

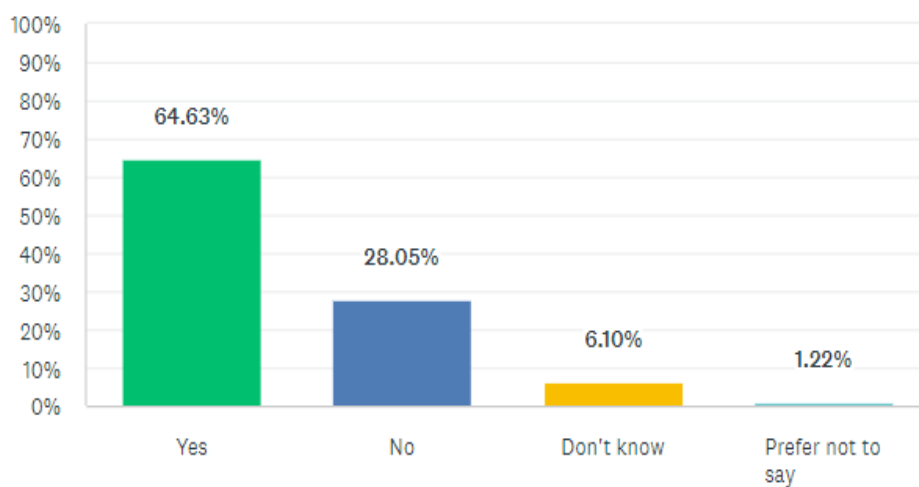
Extract from Young People’s Physical Health and Emotional Wellbeing Project Report 2024: Spotlight on Neurodiverse Respondents

The survey included the following definition:

‘Neurodiverse’ is an umbrella term which can include Autism, Attention Deficit Hyperactivity Disorder (ADHD), Dyslexia, Dyscalculia and Dyspraxia.

Q25. Do you identify, or think you might identify, as neurodiverse?

(You do not need to have an official diagnosis to answer ‘yes’ to this question.)



ANSWER CHOICES	RESPONSES	
Yes	64.63%	53
No	28.05%	23
Don't know	6.10%	5
Prefer not to say	1.22%	1
TOTAL		82

82 out of 154 young people taking part in this survey answered this question.

When asked if they identified, or thought they might identify as neurodiverse, from those 82 answering this question:

- 53 out of 82 (65%) said ‘yes’
- 23 out of 82 (28%) said ‘no’
- 5 out of 82 (6%) said they ‘don’t know’ and
- 1 out of 82 (1%) preferred not to say

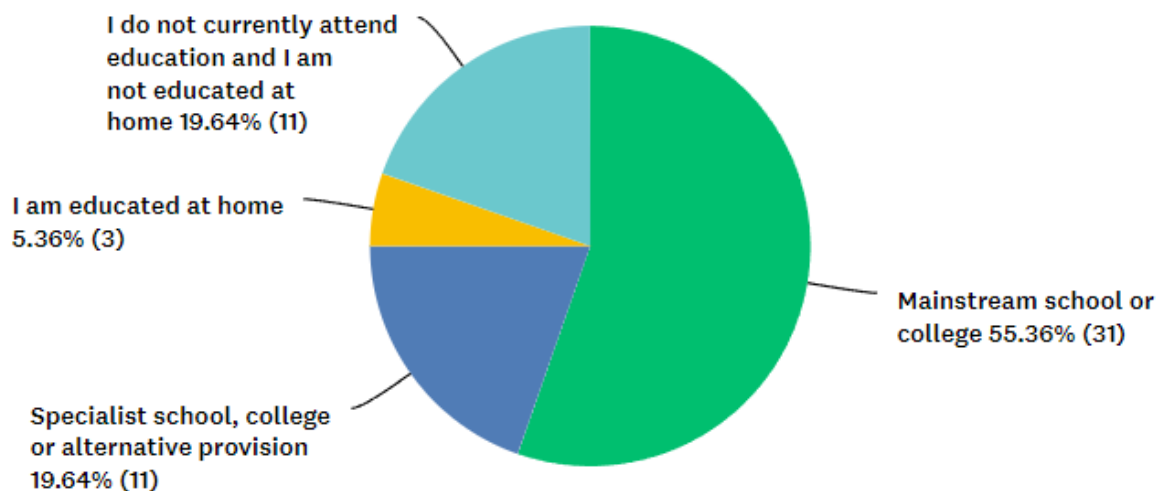
NB: It should be noted that only 82 out of 154 respondents answered these neurodiversity questions. If all other young people taking part in the survey did not identify as neurodiverse:

- for all the young people taking part in our survey, 34% (53 out of 154) said that they identified or thought they might identify as neurodiverse.

34 % is much higher than the current government estimate of 1 in 100 people being autistic, however we were using the wider umbrella term of ‘neurodiverse’, including ADHD, Dyslexia, Dyscalculia and Dyspraxia. The rise in numbers of people asking for assessments for neurodiverse conditions has been widely reported. The reasons for this rise are complex and remain under debate, it is likely to be attributable to a combination of factors. That is outside the scope of this piece of work, however it is important to acknowledge the extent of the numbers of young people identifying as neurodiverse in Worcestershire as this will have an impact on local Health and Care services.

We asked those young people who had said they either did identify, or thought they might identify as neurodiverse, about the education setting they currently attended:

Q26. Which of these education settings do you currently attend?



ANSWER CHOICES	RESPONSES
▼ Mainstream school or college	55.36% 31
▼ Specialist school, college or alternative provision	19.64% 11
▼ I am educated at home	5.36% 3
▼ I do not currently attend education and I am not educated at home	19.64% 11
TOTAL	56

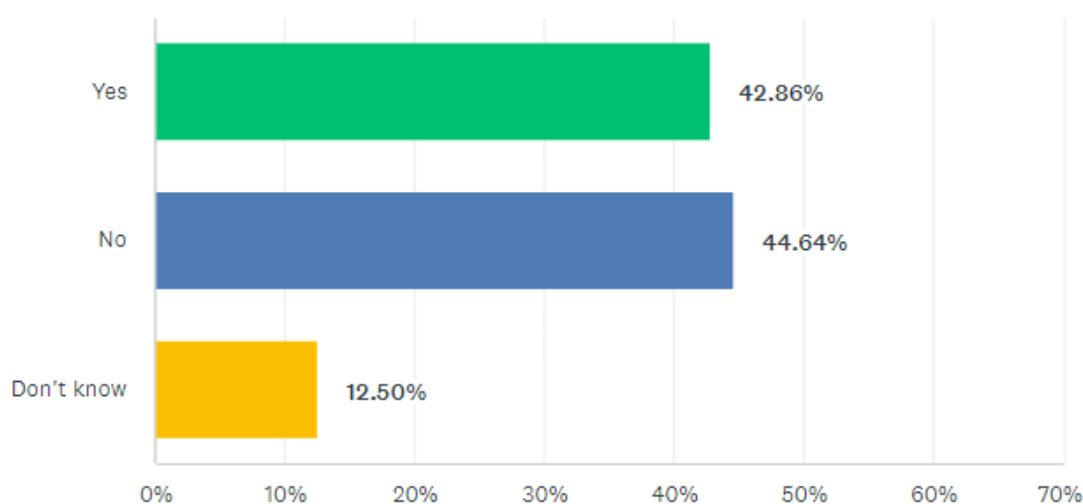
We asked those young people who had said they either did identify, or thought they might identify as neurodiverse, which education setting they attended:

- 31 (55%) said they attended mainstream school or college
- 11 (20%) said they attended specialist school, college or alternative provision
- 3 (5%) said they were educated at home
- 11 (20%) said they do not currently attend education and were not educated at home

NB: we surveyed young people aged 13-25. Of the young people who said they do not currently attend education and were not educated at home, 6 were aged over 18 so would have finished school or college.

We asked those young people who had said they either did identify, or thought they might identify as neurodiverse, whether they had an Education Health Care Plan (EHCP) in place.

Q27. Do you currently have an EHCP in place?

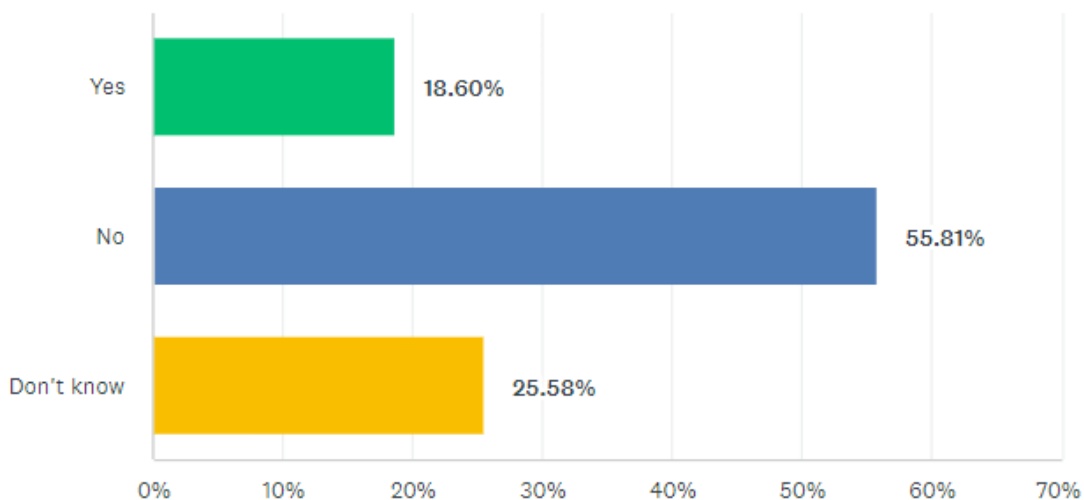


ANSWER CHOICES	RESPONSES
Yes	42.86% 24
No	44.64% 25
Don't know	12.50% 7
TOTAL	56

We asked those young people who had said they either did identify, or thought they might identify as neurodiverse, whether they had an Education Health Care Plan (EHCP) in place:

- 24 (43%) said yes, they did have an EHCP in place
- 25 (45%) said no, they did not have an EHCP in place
- 7 (12%) said they did not know

Q28. If you have an Education Health Care Plan (EHCP) has it provided the support you need?



ANSWER CHOICES	RESPONSES
Yes	18.60% 8
No	55.81% 24
Don't know	25.58% 11
TOTAL	43

43 young people answered this question about whether their Education Health Care Plan provided the support they need:

- 8 (19%) said yes, their ECHP provided the support they needed
- 24 (56%) said no, their ECHP did not provide the support they needed
- 11 (26%) didn't know

Q29. Please tell us more about this

We received 23 comments from young people who identified as neurodiverse about their experiences in education and their Education Health and Support Plans.

They have been grouped into the following themes:

Diagnosis / assessment (2 comments)

I suspect I might have ADHD (friends have also commented on it), but haven't been officially diagnosed or talked to SENDCO coordinator at school.

I am being assessed at the moment. I don't feel like everyone listens to me. They ask what I want but I don't know what is available. They ask what I think but then put something different in reports about me.

ECHP Refused (3 comments)

Social and emotional support not been given. County wouldnt send paperwork off for special colleges...it has made me more stressed

My Mom tried to get me one but Worcestershire would let me have one

We applied for an EHCP but it was declined. I would face benefited from having one to help me up to the age of 25 but now I can not access that help.

ECHP is Helping (3 comments)

I was in a mainstream autism base in school which suited my needs. I'm at sixth form college now in a normal class but I do have access to support if I need it. I am managing ok

I'm in a alternate college with 5 children, my EHCP works good I get the support i need

I go to an A.P and that's good but I'm still waiting for counselling in CAMS and they're trying to get help with trans stuff but it's hard asking.

ECHP is not Helping (6 comments)

Either been out of date or current one has multiple recommendations in it but no one to assess and implement them. WCF, LA all saying they can't help me.

They don't help and are quite bad

The school cannot meet my needs and do not understand me

Everywhere says they can't meet my needs.

Ehcp is not working for me

My school hasn't helped me much with my conditions. They have tried a few things but they make loads of promises to my mum and me when we have meetings then they never happen. I like my school, mates, and some of the teachers are good. But they need more people qualified to help anyone who is neurodiverse because they just don't get it. They think we are just bad kids, bad behaved, rude. But really if they new how our brains worked they might understand so much more. I sometimes shout out the answers or think out loud and I get sent out or a detention. How does that help? I can't make my brain work differently. I get behaviour points for not sitting still, I can't sit still for long. Our brains work differently because we are programmed to go into fight or flight mode, if I understand how my brain works it would be helpful for the adults I trust to be taught how it works.

Transition to adult services (1 comment)

When I became too old for camhs they literally dumped me. I was refused access to adult mental health services, by all the mainstream MH services as being too complicated. I was 9 months without any MH support, despite being prescribed SSRIs and antipsychotic medication. Eventually after a lengthy formal complaint sorted by my Mum, I was all allocated Dr XXXX whom I'm in contact with every 4 to 6 weeks.

Parents needing to complain / fight in order to receive support (4 comments)

School don't help me unless my Dad or Mum complain

Probably some support . Not sure if all of it. It's too long and I can't read it all. I know my mum has had to fight and fight for it

My mum has to keep complaining to school as they don't do the things they should. Because they don't, I end up getting into trouble and often get excluded for a few days. It upsets my mum and makes me feel like I'm a bad person. I can't help it

is at the moment but hasn't in the past and i'm scared about how long i will be funded for college as i missed most school years and i would like to attend education for another couple of years and we are really having to fight for this and it worries me a lot and affects my mental health

Other (4 comments)

Dont know if i have one

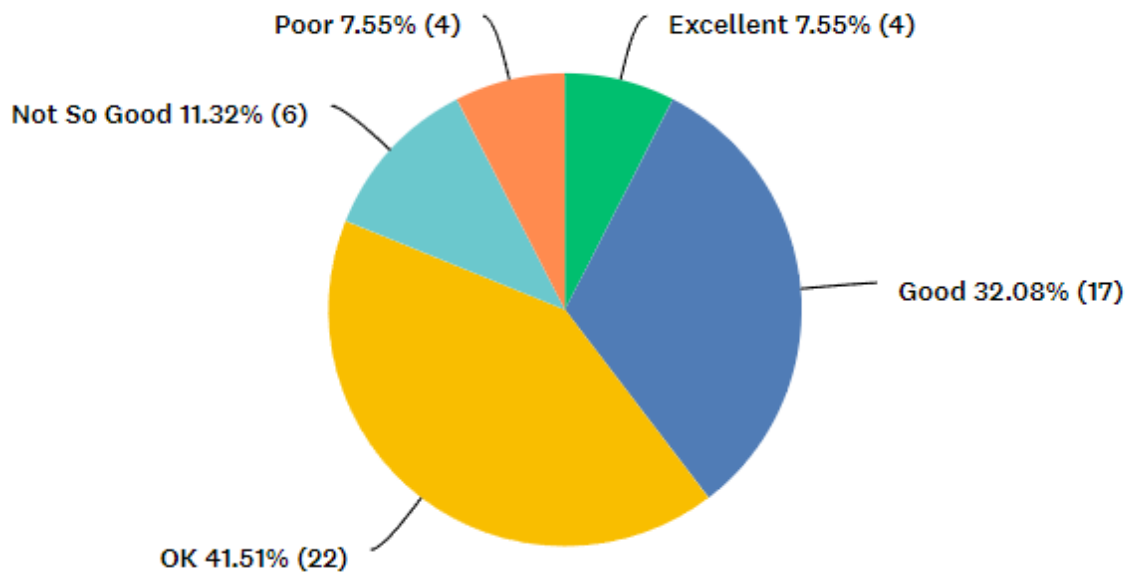
School independent paid by parents

I have graduated from a UK university and attended mainstream school in the past but not in the UK

I feel like my special school is just using me for the money they get from the council which is over £100k I only get two maths lessons and two English lessons a week with some filler rubbish. I'm 18 and still haven't done my GCSEs.

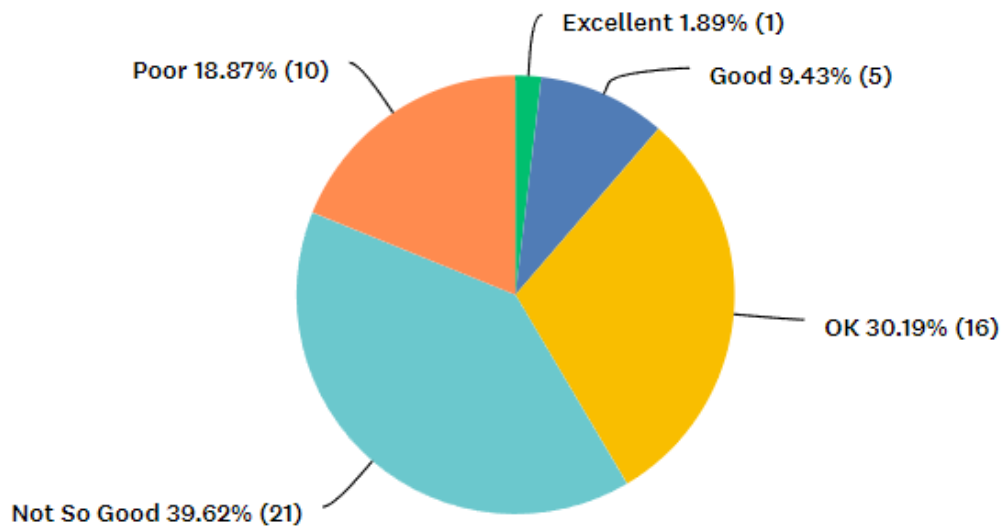
Other Experiences of Young People who identified as Neurodiverse

How would you describe your PHYSICAL health? Answers from Neurodiverse Young People



ANSWER CHOICES	RESPONSES
Excellent	7.55% 4
Good	32.08% 17
OK	41.51% 22
Not So Good	11.32% 6
Poor	7.55% 4
TOTAL	53

How would you describe your EMOTIONAL WELLBEING / mental health? Answers from Neurodiverse Young People



ANSWER CHOICES	RESPONSES	
▼ Excellent	1.89%	1
▼ Good	9.43%	5
▼ OK	30.19%	16
▼ Not So Good	39.62%	21
▼ Poor	18.87%	10
TOTAL		53

	PHYSICAL HEALTH All respondents	PHYSICAL HEALTH Neurotypical	PHYSICAL HEALTH Neurodiverse
Excellent or good	47%	61%	40%
OK	36%	26%	42%
Not so Good or poor	17%	13%	19%

We examined responses from young people who identified or thought they might identify as neurodiverse and compared them to the figures for all our respondents and to neurotypical young people.

For physical health there was a difference between the young people:

21% fewer young people with neurodiversity rated their physical health as ‘excellent’ or ‘good’ (40%) compared to their neurotypical peers (61%).

	EMOTIONAL HEALTH All respondents	EMOTIONAL HEALTH Neurotypical	EMOTIONAL HEALTH Neurodiverse
Excellent or good	27%	43%	11%
OK	30%	35%	30%
Not so Good or poor	43%	24%	59%

For emotional wellbeing and mental health, the difference between the groups was even more pronounced:

Only 11% of the young people with neurodiversity rated their emotional wellbeing or mental health as ‘excellent’ or ‘good’ compared to 43% of their neurotypical peers.

59% of young people with neurodiversity rated their emotional wellbeing or mental health as ‘not so good’ or ‘poor’ compared to 24% their neurotypical peers.

Do you think you have enough information about looking after your physical health? Compared with looking after your emotional wellbeing / mental health?

	PHYSICAL HEALTH All respondents	PHYSICAL HEALTH Neurodiverse	EMOTIONAL HEALTH All respondents	EMOTIONAL HEALTH Neurodiverse
Yes, definitely	24%	15%	19%	9%
Yes, kind of	55%	57%	39%	30%
No	15%	19%	33%	55%
Not Sure	6%	9%	9%	6%

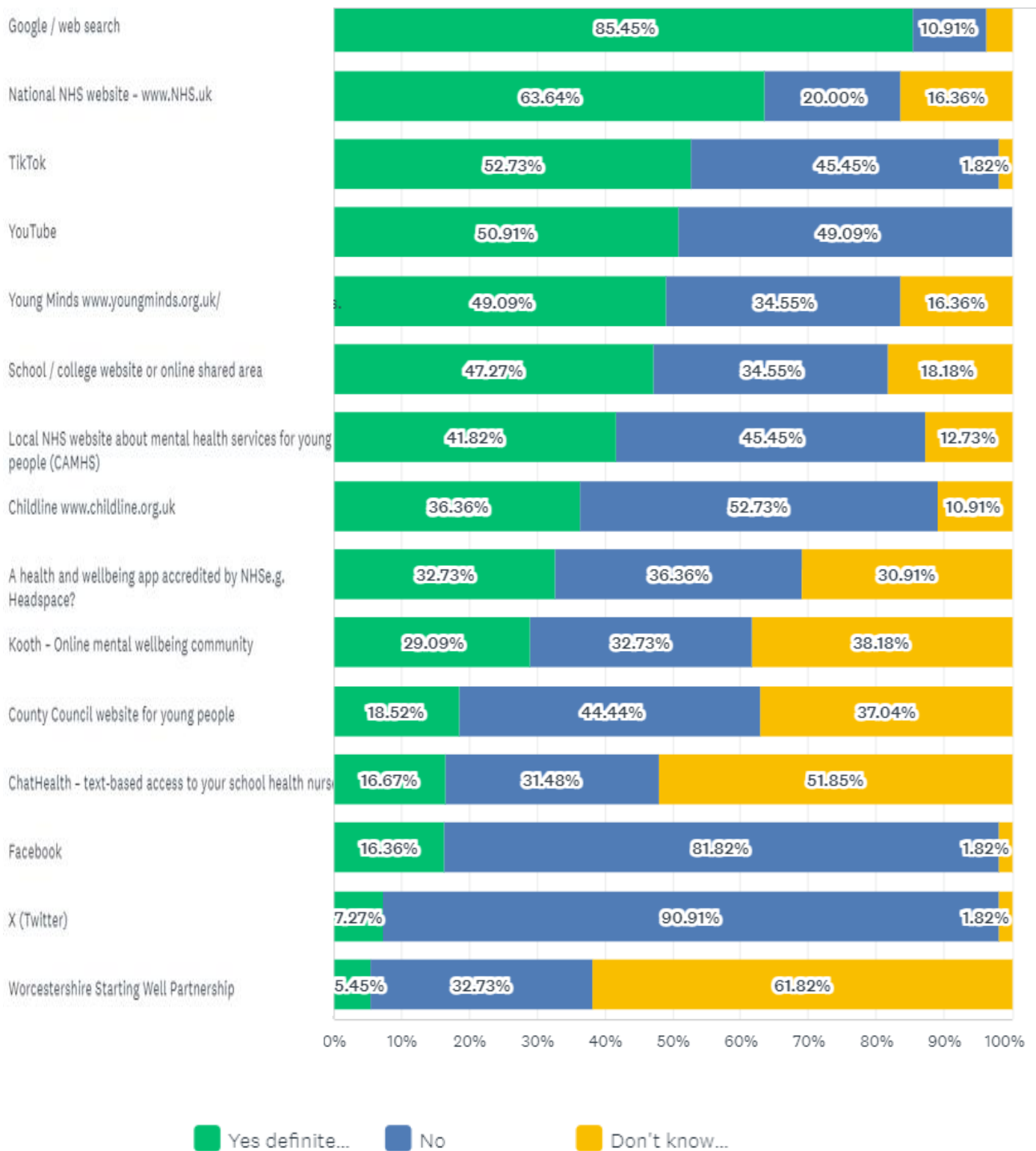
For having enough information about their **physical health**, there is a slight difference in confidence between those who identify as neurodiverse and all respondents.

15% of neurodiverse young people thought they definitely had enough information about looking after their physical health, compared to 24% of all young people.

For having enough information to look after their **emotional wellbeing and mental health**, the difference between the groups was more pronounced:

55% of young people who identified as neurodiverse answered ‘no’ when asked if they thought they had enough information about looking after their emotional wellbeing or mental health. 33% of all young people answered ‘no’ to this question.

Where would you look for information about Health and Wellbeing Online? Answers from Neurodiverse Young People



Where would you look for information about Health and Wellbeing Online? Answers from Neurodiverse Young People

	YES DEFINITELY	NO	DON'T KNOW ABOUT THIS	TOTAL
Google / web search	85.45% 47	10.91% 6	3.64% 2	55
National NHS website - www.NHS.uk	63.64% 35	20.00% 11	16.36% 9	55
TikTok	52.73% 29	45.45% 25	1.82% 1	55
YouTube	50.91% 28	49.09% 27	0.00% 0	55
Young Minds www.youngminds.org.uk/	49.09% 27	34.55% 19	16.36% 9	55
School / college website or online shared area	47.27% 26	34.55% 19	18.18% 10	55
Local NHS website about mental health services for young people (CAMHS)	41.82% 23	45.45% 25	12.73% 7	55
Childline www.childline.org.uk	36.36% 20	52.73% 29	10.91% 6	55
A health and wellbeing app accredited by NHSe.g. Headspace?	32.73% 18	36.36% 20	30.91% 17	55
Kooth - Online mental wellbeing community	29.09% 16	32.73% 18	38.18% 21	55
County Council website for young people	18.52% 10	44.44% 24	37.04% 20	54
ChatHealth - text-based access to your school health nurse	16.67% 9	31.48% 17	51.85% 28	54
Facebook	16.36% 9	81.82% 45	1.82% 1	55
X (Twitter)	7.27% 4	90.91% 50	1.82% 1	55
Worcestershire Starting Well Partnership	5.45% 3	32.73% 18	61.82% 34	55

In the charts above, the positive answers ‘yes - definitely’ and ‘yes - possibly’ have been combined. The results have then been sorted into descending order of preference.

The most popular answers for neurodiverse young people were:

Google, NHSE website, TikTok and YouTube.

This differs to their neurotypical peers notably for ‘school/college noticeboard or website’ - this option was quite popular with neurotypical young people with 55% saying they would use this. For neurodiverse young people this was rather lower at 47%.

Has there been information you have wanted but not been able to find?

Comments from Neurodiverse Young People:

Asperger's in women, managing neurodiversity and masking

I am also autistic and adhd. Despite being 20 I am totally reliant on my mum to help me get the help I need. It is too complicated to navigate on my own. The systems are too unhelpful and sometimes the only way my mum gets me help is by raising a formal complaint. None of my local health professionals have any clue about FND, so I rely on Facebook FND groups for help or people on TikTok who have the same diagnosis.

sleep and how to create good habits

I never know which information is reliable and find it hard to find what I want online

Any advice and support around my diagnosis would of been nice

General mental health support thats good

Everything is online. What if I want to talk to someone? I don't trust many people and some things are difficult to talk about.

Gender identity and gender dysmorfia in neuro diverse people

I have ADHD and I thinkni have more issues and nobody will help just my Mum who keeps trying to get me extra help

Struggle to access and read information online, Need videos with scenarios or simple information Camhs turned down my referral I didn't meet need for social worker or young adults service Autism support declined support I just fall through all the services 19 nearly 20 with no support other than family

Over the last year have you stopped doing relaxing activities? Why?

	NEURODIVERSE Young people	NEUROTYPICAL young people
Proportion who answered 'yes' I have stopped doing a relaxing activity	67%	47%

Overall a larger proportion (67%) of neurodiverse young people said they had stopped doing a relaxing activity in the last year.

The reasons why they had stopped doing a relaxing activity were explored through the comments. As for the whole group of respondents, the two main reasons the neurodiverse young people identified for stopping doing their relaxing activities were evenly split between financial concerns and poor mental health.

These figures show how neurodiverse young people are affected by the same issues - rising cost of living, poor mental health - as all young people. However, the degree to which these issues are impacting appears to be greater for neurodiverse young people.

Digital Access to Healthcare and Support for Neurodiverse Young People

How easy would you find discussing your health or emotional wellbeing concerns on a telephone / video call?

Responses suggest that overall young people would not find it easy to speak about health or emotional wellbeing issues by phone or video call. **Only 8% said this would be easy and 65% told us this would be difficult or they would not be able to do it.**

For neurodiverse young people, 6% said this would be easy and 69% told us this would be difficult or they would not be able to do it.

How easy would you find having somewhere private to have a confidential telephone or video call during the day e.g. to speak to a Doctor or a counsellor?

Responses show that of all respondents **19% would find it difficult** to find somewhere private to speak to a doctor or to access support via the phone or video call and **33% said they would not be able to.**

For neurodiverse young people, 42% told us they would not be able to do this.

How easy would you find having enough mobile phone data or credit to speak to someone via video call or download and use apps?

64% of respondents said it would be easy or ok to have enough mobile phone data or credit. The remaining 36% said it would be difficult or not possible for them to do this.

For neurodiverse young people, 61% said it would be easy or ok to have enough mobile phone data or credit. 39% told us this would be difficult or they would not be able to do it.

Neurodiverse young people have told us that they would find it harder to access healthcare and support on digital platforms than their neurotypical peers.

Their ability to have enough mobile phone data or credit is broadly the same as their peers, but their ability to find somewhere private to have a confidential conversation, and then their willingness to discuss their health or emotional wellbeing concerns on a telephone / video call is less.

Preferred Options for Emotional Wellbeing Support for Neurodiverse Young People

The top ranked options for support for neurodiverse young people echoed the wider group taking part in the survey:

Ranking	Type of support	All young people	Neurodiverse young people
1	One-to-one session out of school / college	72%	75%
2	One-to-one session at school / college	55%	58%
3	Online or text message support, e.g. Kooth	42%	38%

Have you received any support for emotional wellbeing or mental health from school, health, online or other support services in the last 12 months? Answers from neurodivergent young people.

53 young people who identified as neurodiverse answered this question.

Neurodivergent Young People who have received support:

21 of the 53 (40%) told us they had received support for emotional wellbeing or mental health in the last year, this is about the same as all respondents.

Neurodivergent Young People who have requested but not received help:

26 of the 53 (49%) said they had needed support but not been able to get it - this is higher than the figure for neurotypical young people (22%).

The proportion of all young people answering our survey that have needed support but not been able to get any is 40%.

Neurodiversity and Gender Diversity:

In this survey, all 11 (100%) of the young people who identified or thought they might identify as gender diverse also identified as neurodiverse.

Comments from neurodiverse young people:

I am autistic and have burnt out. Going to school made me really ill because I couldn't cope. I want to be at school but it is a nearly a year since I have been properly because the support I need hadn't happened. I miss school and learning and wish people would understand that my brain just doesn't work in normal schools.

Asperger's in women, managing neurodiversity and masking

I am also autistic and adhd. Despite being 20 I am totally reliant on my mum to help me get the help I need. It is too complicated to navigate on my own. The systems are too unhelpful and sometimes the only way my mum gets me help is by raising a formal complaint. None of my local health professionals have any clue about FND, so I rely on Facebook FND groups for help or people on TikTok who have the same diagnosis.

I have ADHD and I thinkni have more issues and nobody will help just my Mum who keeps trying to get me extra help

I'm autistic need face to face real people

I can't talk on the phone due to autism and selective mutism

Autism makes it hard for me yo understand people. This is even harder on the phone or video.

Comments about CAMHS - experiences of neurodiverse young people

CAMHS are not helpful if you have autism

I have had many experiences with CAMHS and Healthy Minds. They are very quick to put you onto a CBT course (I have done four altogether) and CBT does not work for everyone. My mental health would decline more after reaching out to these services as I would end up feeling I was beyond help. They once said to me "you sound like you could have Asperger's, does this sound right to you?" And, as an uneducated young teenager, I said no and the topic was never brought up again. I will now be trying to get an autism diagnosis that could have happened at the start of my counselling [sic] journey

I don't think CAMHS always understand my autism and they get me to try and do things which are really hard for autistics. It makes me feel a failure. It took months to see anyone after I first tried to kill myself. I think things got worse because I didn't have help. I might have been able to stay at school if someone had helped me sooner. I miss school and my life.

CAMHS don't understand autism and how it affects me. They think if I get more friends, everything will be ok but it doesn't work like that

Young People's Physical Health and Emotional Wellbeing Project Report 2024: Recommendations Specifically Relating to Neurodiverse Young People

- When providing information to young people about looking after physical health, emotional wellbeing and mental health, attention should be given to ensure it is accessible to neurodiverse young people, in line with the Accessible Information Standard.
- When offering Healthcare or support appointments to neurodiverse young people ensure that the option to see someone in person is always included.
- Clarify the treatment pathway for neurodiverse young people seeking support for their mental health.
- Investigate why neurodiverse young people are frequently reporting being refused appointments with CAMHS due to their neurodiversity.
- Clarify and communicate treatment pathways for associated conditions such as ARFID (Avoidant Restrictive Food Intake Disorder), Dyspraxia, FND (Functional Neurological Disorder).