging and writing. I have been using AI's such as Woebot and ChatGpt to get help for my mental health. Because my preferred method of communication is writing, while no social care services or consulting or talking therapies accept such methods. They all require face to face or voice communications which are not the first choice in Autism spectrum.

Physical health is OK apart from blood pressure, but my mental health is poor.

My mental health is terrible, and I was under the care of the crisis team over Christmas. Physical health is good.

I have tried to get help many times but due to a lack of understanding of autism no one knows how to help or want to know how they can help. No one tests for problems they just throw medication at it based on what they think the problem is.

I have generalised anxiety disorder which affects my life a lot, and it's mostly due to things related to autism.

COPD.

My mental health is poor. I also have a physical disability, which I can manage.

My health has suffered through not having a formal diagnosis so have gone private.

My life feels very unfulfilling, and it feels like nothing I've done with it really matters. I expected much more to happen in my life by now, but society clearly has other plans. As it stands, I'm stuck in a mediocre job where I only get paid a little over a thousand a month and still living at home at 25, still single and no chance of moving out anytime soon. I often feel there's no point in trying to make my life better anymore.

I suffer with high anxiety and have low energy levels from Vasculitis.

Lots of immune type conditions sarcoidosis, prolactinoma, chronic breast abscess, rosacea, arthritis.

I am currently perimenopausal, which I've heard is even more disruptive for autistic people than usual.

Occupational health questionnaire results said that my mental health is very poor.

Mental health is up & down.

I'm an adult who can't talk openly about their autism. Getting help when you don't want to talk is a vicious cycle.

I feel a burden as nothing works out and no positive experiences.

Going to the Doctor for different mental health diagnosis(es) is very difficult to do as a person with Autism.

Q37- What makes it difficult for you to make changes to your health? You can select more than one.

63 people answered to this question.

31 (47.69%) responded 'Services aren't autism friendly.'

37 (56.92%) responded 'My condition makes it difficult.'

23 (35.38%) responded 'I don't like to leave my house because of my autism.'

8 (12.31%) responded 'I'm too busy at work.'

11 (16.92%) responded 'I don't have enough money.'

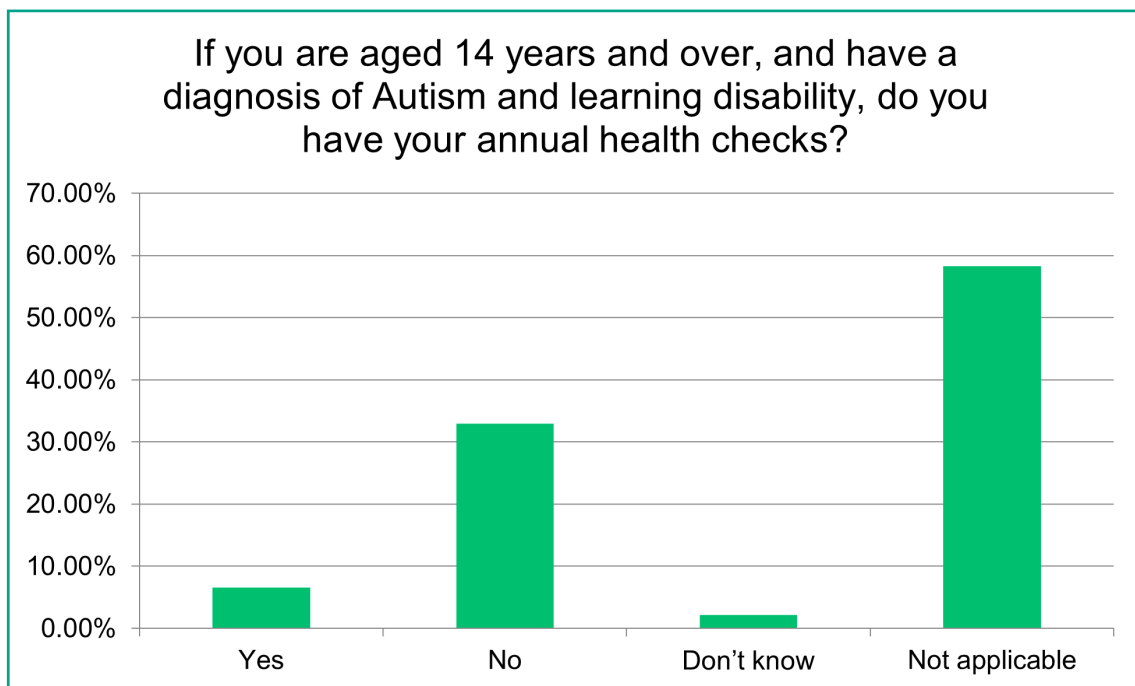
2 (3.08%) responded 'I have too many social commitments outside of work.'

2 (3.08%) responded 'I have family commitments'

11 (16.92%) responded 'Other'.

Q42. You are aged 14 years and over, and have a diagnosis of Autism and learning disability, do you have your annual health checks?

91 people answered to this question.



Priority 5

Building the right support in the community and supporting people receiving inpatient care

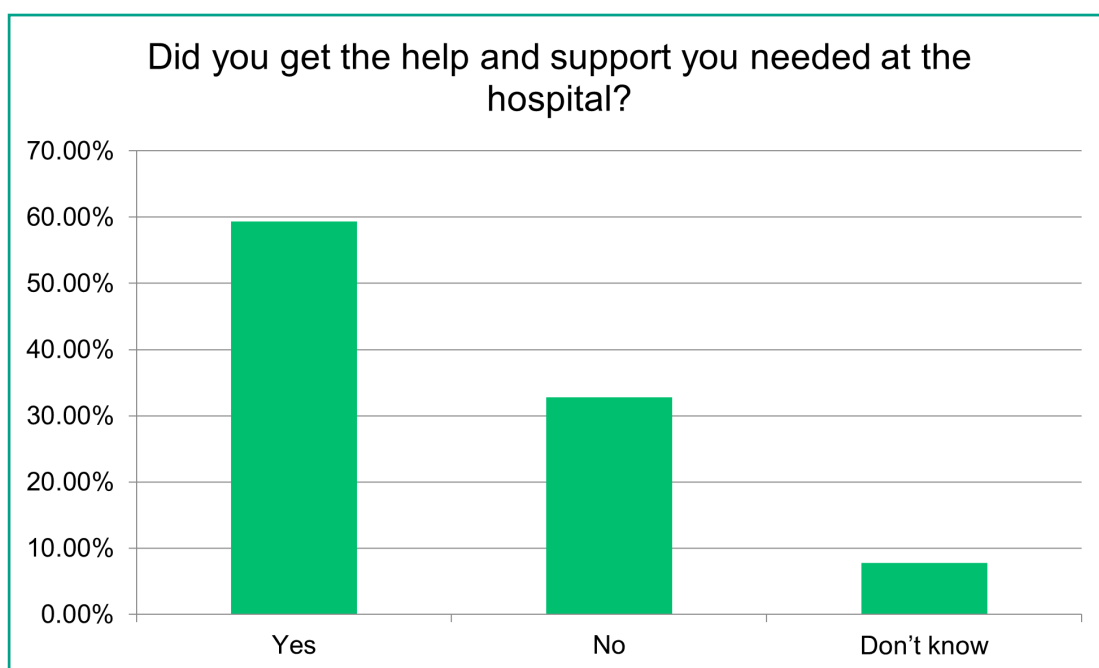
Q43. Have you ever attended a hospital outpatient appointment or been admitted to hospital?

94 people answered this question.

68 (72.34%) responded 'Yes'.

26 (27.66%) responded 'No'

Q44. Did you get the help and support you needed at the hospital?



Q45. What do you think would make hospitals better?

42 people answered this question.

Below are some of the responses

Private rooms for people with autism.

More proper training on sensory sensitives, auditory processing, and clear communication, more patience and less hostility.

The doctors need to listen to what we are saying and not dismiss what matters to us- we are different, and we feel things differently. They need to help us address that not try to make us like them.

Getting the same nurse who knows your history. That you feel comfortable with.

Commutation with GPs and consultants is not quite easy everywhere in the UK. They do not give you, their emails. It is always a number that requires going through several departments to reach your doctor. Most of the time phone calls are useless with lots of miscommunications. I think all hospitals and surgeries should allow their patients choose the way of communication and provide messaging services.

More staff

Seeing different people for speech and language. Seeing the same person would make things easier for my son.

Understanding of Autism and having the time to allow me to adjust to the environment. For the environment to be more autism friendly.

Asking ahead of time if there's anything they need to know that will help, or anything they can do or bear in mind that would be helpful.

Care tailored to the individual patient. Clear medical notes stating their sensitivities, likes, dislikes etc.

Better awareness and appropriate support available.

Some staff good. Better explanation and more time.

The mandatory Autism Training and improved understanding will hopefully help.

Staff having training in Autism.

They seem good enough as they are now, I'm not bothered.

Neurodivergent friendly eg quiet rooms.

more funding.

quiet areas.

Waited 6 hrs to be seen.

need to be more patient and explain things much more explicitly with no figurative language, need to understand level of stress in hospital environment very high so difficult to take things in and auditory processing much slower.

Be more aware of the range of needs of autistic people. Being asked to wait for 2 hours in a public place won't work.

Communication friendly and clear.

More autism support. Appears to normal to have additional needs.

Better understanding of autism and how to deal with meltdowns.

Low arousal spaces within hospital and even on wards would help.

Advance information about the appointment. Why the appointment has been made, information about the way the appointment will be run, waiting times and a picture of the person you are seeing. So the person with autism can be fully prepared and not suffer confusion or have a meltdown due to triggers such as lighting, noise, confusion and waiting around.

better understanding of autism (pda) sensory needs etc and more time.

resources

Q46. Have you ever been admitted to a mental health hospital for inpatient treatment?

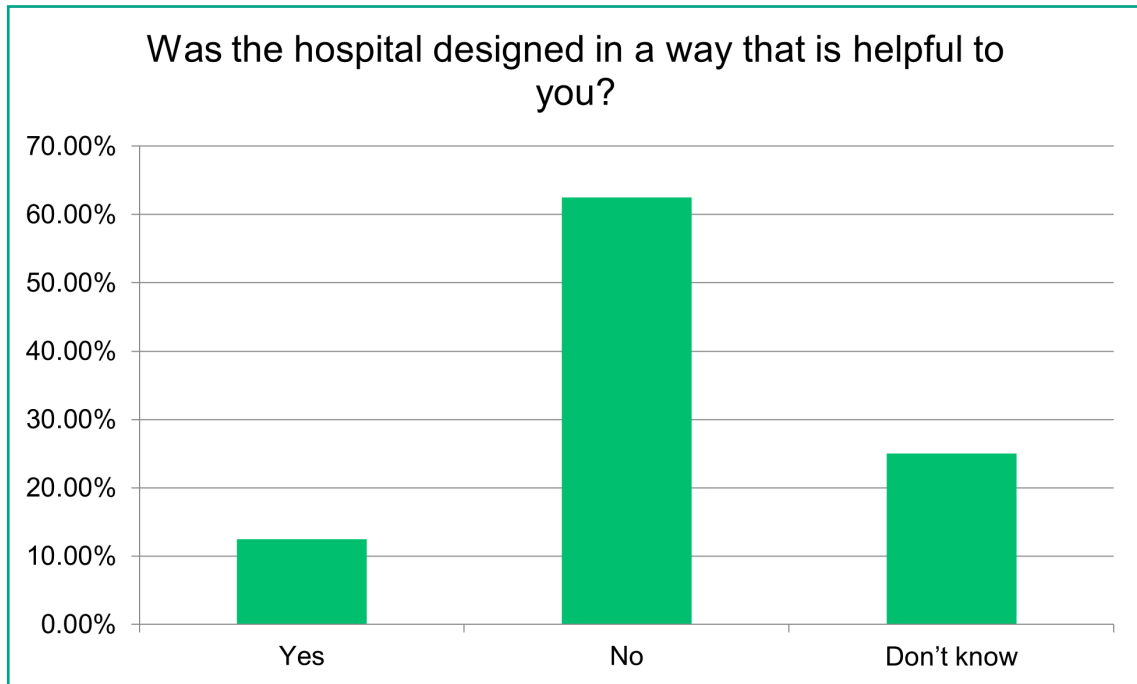
90 people answered this question.

8 (8.89%) responded 'Yes'

82 (91.11%) responded 'No'

Q47. Was the hospital designed in a way that is helpful to you?

8 people answered this question.



Q48. Did the hospital mental health services understand you and help you to get better?

8 people answered this question.

3 (37.50%) responded 'No'

4 (50.50%) responded 'Don't know'

1 (12.50%) responded 'Yes'

Q50. What do you think would make hospital mental health services better?

6 people answered this question.

More understanding of autism and other mental health issues.

I was discharged at nighttime. I could not find my way home. So I slept on the street overnight until a stranger decided to help me to find my bearings.

Staff having training in autism and how to deal with meltdowns.

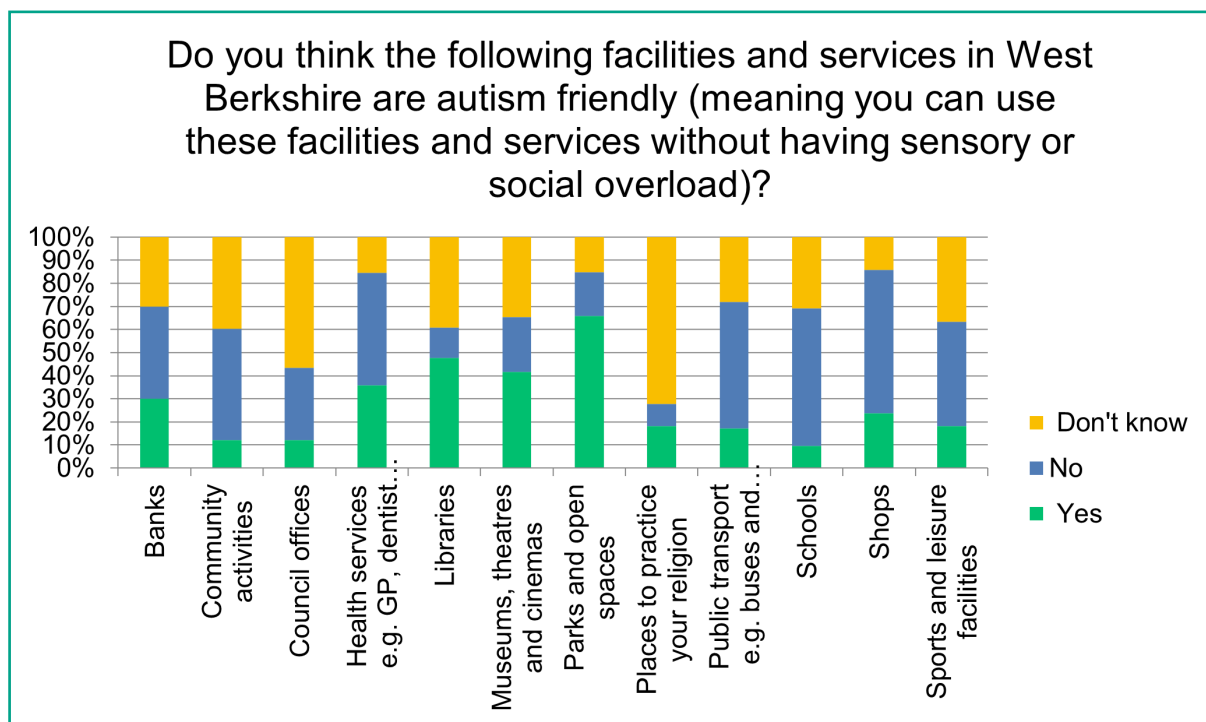
Maybe have an autism assessment.

The first unit was for a range of psychiatric conditions. It was noisy, some patients were aggressive. This made me worse. The second hospital was better but was more aimed at eating disorder patients and not those with ASD and an ED.

Better provision of specialist support. more available supported accommodation tailored to meet needs.

Q57. Do you think the following facilities and services in West Berkshire are autism friendly (meaning you can use these facilities and services without having sensory or social overload)?

86 people responded to this question.



Q58. How do you find out about activities and events in your community? You can tick more than one.

79 people answered this question.

42 (51.85%) responded 'social media, e.g. Facebook, Instagram, Tik Tok, YouTube

40 (49.38%) responded 'Internet'

37 (45.68%) responded 'Through other people e.g. family and friends

12 (14.81%) responded 'Local magazine'

12 (14.81%) responded 'Newspaper'

12 (14.81%) responded 'Through local charities and support groups'

4 (4.94%) responded 'GP surgery'

7 (8.64%) responded 'Through other autistic people

5 (6.17%) responded 'Library'

6 (7.41%) responded 'Other'

5 (6.17%) responded 'TV and Radio'

Priority 6

Improving support within the criminal and youth justice systems

**Q59. Have you had any contact with the police, courts, prison, or probation service?
This could be as a victim, witness, or offender.**

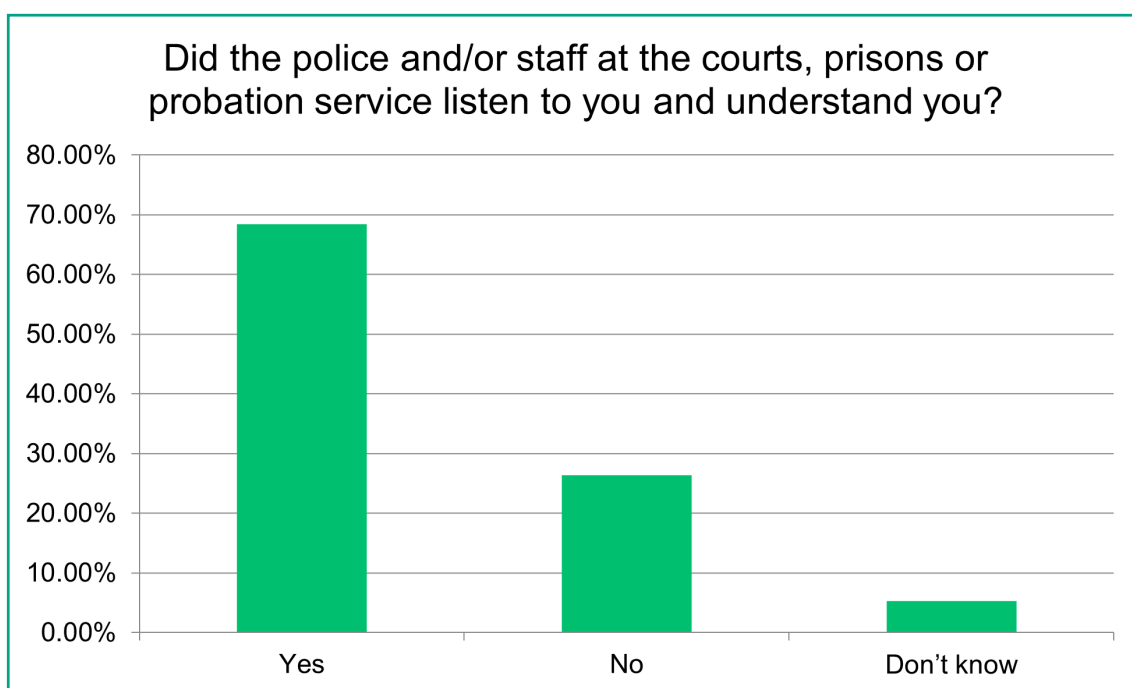
86 people answered this question.

19 (22.09%) responded 'Yes'

64 (74.42%) responded 'No'

3 (3.49%) responded 'don't know'

Q60. Did the police and/or staff at the courts, prisons or probation service listen to you and understand you?



Q62. What do you think would make the police, courts, prisons, or probation service better?

7 people answered this question.

If they I responded to crimes I reported instead of downplaying what's happening to me.

More willingness to listen to people and less emphasis on innocent until proven guilty and evidence, more compassion with victims and witnesses especially young children.

I am frightened of the police because I am not white. I had a bad experience on public transport once - someone threatened to kill me. But when I called the police, they assumed I was the perpetrator and they tried to arrest me. So I don't like dealing with the police.

TVP and WBDC gave me a CPN, not knowing my ASD condition

While my experience with the police was in a different county when I was at university, and my experience was I think the system would be a lot better if certain behaviours weren't put down to arrestable offences, even though I understand that certain behaviours are unacceptable. Plus, helping them to understand why certain behaviours are wrong.

As a victim there was no understanding.

Police need training on how to deal with asd.

Q63 Do you know there is an Autism Alert Card available for free?

84 people responded to this question.

31 (36.90%) responded 'Yes'

52 (61.90%) responded 'No'

1(1.19%) responded 'Don't know'.

Q64. Do you carry an Autism Alert Card?

31 people answered this question.

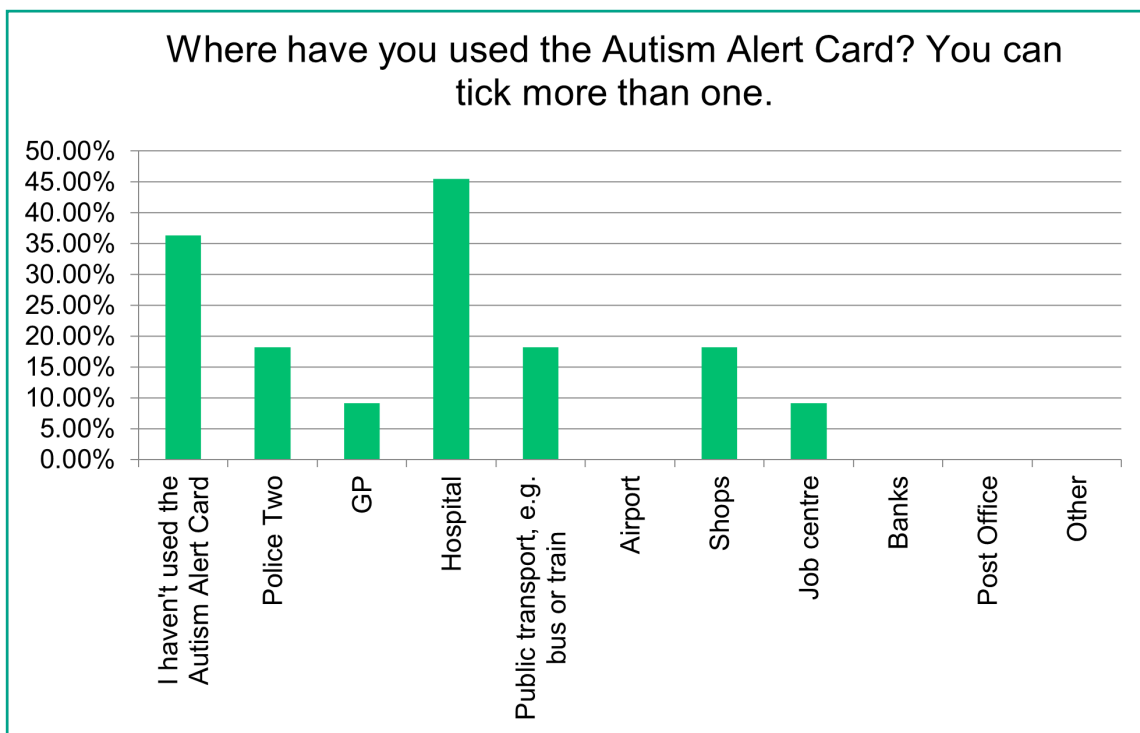
11 (35.48%) responded 'Yes'

19 (61.29%) responded 'No'

1(3.23%) responded 'don't know'.

Q65. Where have you used the Autism Alert Card? You can tick more than one.

11 people answered this question.



Q66. Did it help you get the support you needed?

7 people answered this question.

3 (42.86%) responded 'Yes'

2 (28.57%) responded 'No'

2 (28.57%) responded 'don't know'.

Q67. Do you have any other comments?

43 people responded to this question.

Below are some of the comments

I don't like the idea of the being on a police list of autistic people. Especially given all the revelations coming out about police officers. behaviour.

I was given a CPN by WBDC/TVP, even though I have ASD.

No.

All of this is unknown to me. As soon as is have my diagnosis confirmed I will be accessing services.

I've lived in Berkshire for two years now. I have found it really unfriendly in certain respects. I have never heard so many open and unprompted discriminatory comments about gypsies - I think that this shows a general unease around diversity in Berkshire. Sometimes when I am cycling along the main road people shout nasty things at me from inside passing vehicles, including cars and buses. It makes me feel unsafe.

No support has ever been offered to me even when I am pleading for support and I inform people and services for my neurodiversity.

There needs to be more awareness and understanding of the different ways autism can present, particularly in women, and understanding of masking. As the ignorance is often a barrier to any understanding or accommodation because the most common response you get is 'you don't look autistic' and 'well everyone's a little autistic.'

One of the reasons why I did the survey was to make a point that for a lot of autistic people, especially when they transition into adults, there aren't a lot of services and social groups for adults, at least not as well advertised. In terms of employment, there are a limited amount of services that we can access and there are very few employers that understand autism and other neurodiverse conditions and often don't accommodate very well, so I do think this can be better, for both small and big businesses.

Disappointed that the alert card says "I have autism" rather than "I am autistic". I don't 'have' autism any more than I 'have' left-handedness or homosexuality.

I am waiting for an Autism assessment, and I am 50 years old.

Please come up with some help for adults with autism into the workplace, like a programme with mentoring.

I have been searching for resources such as books, articles, or educational courses that focus on communication and cultural knowledge specifically designed for immigrants with Autism. Unfortunately, I have not been able to find any. I believe addressing the communication needs of Autistic immigrants is crucial for both their mental and physical health, which in turn can alleviate the financial burden on the NHS. Additionally, it plays a vital role in helping them integrate into British culture. Clear information and effective communication are often necessary for people to understand their environment and know how to act or react, and this need becomes even more significant when considering individuals with autism.

I think you need to talk to people as I find questionnaires extremely difficult because sometimes the answers are not simple, hence surveys do not give a true and accurate picture.

People assume you have a learning disability if you are autistic - it is not clear enough to the public that even non speaking people can be very intelligent.

As someone who has become aware that they are likely to be autistic later in life the lack of support is appalling. Especially from the GP.

I would like people to understand that even when autistic people can attend mainstream school, have a job, relationships, children, or a social life, doesn't mean that they have no problems. I would like people to understand that living in a "normal" way is incredibly taxing to an autistic person.

'Things are getting better for autistic people but not quickly enough or with enough funding to support the change. Life is still a long way from fun and easy, or even acceptable.

Would like people to understand that even when autistic people can attend mainstream school, have a job, relationships, children, or a social life, doesn't mean that they have no problems. I would like people to understand that living in a "normal" way is incredibly taxing to an autistic person.

Needs much more support in particular respite on a regular basis does not have to fight for it and regular meetings more info.

Make services more noticeable for parents. Online sessions aren't enough. Kids education is being let down majority.

Things are getting better for autistic people but not quickly enough or with enough funding to support the change. Life is still a long way from fun and easy, or even acceptable.

*Please change language to be more autism friendly.
Identity first language rather than person first is more widely accepted in the autism community.
Eg autistic person rather than person with autism.
Also please refrain from using the medical term ASD as autistic individuals are not disordered.
Change the name from ASD resource units as language is key and as with other areas in society where language is no longer considered acceptable this needs changing NOW to help improve understanding in the wider community.*

Appendix

Methodology

As already mentioned, the survey was open for a period of 6 weeks from 5th June 2023 to 19th July 2023.

The survey was available in printed form on requests. It was communicated through social media posts, emails, residents' bulletins and internal communications at West Berkshire Council.

Respondent Profile

Q1. Are you answering as an Autistic person, or as a parent or carer on behalf of an Autistic adult or child?

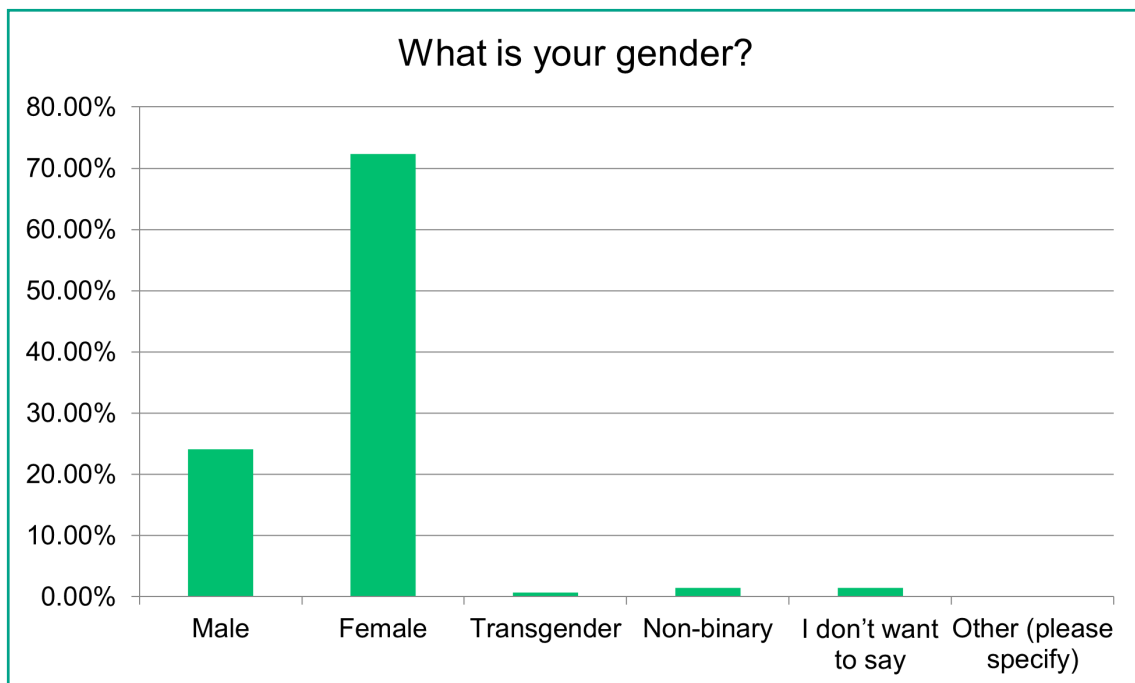
139 of the 144 people responded to this question.

48 (34.5%) identified themselves as an Autistic person

91 (65.5%) as a parent or carer on behalf of an Autistic adult or child

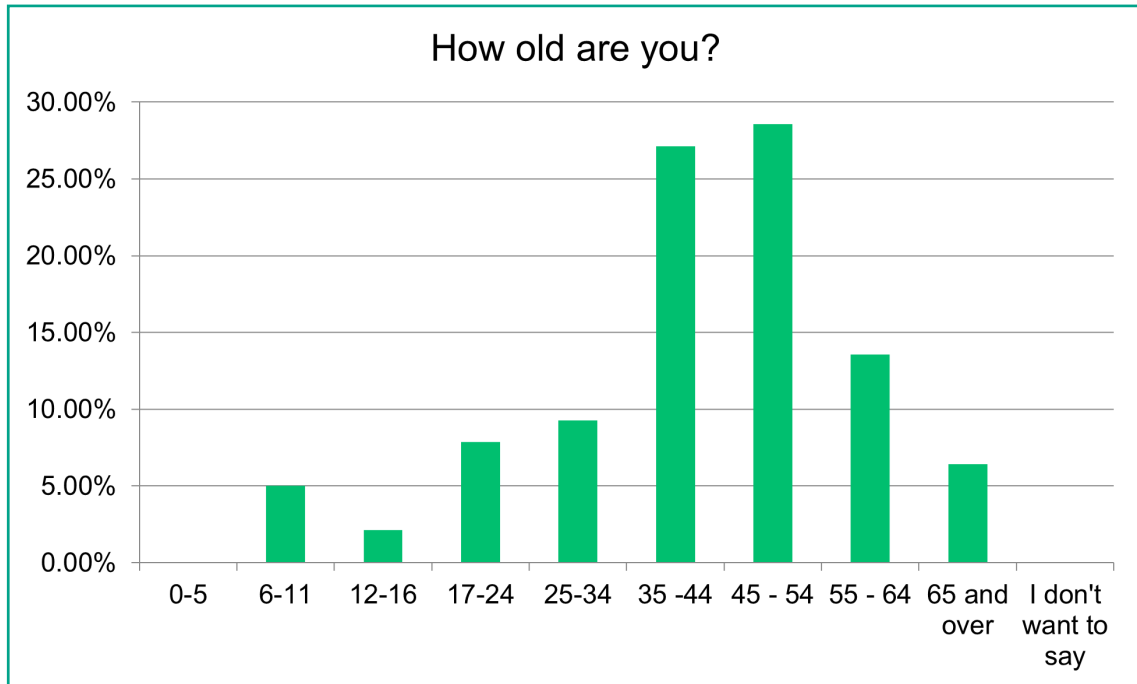
Q2. What is your gender?

141 people responded to this question.



Q3. How old are you?

140 people answered this question.



OUR SINCERE THANKS TO EVERYONE WHO TOOK TIME TO PARTICIPATE IN THE SURVEY