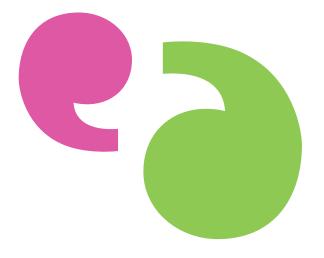


Young people and their families' experiences of Autism and ADHD diagnosis in Northamptonshire







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Summary

In the Autumn of 2023 Young Healthwatch Northamptonshire was commissioned by Northamptonshire's Integrated Care Board (ICB) to carry out research exploring the experiences of young people and their parents and carers who were waiting for an assessment of Autism and ADHD or those that had been recently diagnosed.

To complete this work a survey was designed by Young Healthwatch Northamptonshire and shared across the county. The survey was then adapted for parents and carers. The survey looked at the support that was needed, accessed and struggles that young people and their families had while waiting or being recently diagnosed with Autism or ADHD in Northamptonshire.

Between January and February 2024, a total of 322 people responded to the survey. 115 young people between the ages of 11 and 18 and 209 parents and carers of 11 to 18 year olds. This is thought to be around 5% of those on a waiting list in Northamptonshire. To gather the responses, we worked with local schools and partners. Although every school in West and North Northamptonshire was contacted and offered a paper version of the survey all responses were gathered online.

The top 5/6 things that parents said their young person found hard to deal with were:

- Education 75%
- Mental health 65%
- Maintaining positive relationships with peers 64%
- Social skills 61%
- Social activities 50% and sleep 50%

For young people the thing they found hardest to deal with were:

- Social skills and education both 73%
- Mental health 68%
- Maintaining positive relationships with peers 65%
- Sleep 63%
- Anger 62%

Key findings

- 23% of respondents said their young people were waiting for an ASD diagnosis, 17% said they were waiting for an ADHD diagnosis and 33% said they were waiting for both.
- 23% of young people said that they were waiting for a diagnosis for ASD, 20% said they were waiting for an ADHD diagnosis and 30% said they were waiting for a diagnosis for both.
- The majority of parents and carers did not feel that their child's gender (75%) or culture and religion (91%) impacted their access to services.
- 32% of parents said their young person had no support from any organisation after diagnosis.
- 31% of young people said they had no support from any organisation after diagnosis.
- The majority (71%) of parents wanted their young person to access support at school/college or at home.
- The main way that young people want to access support is in school (51%) followed by 20% at home. Only 8% wanted support in an app and only 4% wanted support online, 1% said on a website.
- 44% of young people did not think that the services available to them had helped them.

Recommendations

- 1. Offer more help or support to young people and their families when they receive a diagnosis for Autism or ADHD, this should be in a format that they can understand easily with signposting to the relevant organisations.
- 2. Work with schools to better support pupils in school. Including autism and ADHD training for all staff, Autism and ADHD awareness across schools including peers.
- 3. Better support for young people and their families with sleep and advice. Including better access or utilisation of the school nursing teams.
- 4. Regular updates for young people and their families about where they sit on the waiting lists for Autism and ADH diagnostic services and appointments.
- 5. Better support for young people and their families while waiting for a diagnosis of Autism and ADHD.

Response from Northamptonshire Integrated Care Board

NHS Northamptonshire ICB welcomes this Young Healthwatch report on young people and their families' experiences of Autism and ADHD diagnosis in Northamptonshire. In the last 5 years, nationally and locally, there has been a significant increase in demand for children and young people requesting an assessment for neurodiversity. We recognise this has resulted in an increase in waiting times and we are keen to work with young people to improve the type of support we can provide with the resources available to use.

This report is very important in helping us to develop our offer. With the diversity of age, gender and where our young people live, there is a good representation to better inform our work moving forward. Families have demonstrated through this survey that the majority of young people do get support, however there is a significant number who do not seem to be able to get the help they need. This report shows there is still a lot of work that needs to be done in Northamptonshire and indeed nationally to better understand what type of support children and young people would find the most beneficial.

We recognise that we must continue to develop our workforce across children and young people services assured by our local SEND improvement boards, Northamptonshire Children and Young People Transformation Programme and Northamptonshire's Mental Health, Learning Disabilities and Autism programme to continue to improve the support we offer.

There is work taking place through NHFT's iDiscover project that offers training directly to children, young people and their families who require further support; and in September 2024, the Partnership Inclusion of Neurodiversity in Schools (PINS) project will be going live in forty primary schools across the county to improve how we can help younger children whether they have a diagnosis or not.

As stated in the Northamptonshire Autism Strategy, the local NHS and our partners are dedicated to the proposition of "no decision about us without us". This important study by Young Healthwatch once again provides the evidence we need to inform our local decisions and we are grateful to Young Healthwatch and all the children, young people and their families who participated in this survey.

Background

This piece of work is to feed into a larger piece of work that Northamptonshire Integrated Care Board (ICB) are doing around support for people who are waiting for services, appointments and diagnosis of ASD and ADHD in Northamptonshire. It is a continuation of work previously carried out by Healthwatch Northamptonshire¹. This work will help the ICB to understand what works well and what needs improving for young people and their families who are waiting for an ADHD or ASD assessment in Northamptonshire and for those who are newly diagnosed.

Across Northamptonshire it is estimated that there are 2,444 and 3,154 children and young people with Autism. It is believed that there are around 2,200 young people on a waiting list for Autism or ADHD diagnostic services. The figures for ADHD is currently not known. The current waiting times for a young person from referral through to first face to face appointment is around 60 weeks with the wait sometimes around 3 and a half years from referral to diagnosis or further support².



https://www.healthwatchnorthamptonshire.co.uk/sites/healthwatchnorthamptonshire.co.uk/files/asd_adhd_project_report_august_2018_final.pdf

² Autism Joint Strategic Needs Assessment 2024 Northamptonshire.

Method

Survey design

Young Healthwatch Northamptonshire was asked to design a survey for 11-18 year olds to ensure that it would engage other young people locally and that the questions asked would be appropriate. At their meeting in November 2024 Young Healthwatch Northamptonshire designed the survey questions. As with previous surveys they agreed that the survey should be no longer than 20 questions, should be available online and in paper format and the paper survey should be no longer than two sheets of A4 paper so that it would not take too long for young people to complete.

Survey distribution

The target was to have a minimum of 100 responses from young people and 100 responses from parents and carers. The responses were to be across both West and North Northamptonshire.

The survey was distributed to every school in Northamptonshire through email to the named Special Educational Needs Coordinator (SENDCo). Phone calls were also made directly to the schools. Northamptonshire Association of Youth Clubs (NAYC) also added the survey to their newsletter.

The survey was also shared across our social media channels (Facebook, Instagram, Snapchat and X (formally Twitter)).

On X posts about the survey appeared on people's timelines around 700 times and on Facebook the posts appeared on timelines nearly 3,600 times. The posts were viewed on Instagram around 150 times.



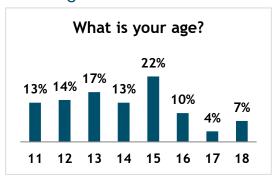
What people told us

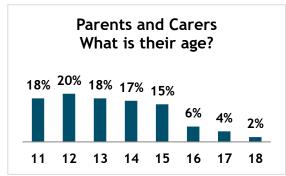
- 113 young people responded to the survey that ran from January to February 2024.
- 209 parents and carers responded to the survey in the same period.
- All figures given are percentages of the answers received for each question, unless otherwise specified.

Demographics

Age

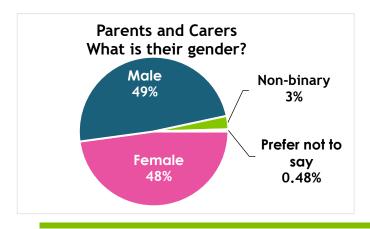
Over 80% of young people that responded were between the ages of 11 and 15, over 87% of parents and carers said that their young person was between the same ages.

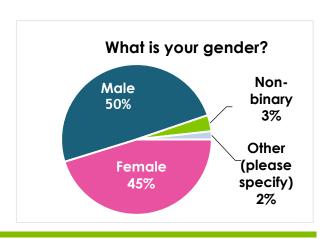




Gender

50% of young people that responded were male and 45% were female. 3% identified as non-binary and two young people selected the other category. Parents and carers told us that 49% of their young people were male and 48% were female, with 3% also telling us that their young person was non-binary. 9% of young people told us that the gender that they identify as was not the gender that they were assigned at birth.

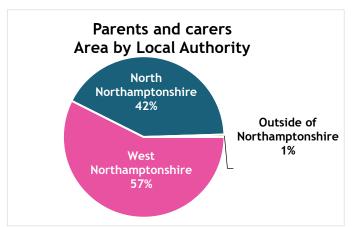


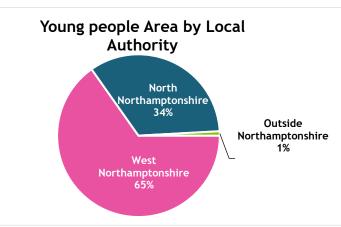


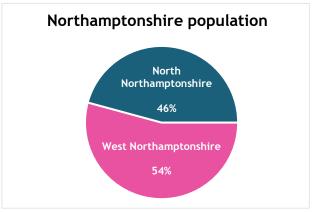


Location

Over half the young people and parents and carers told us that they live in the West Northamptonshire area (65%) and (57%) North Northamptonshire. Less people said that they lived in North Northamptonshire. This is similar to the latest census data³. Where a greater number of the population (54%) lived in West Northamptonshire.







³ 2021 Census data

Ethnicity

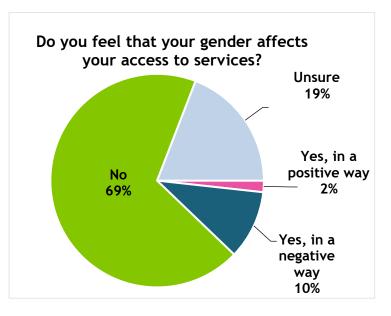
Most young people (89%) said that they were White British. A further 5% said that they were from any other white background. The same percentage of parents and carers (89%) said that their young person was White British. This is relativley close to the census data where 86% of the population in West Northampotonshire identified as White and 90% in North Northamptonshire.⁴

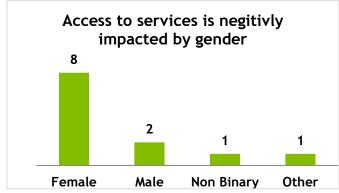
Religion

We asked everyone for their religion. The majority of respondents identified as being Christian or having no religion. Faith was not seen as a particular factor affecting young people or their families' accessing services. Therefore, the minor significance means that the data has not been analysed in detail.

How gender impacts access to services

The majority of young people (69%) did not think that their gender impacted their access to services. 10% of young people said that they thought their gender impacted their access to services in a negative way. Of those that said they thought it impacted them in a negative way 8 young people said that they were Female, 2 were Male, 1 was Non-binary and one self discribed as Agender.



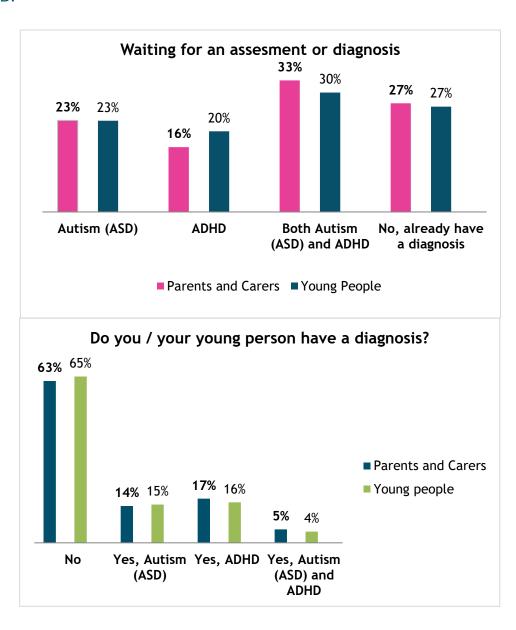


⁴ https://www.nomisweb.co.uk/sources/census_2021/report?compare=E06000061

Services being waited for

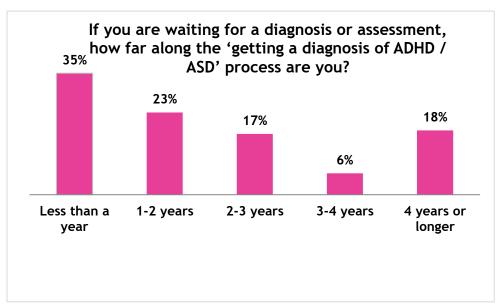
73% of young people told us that they were waiting for a assessment with the expectation of a diagnosis or an appointment for either Autism, ADHD or both. The response from parents and carers was the same 73% of their young people were also waiting for an assessment or diagnosis. (reword) 208 Parents responded and 113 young people. So even though there were nearly double the amount of parents and carers the percentages were the same. We saw similar when we asked if people had a confirmed diagnosis.

We saw that over 60% (63% of parents and carers and 65% of young people) of all participants said that they had no diagnosis and a very small number (5% parents and carers and 4% of young people) had a diagnosis for both Autism and ADHD.

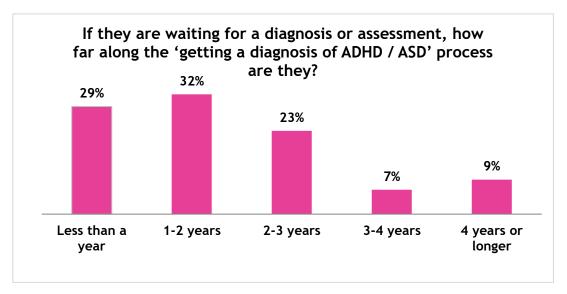


Waiting times

18% of young people told us that they have been on the waiting list for more than 4 years. With over 41% of young people waiting for one year or longer. 35% of young people told us that they had been waiting less than a year. (98 responses)



Parents and carers told us similar, with 39% telling us that their young person had been waiting for 2 years or more. 29% told us that they had been waiting less than a year. (182 responses)

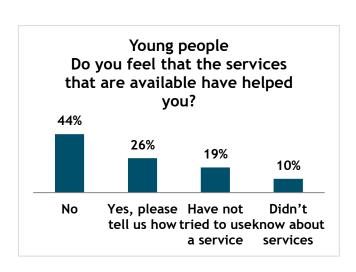


Receiving support

31% of Parents told us that when their young person got their diagnosis, they received no help or support. 10% told us that they got support Parents told us that when their young person got diagnosed, they used a variety of services. Young people told us similar, 31% also said that they received no help or support a further 11% of young people told us that they did receive support. Below is a table of where parents and carers and young people said they received support.

Service	Parents	Young people
Charities (including Enfold and Service Six)	6	1
Council services (including Send Support Service – SSS)	5	1
Autism and ADHD teams (St Marys and Sudborough house)	5	1
School	4	4
Private therapies	2	1
Information Advice Support Service (IASS)	1	1
Family	0	1
GP	0	1
Paediatrician	0	1
CAMHS	0	1
Educational Psychologist	0	1

We asked if young people thought the services that they had used had helped them. 44% said that they didn't feel that the services that they had used had helped. 26% of young people said that they did feel that services had helped. Some told us that the services had only helped a little:



"Teachers are kind of understanding sometimes"

"Only some, give advice on emotions"

"Somewhat, however the services are limited and when more specialist support is identified as being required there is no access to this"

"I think they did a little bit"

"A little bit to help sleep but not much"

"Helped for short periods of time"

"Kind of as it was good when I was having it but now it's stopped it's not ok"

"A little bit not much"

Peer support and feeling listened too were also what mattered to young people:

Be around people like me

Listening and understanding

Helped me talking

Helped me connect with other people like me. Nice to know I'm not alone

They have only helped because I was able to talk to them

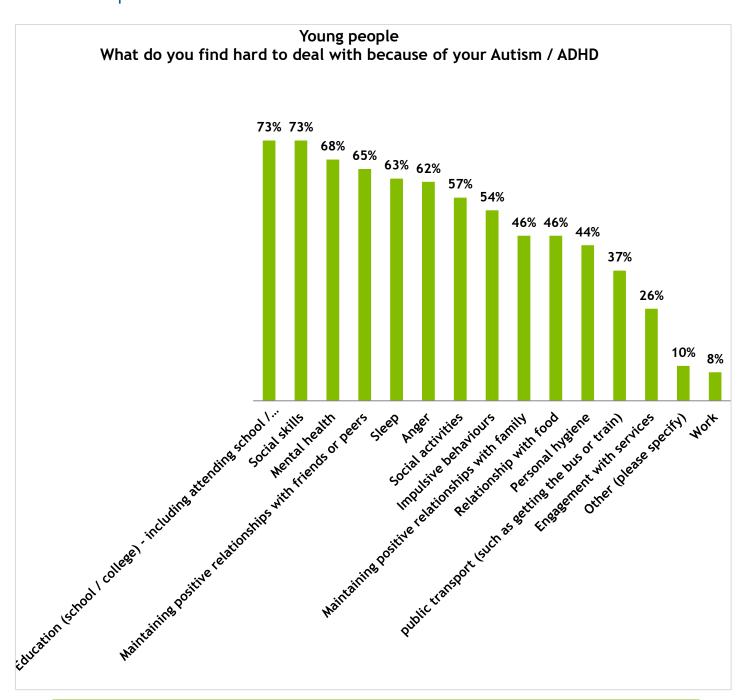
Counselling through school made it a lot easier to talk about possibly being autistic with family and start working towards getting a diagnosis. It helped because there was a trusted adult/authority figure taking my concerns seriously which meant my parents listened to me more

Improved relationship's & ability to share thoughts and feelings

Challenges due to Autism and ADHD

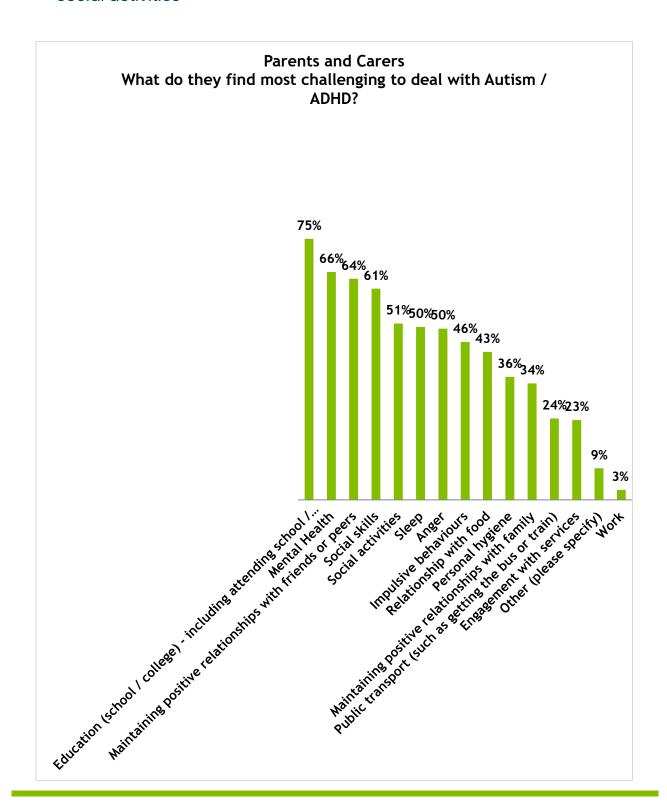
We asked what people felt was hard to for them or their young person to deal with because of their Autism or ADHD, people were able to select multiple answers. The majority of young people (over 50%) told us that the hardest things for them to deal with were:

- Education
- Social skills
- Mental health
- Maintaining positive relationships with friends/peers
- Sleep
- Anger
- Social activities
- Impulsive behaviours



Parents and carers told us similar with over 50% stating that their young person struggled with 7 of the 8 issues that were also identified by young people.

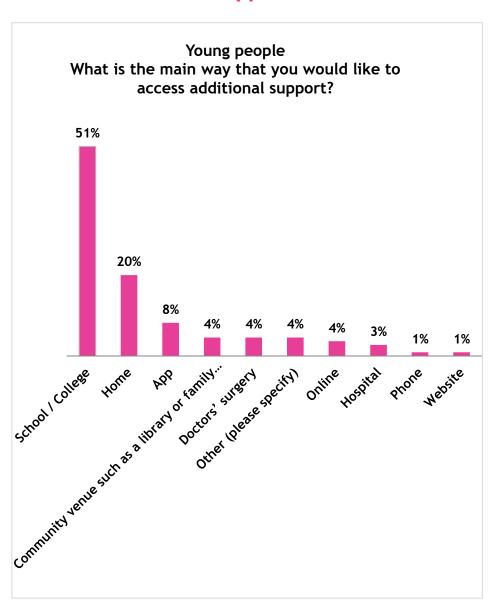
- Education
- Social skills
- Mental health
- Maintaining positive relationships with friends/peers
- Sleep
- Anger
- Social activities

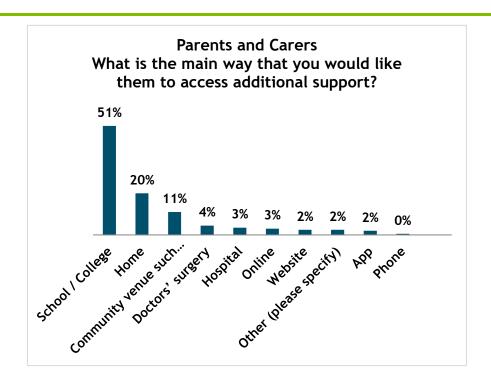


Support that is required

Where young people would like to access support

We asked young people where they would like to access support, we asked them to tick one option. The majority of people (51%) told us that they would like to access additional support in an education setting such as school or college. A further 20% of young people told us that they would like to access additional support at home. Very few young people (12%) told us that they would like to access additional support in an online format, such as an app or website. (112 responses) Parents and carers told us the same, 71% told us that they thought that their young person would like to receive support in school or at home.





Support from the school

A high proportion of respondents felt that they require more support and understanding from their school. This was mentioned by 24 respondents. Some responses indicated the lack of understanding from their teachers:

"More support in secondary school. I had suffered from bullying, and the teachers were useless in my case. They didn't seem to understand how to deal with me."

Respondents felt more structure was needed in terms of their learning and an understanding of their individual needs:

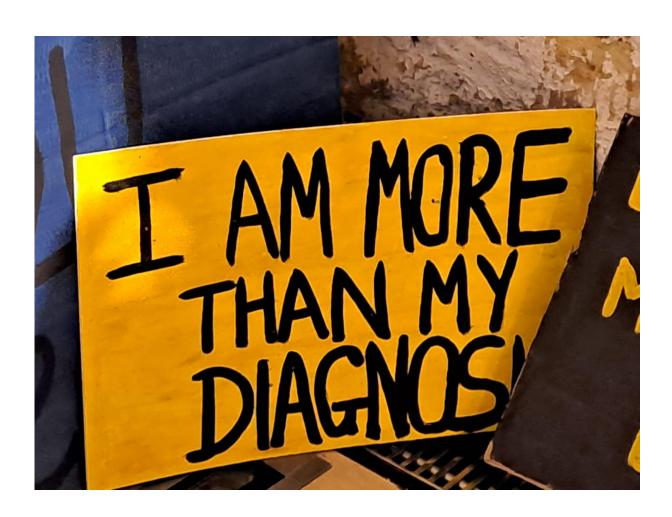
"Help with breaking down homework and revision into manageable chunks and getting the motivation to do any of it."

"Support in school with lessons/work and for a better understanding of me and my problems."

One student highlights the communication between themselves and their teachers. They make reference to being reprimanded without the explanation they need, resulting in confusion and frustration for the student:

"Teachers/ schools taking into consideration my diagnosis and the traits I have because of it, when it comes to teaching methods used in my learning. I get distracted, reprimands me for not paying attention. I don't always understand what I've done wrong. I politely ask in a respectful manner what I've done wrong because my neurodivergent mind and thought process isn't the same. I get minimal explanation and sometimes further reprimanding for seeming insubordinate. Leaves me confused and frustrated as no one has explained what I've done wrong."

A respondent suggests way that support can be improved, including more integrated educational support; taking into account the student's needs and more acceptance of their difficulties.





"Understanding; full support from all education providers, instead of discrimination or being dismissive. Help, guide, assist and have a thought of what the individual needs....smaller classes"

Respondents also names specific ways in which the school could support them:

"At school, help with anger, anxiety, sleep"

"Help at school, help with anger and tics"

Understanding of the students' needs

A common theme was the need for students to have better understanding and awareness about their condition, which can help them to make sense of their difficulties:

"I need to know what's wrong with me, why am I like this and why is everything is so hard."

"A better understanding of what's going on with me; easy to understand education around autism."

A couple of responses indicate that what is in place has not been sufficient, with generic information/leaflets not providing them with the insight they require:

"I had no support or help following my diagnoses. My mum was just given a leaflet. Some people said they had helped me when I had never even met them."

"They don't really care or just spew off generic advice that I could've come up with myself."

Specific therapies/training

A few respondents mentioned that access to counselling, social skills training and other wellbeing support would be beneficial. One respondent suggested dietary advice would be helpful. Additionally, a respondent makes reference to the need for the counselling to be readily accessible:

"Cognitive behavioural Therapy or other targeted trauma support."

"Counselling easily to get hold off in immediate."

"Autism specific emotional wellbeing support e.g. anxiety work and autism specific social skills support."

"Social skill training learning about my ADHD, as we are all different."

"Social skills and organisation."

"Dietary help."

A less emotion-focussed approach is required for one respondent:

"I don't feel that PIC at school has done me any good, as they focused on my emotions instead of helping me with other stuff. I don't feel I have issues with my emotions."

Peer support

A couple of respondents saw the benefit in the share understanding with others going through the same process:

"Meeting other teenagers for groups."

"Youth clubs, workshop, groups."

"Youth groups that are made for kids with disabilities, so they can learn to socialise."

Assessments and diagnosis

For many being able to have an assessment and diagnosis is what they feel they need from the situation to give them an understanding of where they stand, minimising in uncertainty:

> "I would love answers and would like my assessment to go fully forward, so I know where I stand when getting help. It's hard to get help when people are saying 'well that might be autism or ADHD so we will wait till we find out'. it's very hard."

For one respondent, the diagnosis will provide them with the opportunity to visibly share that extra support and consideration would be appreciated, which otherwise would not be apparent:

"An official diagnosis so that I can have full support in school and be able to wear a sunflower lanyard in certain situations that may be stressful for me, so that people around me know I may need extra support e.g. staff members of public places like airports."

One respondent, considered the issue of getting a private diagnosis:

"I would like to be supported for Autism when I already have a private diagnosis, but they won't accept it in the NHS."

Uncertainty of what is required

When people were asked what support they would like, which is not already in place, 19 respondents provided vague answers; they were unsure or answered in non-specific terms:

"I don't understand how I can be helped."

"Literally any support."

The experience of waiting for a diagnosis for Autism (ASD) or ADHD

Too long/waiting lists

We asked respondents for any further feedback they have about waiting for an Autism or ADHD diagnosis and the majority of respondents make reference to the length of time they have to wait for a diagnosis:

"It's a very long and anxious wait; I feel failed."

"The process for a diagnosis takes far too long and schools lack understanding of how hard it is to live with these conditions!"

"It's just too long."

A couple of respondents mention that they have chosen to go private due to the long wait, as one respondent below describes:

"Because of the long wait we went for a private assessment, which was completed quickly."

Poor communication

Respondents mentions that during this long wait there is a lack of communication and unanswered questions, which intensifies the situation and leads to uncertainties. There is a sense they feel ignored:

"It's been a very long process with no contact. We can't even get hold of the service to find out where I am on the list."

"I have heard nothing about any updates of what's happening."

"I'm a really really impatient person, so it's really difficult to have to wait and not have any answers and know how long it is going to take."

This has resulted in individuals not having the necessary understanding of the processes and timescales:

"Not being told the different stages of assessment and timescale."

Lack of support

Respondents mentioned that in addition to the long wait, they feel there is a lack of support, with a sense of being dismissed.

"It was a long wait for no actual help at all."

"It's too long, nobody cares, nobody can tell you how long the wait is, they have no staff to deal with anything."

"No one will talk to you; you are put to one side or an answering machine no one ever replies. I am lost and feel let down and unsupported. Some days I really struggle."

There is a sense of being forgotten about after the diagnosis and in need of support:

"I feel like the emphasis is on diagnosis rather than management of symptoms. There is so much focus and staff allocation to assessment and diagnosis that the actual support and required services have been forgotten."

Some respondents described the impact on them, feeling isolated, frustrated, and anxious:

"Very anxious and stressed about how long it will take to get the diagnosis as I am about to start my GCSEs."

"It's long and lonely."

"It's frustrating having to wait so long."

Not getting the diagnosis at the time it was needed.

Respondents described the key time for the diagnosis is during childhood, and if that does not happen then there could be issues getting the diagnosis further down the line:

"I got assessed when I was 8 years old, but they didn't diagnose me on the grounds that I gave eye contact, even though I ticked in every other box and now I'm 18 I asked for the adult services to reassess me but they refused because I had already been tested. But I have a private diagnosis as well as an eating disorder, that is mainly seen in autistic people."

"NHS school age referral' paperwork is clearly geared towards much younger children, which means accessing the services as a teenager is harder. The young person being referred has very few sections of paperwork to fill out (mostly for parents to complete) and some of the phrasing is patronising, or only asks about when you were between the ages of 5 and 12"

Limiting impact of their lives

The impact has been far-reaching, with respondents often describing how isolating it can feel and consequently withdrawing themselves, with the sense of feeling different to their peers. This has a life-long impact:

"I know it stops me from trying new things. I'm not doing well in school; I don't understand them, and they don't understand me. I avoid people mostly."

"I cannot remember as I was 4 when I was diagnosed, but my experience growing up with autism was definitely different to my peers. I felt alienated through most of my life, and I think that has had a long-lasting effect on my mental wellbeing over time."

Acknowledgements

Young Healthwatch Northamptonshire would like to thank:

- Young people and their parents and carers across Northamptonshire that took part in the survey
- Every organisation that supported us in spreading the message online about the survey including:
 - En-Fold Northamptonshire
 - Youth Works
 - West Northamptonshire Voices in Partnership
 - North Northamptonshire Parent Carer Voices

About Healthwatch West and North Northamptonshire

Healthwatch West and North Northamptonshire is the local independent consumer champion for health and social care. We are part of a national network of local Healthwatch organisations. Our central role is to be a voice for local people to influence better health and wellbeing and improve the quality of services to meet people's needs. This involves us visiting local services and talking to people about their views and experiences. We share our reports with the NHS and social care, and the Care Quality Commission (CQC) (the inspector and regulator for health and social care), with recommendations for improvement, where required.

Our rights and responsibilities include:

- We have the power to monitor (known as "Enter and View") health and social care services (with one or two exceptions). Our primary purpose is to find out what patients, service users, carers and the wider public think of health and social care.
- We report our findings of local views and experiences to health and social care decision makers and make the case for improved services where we find there is a need for improvement
- We strive to be a strong and powerful voice for local people, to influence how services are planned, organised and delivered.
- We aim to be an effective voice rooted in the community. To be that
 voice, we find out what local people think about health and social care.
 We research patient, user and carer opinions using lots of different ways of
 finding out views and experiences. We do this to give local people a
 voice. We provide information and advice about health and social care
 services.
- Where we do not feel the views and voices of Healthwatch
 Northamptonshire and the people who we strive to speak on behalf of, are
 being heard, we have the option to escalate our concerns and report our
 evidence to national organisations including Healthwatch England, NHS
 England and the Care Quality Commission.



About Young Healthwatch Northamptonshire

Young Healthwatch Northamptonshire are a group of young people between the ages of 11 to 24 who are health and social care champions.

What we do:

- Look at local health and social care issues
- Give young people a voice for all aspects of health and social care locally.
- Work with professionals on the health and wellbeing of young people locally and nationally
- Set our own work plan
- Learn new skills
- Report back to the Healthwatch Northamptonshire Board

YHWNorth1



If you are a professional that wants to work with us please contact us on the details on the next page or email younghealthwatch@healthwatchnorthamptonshire.co.uk



About Connected Together CIC

Connected Together Community Interest Company (CTCIC).

We have expertise and experience in delivering community engagement, research, surveys, training and more. Connected Together Community Interest Company (CIC) is the legal entity and governing body for Healthwatch Rutland and Healthwatch Northamptonshire.

The remit of the Connected Together CIC includes:

- Contract compliance
- Legal requirements
- Financial and risk management
- Sustainability and growth
- Agreeing strategy and operations
- Agreeing policies and procedures



Appendix – Survey questions

Indian	7. What is y religion? Buddhist Christian Hindu Jewish Muslim Sikh No religio Rather no	on ot say ease	to services? Yes in a positive way Yes in a negative way Unsure Do you have a confirmed diagnosis? No Yes Autism (ASD) Yes ADHD Yes Autism (ASD) and ADHD	4. What is your gender? □ Female □ Male □ Non-binary □ Prefer not to say □ Other (please specify) 9. Do you feel that your culture/religion affects your access to services? □ Yes in a positive way □ Yes in a negative way □ No □ Unsure 12. If you are waiting assessment, how for diagnosis of ADHD / process are you? □ Less than a year	5. Is this the gender you were assigned at birth? Yes No Prefer not to say 10. Are you waiting for an assessment/diagnosis for? Autism (ASD) Both Autism (ASD) Charles and ADHD Charles and AD
	peers or lessons	13. If you diagno: support	Yes Autism (ASD) and ADHD u have a confirmed sis, have you recieved	'	
□ Engagement with services □ Personal hygeine □ Work □ Public transport (such as getting the bus or trair □ Other (please specify)	n)	□ I have I did no □ Yes (p	e a confirmed diagnosis but it want or need any support please tell us who supported		oung lealthwatch Northamptonshire

Autism (ASD) and ADHD Survey

	Have not used this service	Very Accessible	Accessible	accessible nor inaccessible	inaccessible	Very inaccessible	available have helped you? □ No		
Counsellors (paid for)	0	0	0	0	0	0	□ Have not tried to use a service □ Didn't know about services		
Staff at School or college	0	0	0	0	0	0	□ Yes, please tell us how		
Charities	0	0	0	0	0	0	17. What support would you like, that you don't alread		
Prescribed medication	0	0	0	0	0	0	have? 18. What is the main way that you would like to acceadditional support? (please pick one)		
Family and friends	0	0	0	0	0	0			
Staff at GP surgery	0	0	0	0	0	0	□ School/College □ Online □ Home □ Phone		
Staff at hospital	0	0	0	0	0	0	□ Community Venue such as a library or family cer □ App □ Doctors' surgery □ Website		
School nurse	0	0	0	0	0	0			
Youth counselling services available in Northamptonshire - CHAT Youth Counselling, Service Six, The lowdown, Time 2 Talk and Youthworks	0	0	0	0	0	0	Hospital Other (Please specify) State anything else that you would like to tell about your experience of waiting for a diagnosis f Autism (ASD) or ADHD?		
Faith group or Youth club	0	0	0	0	0	0			
Other (please tell us)	0	0	0	0	0	0	Young		
6. Other (please s	pecify) .						healthw Northampte		

Contact us

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