

# Autistic young people and mental health services

Key findings and recommendations from the issues raised by parents and carers of autistic children and young people in Northumberland who use or have used NHS mental health or autism diagnosis services.

## Contents

Context	3
Who we heard from	3
Summary	4
Seeking support	5
The referral and assessment process	6
Schools	7
School nursing service	8
Primary Mental Health Care service	9
Children and Young People Service	10
Crisis team and other services	12
Signposting to charitable services	12
What you would like to tell services?	13
What did children and young people say?	15
Recommendations	15
Conclusion	19
Responses from providers and commissioners	20
Appendix 1 support services	23

## **“We’re scared parents with even more scared children”: Are NHS mental health services working for autistic children and young people?**

### **Context**

Healthwatch Northumberland is your health and social care champion. We make sure NHS leaders and other decision makers hear your voice and use your feedback to improve care.

We recently heard from local families that some NHS mental health services aren't working for their autistic children. To get a better picture of what is happening we asked people in Northumberland for anonymous feedback about their experiences of mental health services including what is working well and what could be better. We heard from parents of children with a formal autism diagnosis or currently being assessed, or where there is an indication of autism. We asked for feedback on different services that families were involved with including school nursing, Children and Young People Service (CYPS), Primary Mental Health Work Service (PMHW), Universal Crisis Team (UCT) and any other services.

We worked with parents to create our feedback form to make sure the information we were requesting was appropriate and gave enough opportunity to provide relevant feedback on services. Thank you to everyone who shared their views and experiences with us and helped to promote our request for feedback.

We are aware there are issues not only in Northumberland but also nationally with recruitment and retention of staff across the health and social care sector and appreciate that feedback should therefore be considered within this wider context.

This report is an overview of the findings and draws out key recommendations on the issues raised by parents or carers of autistic children and young people who use or have used NHS mental health or autism diagnosis services. We have mainly referred to 'parents' throughout the report as the vast majority of responses came from parents. We have abbreviated Children and young people' to CYP for the purpose of this report.

### **Who we heard from**

We heard from 90 people – 87 via our online feedback form and three by other means. We received responses from right across the county, the highest number from Ashington and Blyth and then Cramlington, Bedlington and Seaton Valley. We also heard from parents of children and young people across all age ranges. Most responses related to children aged 0-12 (65%), then aged 13-15 (22%) and a smaller proportion of responses were related to ages 16-17 (7%) and 18-24 (6%). 60% of parents said their child was male, 38% said their child was female and 2% preferred not to say.

Over half of the responses were related to children or young people diagnosed as autistic, nearly a third were undergoing, or had been referred for, an autism assessment or were showing signs of autism but had not yet been referred. The remaining responses were for children whose primary diagnosis was ADHD, learning difficulties or mental health.

## Summary

Throughout all feedback around seeking support for autistic children's mental health and of getting an autism (or other neurodivergent type) diagnosis we heard some repeated themes. Whilst feedback has been given in relation to individual services there are also themes reflecting more generally frustrations or difficulties experienced around the wider 'system' of seeking support including how different services work together.

Those who had positive experiences gave feedback on good relationships with individual staff at services and the impact or help they had or were providing to their child. Better experiences of accessing services were related to early recognition and help from schools or GPs or other health professionals.

We heard repeated words or phrases to indicate the difficulties parents had. The words 'struggle' 'fight' and 'battle' were common with parents feeling they weren't being listened to or had to 'prove' there was a problem. Phrases like 'ticking boxes', 'jumping through hoops' and 'meeting thresholds' arose with one person relating it to a computer game where you had to go through levels to get to the end.

*"The main struggle we had was getting someone to actually listen."*

Those who had struggled but understood the system and had the confidence to push for help expressed concern for other parents who may not.

Some parents mentioned either that they were made to feel they were fabricating or exaggerating concerns - "I looked like a crazy mum" - or that they were being blamed for their child's

behaviour, such as having their own mental health issues or their parenting explored or questioned.

*"Made the issues more about me not coping, when in fact I wasn't coping with my child's behaviour."*

Parents mentioned a lack of support for autistic children and young people's mental health both pre and post diagnosis, although particularly post diagnosis. Many felt they were left to do their own research on autism or other neurodivergent conditions and the support available.

Some parents told us how their own mental health had deteriorated because of the struggle to get their child diagnosed - "It takes far too long (for us four years) during which time my mental health has I feel been irreparably damaged"- or due to the struggle to get ongoing mental health support for their child - "we no longer live but we survive".

Parents felt that early intervention for children and young people's mental health was important to prevent them getting to crisis point, however, help received tended to be more likely at crisis point and was not necessarily an ongoing offer despite mental health issues continuing.

*"Accessing services when not in crisis appeared an impossible task."*

Difficulties in getting an initial referral to services, high thresholds for accessing support, long waiting times and being referred between services were the main issues raised.

*"Having a child with mental health issues is terrifying and isolating and the waiting is torture."*

## Seeking support

We asked parents when they first sought mental health support for their child. 72 people responded to this; around a third of responses being either within the past year and the same amount said four years or over. The remainder were an even split between two to four years and one to two years. For those who did seek support a number of years ago it did not necessarily translate that they were not recently or currently still involved with mental health services. This demonstrates that either it took some time to get support or that there has been a need for recurrent support at a later date.

Regarding what first prompted parents to seek support, most responses were around their child's behaviour such as anger, emotional outbursts, or meltdowns and some of the responses included concerns around behaviour towards siblings. Other responses related to increased anxiety or panic attacks with several mentioning this being heightened during the pandemic. Over 10% of responses were around suicidal thoughts including one suicide attempt and a further 5% around either self-harm being carried out or concerns about it. Other parents mentioned difficulties with speech or communication or developmental delays, social difficulties or a child unable to attend school due to high levels of anxiety. Several parents were aware of autistic traits particularly if siblings had been diagnosed and sought support because of recognising these in their child.

Nearly three quarters of people initially sought support from their GP or school with an even split between both. The next highest were health visitors and then CYPS and others like nursery or social services. Whilst we did not ask for specific feedback on people's experiences of seeking support, several parents mentioned again feeling dismissed or not listened to when they tried to seek support from their health visitor or school. Again the issue of parental blame arose with two parents stating they were referred to parenting classes despite feeling this was not needed.





## The autism referral and assessment process

We asked parents if they had anything to say about the autism assessment and referral process and received 52 responses. Again, words like 'struggle' 'fight' and 'battle' were common with parents feeling they weren't being listened to or had to prove there was a problem. The themes of feedback received are outlined below.

### 1. Timescales

Whilst several people mentioned a positive experience of the assessment process stating that it was quick or did not take as long as they expected - *"No problem with the referral and assessment process. It was fairly quick (in comparison to the timescales given by other people I know) and smooth"* - just under half (25) of those responding had a less positive experience of waiting times citing that the time taken to receive a diagnosis was too long.

Two people mentioned paying privately for a diagnosis due to difficulties. The feedback was either around the autism assessment directly and/or the time taken for the referral for an assessment to be accepted or for other agencies such as schools, GPs or health visitors to recognise there was an issue and to make an appropriate referral for assessment. *"It took me nearly ten years to get a diagnosis. My child and me were let down by every single system."*

The role of school was a theme with two people mentioning the process being better due to the involvement of school staff who were pro-active in awareness or understanding of autism and mental health and five people conversely mentioning difficulties or delays in the process due to school not recognising autism and 'masking' traits, especially in girls. *"My daughter was missed by school entirely because schools don't understand autistic masking or autism traits commonly found in girls."*

### 2. Process

We received feedback around the process of the autism assessment. A few people gave positive feedback - *"The autism assessment was really great, really in-depth and I felt confident that the diagnosis was a true reflection of the evidence gathered"* - but much of the feedback provided was around the difficulties encountered. One major theme was about communication such as having limited information about what is happening or will be happening, who is involved, and having to chase various agencies for updates. *"At no point did anyone tell us about the process, the steps involved or who we would meet along the way and what their role was."*

Other issues raised were around the communication between different agencies or professionals involved such as staff changes or turnover leading to delays and/or difficulties for the child or young person. *"There was lots of blame (between agencies). This happened quite a few times. I felt stupid in the middle like folk were just covering their backs and blaming anyone but themselves."*

We also heard from some parents who felt the referral and assessment process was lacking due to not recognising or covering other possible conditions and additional neurodivergences such as sensory processing disorder (SPD), hypermobility, pathological demand avoidance (PDA) and oppositional defiant disorder (ODD). We received feedback from two people about PDA not being recognised or accepted as a condition in Northumberland, leading to difficulties in accessing support, for example, because parenting techniques are different than for an autistic child.

### 3. Support after diagnosis

Several parents mentioned a lack of follow up support after diagnosis and a feeling of being left to do their own research around autism or other conditions, how to manage it and the support available - *“As soon as they were eventually diagnosed they were discharged and we were told it was up to us to research and learn how to support them”*.

This was particularly difficult for parents where their child had enduring or ongoing mental health issues as it was felt there was no follow-on support for this or that they had to start a process of seeking support for this elsewhere. Some feedback centered around the feeling that mental health issues in autistic children and young people were being dismissed simply as ‘part of the autism’ leading to this lack of support.

*“It is very common that people on the autistic spectrum have anxiety and mental health issues. This is not autism but the effect of having to adjust to the world around them and the many challenging situations they face.”*

#### Schools

We asked parents about what type of educational setting their child attends, the school’s role in accessing support and feedback about the school nursing services. Of the responses received 70% of children attended mainstream schools and 10% attended a special school with the remainder either having left education, in alternative educational provision or in education other than at school. A few children had no educational provision due to anxiety and mental health distress with one unable to access any education at all and others unable to continue attending their registered school.

#### Role of the school in accessing support

As outlined in some feedback around the referral and assessment processes for an autism diagnosis, schools did appear to have a key role in parent’s experiences of accessing support. Of those who gave more detailed feedback it was divided evenly between those who felt the school had a positive impact and those who felt the school had a negative impact. For those who gave positive feedback it was felt the

school was instrumental or went over and above in accessing support, or being good at liaising with different services to ensure the CYP needs were met. *“School was one of the main drivers behind getting support for my child.”*

*“The school have gone above and beyond.”*

In addition, many parents mentioned the role of schools in making referrals to CYPS or PMHT or other services like school health, speech and language therapy, emotional wellbeing and behaviour support, or for an educational and health care plan. Positive feedback was particularly pronounced for those CYP who attended special schools, perhaps due to staff understanding of additional support needs or required referral processes.

For those parents who gave negative feedback it was felt that the school did nothing to assist the process of getting support and some mentioned this was despite sometimes asking repeatedly for help. Again, we heard the issue of not feeling listened to. *“They accused me of making it up rather than assist.”*

Common themes were around schools not recognising autism in children who 'mask' in school, not being aware of potential autistic traits, not recognising mental health or wellbeing issues or not meeting the CYP individual needs generally.

*"Absolutely no mental health support at school and no understanding around mental health issues."*

Some parents gave feedback around the fact that children were only perceived to be 'struggling' if not achieving educationally instead of there being a focus on wellbeing or social difficulties. A few people mentioned problems in communication between the school and other agencies leading to delays or difficulties getting appropriate support, for example, not providing relevant information to assist with referrals.

### **School nursing service** (delivered by Harrogate and District NHS Foundation Trust)

36 people responded to provide feedback on school nursing services. Most were either currently involved with the service or had been within the past year. Just under half of those said it was easy or very easy to access the service but only 39% of people giving feedback on the support received rated it as positive or very positive. Of those that did give positive feedback the main theme was around praise for individual nurses and them being compassionate, understanding or for their good communication skills - *"The support was excellent - understanding and compassionate"*.

For those who provided negative feedback the main issues raised were around delays in getting help or support either due to waiting lists or awaiting

contact or issues with staffing. One person mentioned being unaware of the service. Another theme was parents feeling that they were passed over between different services without getting help or because they were informed the issues were too extreme for the nursing service to deal with.

*"The nurses were friendly but couldn't offer any support and referred us to mental health team who said anxiety and autism was beyond their remit."*

One person told us that whilst they knew the service wasn't appropriate for their child, they had to go through that pathway to be referred to a different and more appropriate service.

*"School nursing team took ages to engage and knew like me, that as soon as they heard their story and met them that they needed more specialist support but we HAD to use that pathway even though it was pointless and time-wasting."*

Feedback on support received was varied. As outlined some of this was positive and related to the qualities of individual staff but others mentioned difficulties because of changeovers of staff, having different experiences dependent on staff, and support not being consistent or regular enough for their child.

*"They built a good relationship with school nurse and opened up to her then she left and school health withdrew from helping my child."*

Others found the staff unsupportive or not helpful for their child's situation. A few parents mentioned not feeling supported; again the issue of feeling blamed was raised.



## Primary Mental Health Work Service (delivered by Northumbria Healthcare NHS Foundation Trust)

39 people said they had been involved with PMHW. Over half of these were within the last year including 11 who were currently involved. Just under a quarter of people were within the last two years with the remainder either not disclosing or saying their most recent involvement was over two years ago. We have concentrated mainly on feedback from involvement within the past year. We note that for a few responses there seemed to be possible confusion with CYPS indicating that the roles of and involvement with different services can be unclear. The themes are outlined below.

### 1. Timescales

The main theme we heard was around long timescales for accessing help, with a few parents mentioning they were concerned this would lead to an escalation of mental health issues. One parent said because of long waiting lists they sought private help but then were refused help due to involvement of another service. *"Had a roughly nine month wait for an appointment. By then their mental health was so bad we had been forced to pay private. When mental health got in touch I was told they couldn't work with them now as they were seeing someone else!"* Several parents mentioned that they felt the support offered was too time limited or that their children were discharged too early despite ongoing mental health issue, with one saying this resulted in a relapse.

### 2. Access

Over three quarters of those involved within the past year said they found the service difficult or very difficult to access. *"It's a huge fight to be seen. Too many people chasing too few appointments."* As with previous feedback the role of schools was mentioned regarding accessing help, with a couple of parents feeling a delay in getting help was attributed to the school not believing anything was wrong.

Parents also raised issues of referrals not being accepted with some saying their child's needs were too complex or conversely not having a high enough need, or being passed between alternative services. One parent mentioned the difficulties of direct self-referral as opposed to through a GP or school - *"There did not seem to be a route open to me as the child's parent to refer or ask for help"*.

### 3. Support

We heard from people that their CYP experienced difficulties with support due to different professionals being involved, for example, due to changes in staff and this being confusing and detrimental to an autistic child especially if they had bonded well with a particular member of staff. *"It was very long winded, confusing, and so many different doctors etc."*

It was also felt that support was sometimes inconsistent, too infrequent or unsuitable, for example, due to the sessions taking place in school, virtually, in an uncomfortable environment or not being able to have a parent present. *"They refused to attend appointments because they were in school time and they were losing valuable time in lessons."*

A theme of communication was apparent including a couple of parents whose CYP were discharged before being seen because of communication difficulties. However, positive feedback tended to centre around individual staff and the good connection or communication they had with the CYP. *"Easy to speak to in confidence, thorough."*

## Children and Young People Service

(delivered by Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust)

65 people gave us feedback about the Children and Young People Service (CYPS) with three quarters of those stating they had been involved within the last year, including 40% who were currently involved. Of the remaining responses the vast majority had been involved one to two years ago and a small number of people stated they had been involved over two years or did not specify a time. We are aware that the feedback received may not solely be about mental health support as many parents have also had involvement from CYPS for the autism or ADHD diagnostic process. There may therefore be crossovers and similarities to feedback on the referral and assessment processes for diagnosis. Key themes:

### 1. Timescales

As with feedback on other services the main theme was around waiting times. Several people mentioned they felt this was too long with a couple stating there was no support whilst waiting. *"The routine waiting list is beyond any level of acceptable."* However, others gave feedback that the referral was accepted quicker than they expected with some again mentioning the role of the school in either helping with this or hindering the process. *"We were referred and the wait was quite short."*

### 2. Access

Just over two thirds of respondents found it difficult or very difficult to access the service, just over a quarter found it easy or very easy and the remainder did not specify. The main theme around access was around either the rejection of the referral, being passed between agencies or a feeling that the threshold for getting help for mental health is too high. *"Still waiting for support and their response was 'unless they are a risk to themselves or are deemed a significant risk to others there is nothing we can do'."*

We also heard from some parents who felt that the pathway for getting mental health support from CYPS was difficult for autistic children as it was dismissed as being part of their autism. *"They tell you they are 'not commissioned to deal with issues arising from autism'."*

Some people who responded had accessed CYPS on more than one occasion and found this a struggle. *"I had to fight tooth and nail to get back to CYPS. I genuinely believe if we hadn't got back either my child would be seriously hurt or dead, or caused me a serious injury."*

### 3. Support

Staffing issues arose as a major theme in terms of feedback on the support given. This centred around a change of staffing leading to issues of inconsistency of support, difficulties for CYP having to repeat information to different people and building a rapport with someone and them leaving. *"Extremely high staff turnover making it impossible to form relationships."* Again, these issues may be more difficult for an autistic CYP. *"Great staff but never say when they move you to a different person. If they are dealing with autism, ADHD or attachment, they should really make sure they are not causing further issues with relationships and attachments as well as anxieties to children and their families."*



Other issues were around staff not understanding the child or more generally autistic children's needs. For example, having a trainee staff member sit in on an appointment or having a last-minute change of staff on an appointment without prior warning, having a change in appointment venue, having to travel or not facilitating home visits. A couple of parents mentioned difficulties due to not being involved in sessions and therefore being unaware of progress and one raised the difficulty caused by speaking to parents in front of children as this can lead to distress for the CYP. We also heard that some staff did not recognise 'masking' in autistic children leading to difficulties getting appropriate support.

Again, themes of parents not feeling listened to or supported were a feature, with several saying they felt judged or were blamed for their child's difficulties. *"Feel unlistened to, very unsupported and frankly at a loss to what more I can do!"*

Where we received positive feedback, this was around good individual staff - *"We have been lucky and believe we have an amazing therapist"* - their communication with the CYP concerned or their impact - *"They have become so much more comfortable within who they are and they're a much happier child"*.

The lack of support after diagnosis was again a major theme with some parents saying this was despite their child still having mental health difficulties. *"I feel like they just deserted them and they've been forgot about."* People told us about having to do their own research or seek their own support. *"How did we learn about masking and ASD - we read forums, and Toby Henderson and Cygnet information. No one at CYPs guided us in the complexities of ASD behaviours."*

## Crisis team and other services feedback

Fewer people gave feedback on the Universal Crisis Team (delivered by CNTW) as many stated they had not been involved with this service. 11 people said they had experience of using this service, around half within the past year and nearly a third within the last one to two years. Most people (60%) found the service easy or very easy to access.

There was positive feedback around the support given to both parents and the child but for some people the time taken for a return call or an assessment was felt to be too long due to the urgency of the crisis. A couple of parents said the difficulties in getting their child to engage and for some the support given, was not felt to be helpful for the situation. One mentioned that the response of being told to call the police was unhelpful for their situation as would risk escalating the crisis, and that at other times the threshold for accessing help was too high as was not available unless their child was actively trying to take their own life, as opposed to expressing suicidal thoughts.

We received very little feedback on other services to enable us to draw out specific themes although a few parents said they had a positive experience with family therapy, speech and language therapy, an educational mental health practitioner and Portage (a home learning service via Northumberland County Council). One parent expressed a concern over long waiting times for the Talking Matters Northumberland service.

## Signposting to charitable services

34 people told us they were given information on charitable or voluntary services which may be able to provide support. Nearly a quarter of people felt positive about this describing it as being useful or helpful. *"It's very helpful. We've been able to access support groups for us as parents and also for our child. This has all helped in our understanding of what autism is and who our child is."*

However, most responses expressed some pessimism. The feedback centred around parents feeling 'fobbed' or 'palmed' off. Some people expanded on this to say that they felt charities should not replace NHS or clinical services and that some of the options of support given were unsuitable due to the severity of their child's mental health issues or their individual child's needs or due to the location or type of service. *"It is quite depressing to a parent looking for help to be sent a sheet of contacts and told 'here you go, this is it'."*

Some parents felt overwhelmed about having to deal with or seek support alone and did not necessarily have the confidence, time or motivation to follow up. *"Very vague information. Requires a lot of confidence from parent to seek support."* Many parents did their own (sometimes lengthy) research either to educate themselves to better support their child directly or to find support groups/services. This was particularly in situations where they felt the organisations signposted by NHS services would not be able to provide appropriate help for specific needs, for example, for PDA, selective mutism or girls (and older girls) who 'mask'.



## What would you like to tell services ?

We asked parents what they would like to tell the people who provide NHS mental health services about what worked well and what could be improved and if their children had anything to say about their experiences.

We received 81 responses and some strong themes emerged, many of which have been outlined in previous feedback.

Key themes:

### 1. Good staff

The positive feedback we received was around there being some good staff within services, particularly individual staff who had really helped a child or young person or understood them well. Word like 'caring', 'talented' and 'understanding' were used and there was a recognition that many were working very hard under difficult challenges such as being understaffed or having a heavy workload. *"Workers have all been genuinely great, very caring, understanding, knowledgeable, engaging and earnest. Fundamentally the service falls short due to lack of funding, staffing and resources."*

### 2. Being listened to

Many parents felt they or their children were not being listened to or taken seriously both in terms of accessing support or during treatment. Much of the feedback related to a feeling of 'being fobbed off' or having to 'fight' to get support or get someone to recognise their need for help. *"If my child's concerns about what would/wouldn't work for them had been listened to, then it might have been a different story."*

### 3. Early intervention

We heard that parents felt early intervention and diagnosis was very important and support should be proactive rather than reactive to a crisis. The wider role of school, GPs, health visitors and other services in helping with this for early recognition was noted. We heard that educational attainment shouldn't be the only benchmark for getting support as wellbeing concerns are also important particularly for children who 'mask' in school. *"Everyone is shouting 'don't be afraid to ask for help'... unfortunately when they do, it is not available when it's needed."*

### 4. Better post diagnostic support

Parents told us that better post diagnostic support would be helpful. This may be support around diagnosis to understand and accept the complexities of neurodivergence or support with ongoing mental health rather than mental health problems being assumed to be a normal or acceptable part of autism. *"To diagnose and discharge is a disgrace especially when a child has answered clearly what they think they need help with."*

### 5. Parent and family support

We heard that more support for parents and help as a family unit, especially where a child has siblings accessing the same services, would be useful. More communication or information about the diagnostic process was mentioned by a few parents including the possibility of a booklet or training for parent special education needs groups. *"There is no kind of support offered to a parent that might think their child has additional needs. There is no one to talk to, no one to turn to for advice and no one to listen to parents' concerns especially if they don't have a good family or friends support group around them."*



## 6. More consistent support

Some parents mentioned a need for more consistent support, particularly important for autistic CYP. This may be around how long they are given support, how often a CYP is seen, where they are seen and who sees them. Problems with staff recruitment and retention were also recognised. *“Don’t just give up before you even started, these kids need time – a lot of time – especially to build trust in someone to be able to open up to them.”*

## 7. Being holistic

The communication and pathways between different services or for different professionals within the same service, for example, for children with dual or multiple diagnoses, was raised. This was related to a feeling of being ‘passed around’ between services for suitable support. We also heard that if communication or processes were better or more streamlined people would not have to repeat their story again or go through lengthy separate diagnostic processes. A ‘one stop shop’, single point of access or a key staff member was suggested.

*“Too much time spent asking the same questions over and over for different services/staff. This has to be connected across services.”*

## 8. Staff training

Training, particularly autistic led training, for staff delivering mental health or diagnostic services was brought up by some parents to raise awareness of how autistic children present including ‘masking’. This was also suggested as a wider issue for schools and other health professionals. *“I think doctors should be provided training and better assessment tools. Not all autistic people are the same and it may look very different depending on the person.”*

## 9. Valuing autistic people

We heard from parents that they would like services and support available that accepts and values autistic and other neurodivergent children, young people and adults rather than try to change them or make them conform to neurotypical standards. *“How autistic we seem to you or how well we can pretend not to be autistic is not the important thing.”*

Having many different professionals or services involved can also exacerbate a feeling that there is something ‘wrong’ with being autistic. Peer support was suggested as being helpful and we heard from someone whose child had a very good experience of diagnosis due to a focus on the positives. It was also mentioned that many autistic CYP will have autistic parents who may need reasonable adjustments to assist in accessing services.

**“I think doctors should be provided training and better assessment tools. Not all autistic people are the same and it may look very different depending on the person.”**

## What did children and young people say?

We did not receive as much feedback directly from children and young people but again what we did hear had some consistent messages.

Some told us about the good relationship they had with staff and the bond they had made or how they had helped them - *"my current worker is the best one I've had, I don't understand why I am the way I am but she helps me to think things through a bit more"*.

However, nearly a quarter felt they did not get the right support or worryingly felt that it was worthless or a waste of time - *"why do people come along, say who they are and leave without doing anything?"*.

Some CYP also told us of difficulties engaging with staff who may not fully understand them or autism generally. *"The mental health professional I saw at the NHS didn't seem to know very much about 'masking' in autism, so they didn't realise that the appointments themselves were very stressful. I don't think they always believed me when I said how bad I was feeling because on the surface I appeared to be okay."*

We also heard of problems due to changeover or turnover of staff - *"Seeing the same person each time is better. When we like someone, and you take them away or they leave it is hard talking about myself to someone new again"*.

## Recommendations

The following recommendations have been co-produced with Northumberland Parent and Carer Forum and developed from the feedback of all parents, carers and CYP who contributed to this report.

The recommendations focus on issues of communication, training, access and care and suggest ways providers and commissioners can improve the experiences of autistic CYP and their parents/carers when seeking mental health support or a diagnosis of autism or other neurodivergent conditions.

<b>Who</b>	<b>Recommendation</b>	<b>Benefit</b>
<p>CYPS – identification and assessment</p>	<p>Review current leaflets and consider investment in a short information video about the neurodevelopmental assessment process (including information about the recognised various conditions) that parents and children can access</p>	<p>Children and young people and their parents/carers understand what to expect during the assessment process, reducing anxiety and promoting confidence</p>
<p>CYPS – screening and support</p>	<p>If currently unavailable develop a screening tool (or adapt any existing similar peer service tools) for other comorbid mental health and neurodivergent conditions alongside the autism diagnostic process. Newcastle University has an <a href="#">adapted anxiety scale for children (ASD)</a></p>	<p>Communication is improved between professionals and services involved with CYP who have comorbid conditions</p> <p>An escalation of mental health problems is avoided during the diagnostic process</p>
<p>CYPS – understanding, acceptance, and celebration</p>	<p>Foster a culture of celebration and valuing neurodiversity throughout the diagnostic process, explore and look at positives rather than perceived deficits. Focus on practical tools to achieve desired outcomes rather than medicalised labels</p>	<p>CYP understand and accept their diagnoses, and feel positive about their differences</p>
<p>CYPS – identification and assessment</p>	<p>Look at best practice from other tier 3 CAMHS services in relation to diagnostic process around neurodiversity, other comorbid conditions (including those that may not currently be given any NHS support provision in Northumberland such as PDA)</p>	<p>The CYP and parent/carer experience is improved by learning from existing models</p>
<p>CYPS – screening and support</p>	<p>Look at best practice from other tier 3 CAMHS services in relation to how best to support mental health in neurodivergent CYP to ensure diagnostic overshadowing does not prevent access to mental health support</p>	<p>Neurodivergent CYP experience improved access to services, preventing escalation of mental health problems</p>

PMHW – screening and support	Review packages of mental health support to ensure they meet needs of neurodivergent CYP particularly in relation to ‘time-limited’ therapy, waiting times and communication	Neurodivergent CYP experience improved access to services and treatment, preventing escalation of mental health problems
ICB/ND Graduated Response Group and Autism Partnership Board – identification and assessment	Support/develop multi-tier triage using a consistent assessment process to be developed and used across all services	Neurodivergent CYP and parent/carers experience improved access to services, preventing escalation of mental health problems
ICB/ND Graduated Response Group and Autism Partnership Board – screening and support	Simplify the pathways for accessing support for autistic CYP both for the diagnostic process and pre and post diagnostic mental health support to deliver holistic support. Mental health services to continue to run alongside the neurodevelopmental assessment process	Autistic CYP experience ‘no wrong door’ and do not ‘fall through the gaps’, preventing escalation of mental health problems
ICB/ND Graduated Response Group and Autism Partnership Board – screening and support	Ensure readily available and accessible information for CYP and their parents around the full range of services and therapeutic help available for mental health including referral processes. Lincolnshire Partnership NHS Trust has co-produced a helpful <a href="#">parent/carer support guide</a>	Neurodivergent CYP and parent/carers understand what different services provide and how to access them, resulting in timely and suitable support
ICB/ND Graduated Response Group and Autism Partnership Board – screening and support	Refresh guidance or working practice on how best to communicate with parents and carers whose CYP are accessing services to ensure they are appropriately updated or involved in their child’s care (whilst balancing the need for confidentiality)	Parent/carers experience reduced uncertainty, resulting in lower levels of anxiety and improved wellbeing

ICB - understanding, acceptance and celebration

Promote training for mental health professionals to help recognise how autistic adults and children may present and to make services (and therapeutic interventions) more autism friendly. Ideally autistic led training, or training that is co-produced with autistic people and/or their parents or carers  
 National Autistic Society alongside MIND has produced a [good practice guide](#) for mental health professionals involved in talking therapy.  
 NHS England commissioned resource: [Supporting autistic children and young people through crisis](#)

Neurodivergent CYP experience improved care and treatment when receiving mental health support  
  
 Improving care and treatment for autistic CYP receiving mental health support

ICB - understanding, acceptance and celebration

Invest in autism (understanding/ acceptance) training for school staff, school nursing services and other health services such as GPs, family hubs and health visitors to help early intervention. Again, ideally autistic led or co-produced training. This should include a focus on internalised presentation as 'masking' in school is an issue for many children, particularly but not exclusively in girls.  
 Now live: [The Oliver McGowan Mandatory Training on Learning Disability and Autism](#)  
 National Autistic Society has training modules, including one on '[Women and Girls](#)'

Families experience timely neurodevelopmental assessment and/or referral for mental health support, preventing deterioration in mental health and wellbeing

ICB - screening and support

Promote training and facilitate a forum for 'regional' SEND Coordinators to share good practice, advice, information and services with mainstream schools including around the mental health offer for neurodivergent CYP

Neurodivergent CYP know what mental health support is available and experience improved access to services



ICB/ Northumberland County Council - screening and support	LA/HINT team to share 'Ordinarily Available Provision' document more widely in a range of accessible formats - including with parent carers and mental health services	Neurodivergent CYP experience 'reasonable adjustments' in school as the norm rather than the exception
ICB - screening and support	Ensure any commissioned post diagnostic services that support autistic CYP and their parents or carers are co-produced with the chosen provider and parent/carers e.g. Northumberland Parent and Carer Forum. Charitable services should complement but not replace NHS services particularly where clinical mental health support is required	By hearing from those with lived experience, neurodivergent CYP and parents/carers find post diagnostic services valuable
ICB - understanding, acceptance, and celebration	Co-create with CYP, families, PCF and parent carer peer supporters a strategy to imbed an ethos of co-production across all CYP mental health services	Strategy and policy is improved because it is informed and developed by lived experience

## Final conclusions

This report focuses on the lived experience of parents and carers and autistic children and young people, summarising their feedback around accessing and receiving NHS mental health support and neurodevelopmental assessments.

The recommendations resulted from the stories we were told and have been co-produced with Northumberland Parent Carer Forum who we thank for their time and insight. Thank you again to everyone who generously gave their time to feedback, helped to promote our project and with formulating the initial feedback form and recommendations. Thank you also to the providers and commissioners who took the time to listen and respond to what we heard.

A draft copy of this report was shared with service providers and commissioners. Responses from North East and North Cumbria Integrated Care Board, Northumbria Healthcare Foundation Trust Primary Mental Health Work Service (NHCT PMHW) and Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (CNTW) are outlined below.

## **NHS North East and North Cumbria ICB response**

Our thanks go to Healthwatch Northumberland for putting these vitally important services in the spotlight, and gathering so many insights from the young people and families who rely on them.

This group of services is commissioned for local people by the North East and North Cumbria Integrated Care Board (ICB), and provided by Northumbria Healthcare NHS Foundation Trust, and Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust. The ICB was established on 1 July 2023, replacing the previous Clinical Commissioning Groups.

We are very much aware of the importance of these services to families across our area – particularly in view of a major increase in demand over the past three years. Early diagnosis and support are important, as well as the chance for young people and families to have a voice around the services they use.

We know that too many people in our region wait too long to be diagnosed with autism or other neurodevelopmental differences, meaning that early help and support is delayed. We also know that without a medical diagnosis of autism or neurodiversity, help, support and reasonable adjustments can be difficult to access.

One of our key aims is therefore to work with young people, families and NHS providers to enhance these services. Over recent months we have sponsored an event led by We Are Human Too, so we could learn from the experiences of 100 people as they considered how we can best help people live good lives in the community. Another important step was the appointment of a person with lived experience of autism as a member of our internal subcommittee which leads on mental health, learning disabilities and autism.

Our work is based on the principle that commissioners, providers, and delivery partners across all pathways will listen and learn from people who have a lived experience, families, and supporters. That their experiences will underpin the planning, design, and delivery of all services so that autistic people and people with neurodiversity are supported, included, understood, and encouraged to achieve the best of life outcomes in line with the same expectations we have for the rest of our population.

## NHCT PMHW Service response

The NHCT PMHW Service has now had an opportunity to reflect on the findings of the recent Healthwatch Northumberland report outlining the experiences of autistic young people accessing mental health support in Northumberland.

This has provided us with an invaluable insight into the individual journeys of young people and their families who have accessed support from the PMHW Service. We acknowledge the current challenges that families are reporting in accessing the right source of mental health support, at the right time, within the right part of the graduated mental health approach.

We accept that improvements are needed in the communications with families and this is an area that we are always striving to get right and improve wherever possible. We accept that improvements are needed to ensure that families are more aware of the role of the PMHW Service and our targeted early intervention offer for young people who are autistic.

We are continuing to work on improvements to access and wait times in the service. We now have a direct route for families to seek advice, support and referrals via our telephone consultation line and direct referral into the service.

We look forward to addressing the recommendations for the PMHW Service within the report to ensure that we review our current intervention pathways to ensure that they meet the needs of the autistic children and young people who access the support of the service.

## CNTW response

We welcome the opportunity to hear about the experiences of young autistic people and their parents and carers in this Healthwatch Northumberland report. It's important for us to learn about and understand the challenges people accessing our mental health services face.

We acknowledge that there has been an increase in waiting times for access to mental health support for young people due to a national increase in demand for the service over the last couple of years. The waiting times for access to our neurodevelopmental pathway, including autism services, have significantly increased since December 2022. Once children are within the diagnostic pathway, some children and families have unfortunately experienced longer delays than we would like. We aim to reallocate as soon as possible and keep families up to date.

Currently our Universal Crisis Team (UCT) under 18 pathway are assessing 100% of very urgent referrals within four hours. However, we understand that due to workforce challenges being experienced locally as well as nationally, call backs and planned visits following these initial assessments may be delayed. UCT staff endeavour to offer updates to families and young people who are waiting for a visit to explain the situation and offer a revised timeframe.

Workforce challenges are impacting the NHS nationally and are contributing to longer wait times for patients. As a trust, we are working hard to both recruit and retain staff to ensure all of our patients' needs are met.

We are pleased to hear that most people found the UCT easy or very easy to access and that parents and their children had positive experiences of the support the team provides. However, we understand that young people and their families contacting the UCT might be worried about being asked to contact the emergency services during a mental health crisis. Our clinical specialists will only recommend this course of action, or make contact with the emergency services themselves, if the information they receive indicate an immediate serious risk of serious harm, injury or loss of life.

Parents and children who have accessed our CYPS told Healthwatch Northumberland they would benefit from better communication about the diagnostic process. In September 2022, we introduced a new information leaflet for families which is designed to help them understand the assessment process and where they can seek support whilst on the pathway. Whilst creating the leaflet, we worked with Northumberland Parent Carer Forum and Calmer Therapies to make sure the needs and views of parents and carers were considered.

Parents and children also expressed concerns to Healthwatch Northumberland about the availability of post diagnostic support. We're pleased share that from 26 May 2023, post diagnostic support will be provided by The Toby Henderson Trust, an independent autism charity in the North East. We recognise that our community, voluntary and third sector partners play an equally important role in supporting people with mental health issues across our region and we are continuing to work collaboratively across the system to develop this further.

## Appendix 1. support services

We asked parents and carers about voluntary and charitable services that they have used and that have been useful in accessing support. Those we could obtain relevant signposting information for are listed below.

[Happy Faces Prudhoe](#)

[Autistic Girls Network](#)

[Inside of autism training](#)

[Autistic Self Advocacy Network](#)

[Operation Diversity Academy](#)

[Education Other than at School](#)

[Not Fine in School](#)

[Escape Family Support](#)

[Contact](#)

[Tanga Club Hexham](#)

[National Autistic Society](#)

[Pathological Demand Avoidance Society](#)

[Newbold Hope](#)

[The Nurture Programme](#)

[Missing the Mark](#)

[Streetwise](#)

[Pass it on Parents](#)

[Northumberland Family Hubs](#)

[Tynedale and NE Autism Support](#)

[Autism North East](#)

[The Toby Henderson Trust](#)

[Complex Connections](#)

[Tim Lamb Centre](#)

[WECAN](#)

[Northumberland Information Advice and Support Service](#)



# Contact Us

Healthwatch Northumberland  
Adapt (NE), Burn Lane, Hexham  
Northumberland NE46 3HN

tel: 03332 408468

text: 07413 385275

email: [info@healthwatchnorthumberland.co.uk](mailto:info@healthwatchnorthumberland.co.uk)

website: [healthwatchnorthumberland.co.uk](http://healthwatchnorthumberland.co.uk)

Facebook: [@healthwatchnorthumberland](https://www.facebook.com/healthwatchnorthumberland)

Twitter: [@HWNland](https://twitter.com/HWNland)

Instagram: [hwnland](https://www.instagram.com/hwnland)