NHS
Greater Manchester

Children and Young People's ADHD Services

Engagement Report

January 2025

Children and Young People's ADHD Engagement Report

Version control

Date	Version	Updates from	Reason for change
23/12/2024	1	Engagement team	First draft
16/01/2025	2	Updates from engagement team, lived experience group and commissioners	Accuracy updates
03/02/2025	3	A Mitton	Updated format

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Section 1: Introduction and overview

Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is a condition in children and young people that makes it more difficult for them to focus, sit still, and control their impulses.

ADHD is part of a group of neurodevelopmental conditions that affect how our brain functions. Other neurodevelopmental conditions include Autism and speech and language conditions. Neurodevelopmental conditions are not mental health conditions. Based on national data, we estimate that there are nearly 30,000 children and young people with ADHD in Greater Manchester.

We are working to improve wider neurodevelopmental support for children and young people, focusing on ADHD and Autism.

This report sets out what we have learnt from 9 weeks of engagement exploring how we can improve ADHD services with children and young people, their family and carers, and professionals from across Greater Manchester. In total, we engaged with over 1,000 people in different ways and reached many thousands more. It is an unbiased review of key themes people shared with us, however, whilst it is comprehensive it does not include every point. For the full details, please see the appendices.

The report will be used to further shape the proposals for improving children and young people’s ADHD services. We will share updates on our website of what has changed because of the engagement, particularly around the recommendations.

Engagement will continue with the lived experience groups (children and young people, and parents and professionals) who will work alongside us to act as sounding boards and support the codesign of future models. Wider engagement and consultation may also be needed depending on how the proposals change.

Our thanks go to all our colleagues and partners who have supported us to involve people. Our even greater thanks go to all those who took the time and trouble to engage with us and share their experiences, thoughts and ideas – we are very grateful.

This report will be published on our website and shared widely. If you would like it in a different format or language, would like a printed copy, or have any questions, please contact us.

What people told us – the key themes

1. People are experiencing very long waiting times, and this is making the symptoms worse, and the service needs to change.
2. People feel there is a lack of support whilst on waiting lists and they need earlier intervention/access to support.
3. There is generally a lack of communication at all points in the journey.
4. People need a diagnosis to access support.
5. Schools have huge role to play in supporting children but are sometimes seen as gatekeepers. Schools need more help and training to support children with ADHD.
6. Lack of integration between services, as well as issues with access, right to choose, acceptance of private diagnosis and shared care.
7. Medication should not be the only support on offer and doesn't work for many. Currently there is no other option Post diagnosis support is key, this is a lifelong condition, just having a diagnosis is not enough.
8. The impact on the family and family history both need more prominence and consideration.
9. Every is child is unique and the services aren't responsive to that.
10. People are generally supportive of prioritisation.
11. There are inequalities in terms of access and experience. This is related to geography and some characteristics including age, gender and families on low incomes.

How we engaged

Online survey (support offered over the phone)

562 people completed the survey, either online themselves or with help through our phone number. We have also printed surveys and promoted the survey and involvement at all events across Greater Manchester. The details of who responded is on the next page.

Greater Manchester Youth Network

It was always going to be hard to hear directly from children and young people, so we worked with the GMYN to engage with them. They engaged with 25 young people on our behalf and are setting up a young person led lived experience group to continue to work with us on the project.

Focus Groups

We held focus groups - 1 online and 1 face to face attended by 15 people. We also visited First Point in Bury to discuss with some of their staff and clients the experiences of services. The focus groups were open to professionals and those with lived experiences to share their thoughts and feelings with us.

Locality Engagement

We took our survey and information out into each locality on our information and engagement stalls throughout the period of engagement. Through this we interacted with approx. 412 People over 24 events across Greater Manchester.

Case Studies of lived experience

We have collected lived experience case studies from 4 parents/carers of children and young people with ADHD.

Social Media

Through the engagement period we published:

- 6 organic posts on our GM ICP Facebook with a combined impression or reach of 14,704
- 5 organic posts on our Instagram with a combined impression or reach of 610
- 2 organic posts on X with a combined impression or reach of 905

Website

We have also had 3,540 visits to our children and young people's ADHD page on our GM Integrated Care Website during this period.

Mobile number

We took a number of calls and also offered the opportunity for people to text or WhatsApp us.

Who answered our survey

It is important that we understand who answered our survey. As can be seen in the charts below the survey was mostly completed by adults, particularly the parents, carers or guardians of those who were currently involved in accessing services or who had been referred and were on the waiting list.

Chart 1. The numbers of the different people who completed the online survey

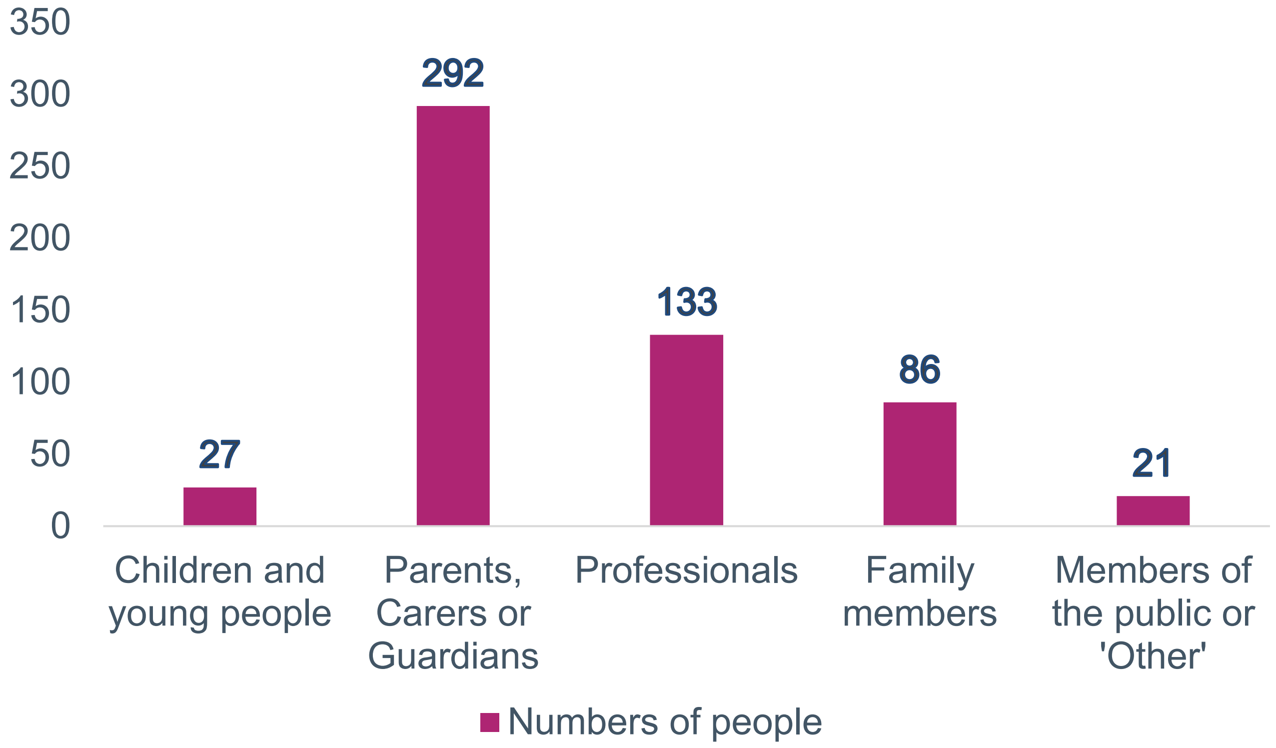
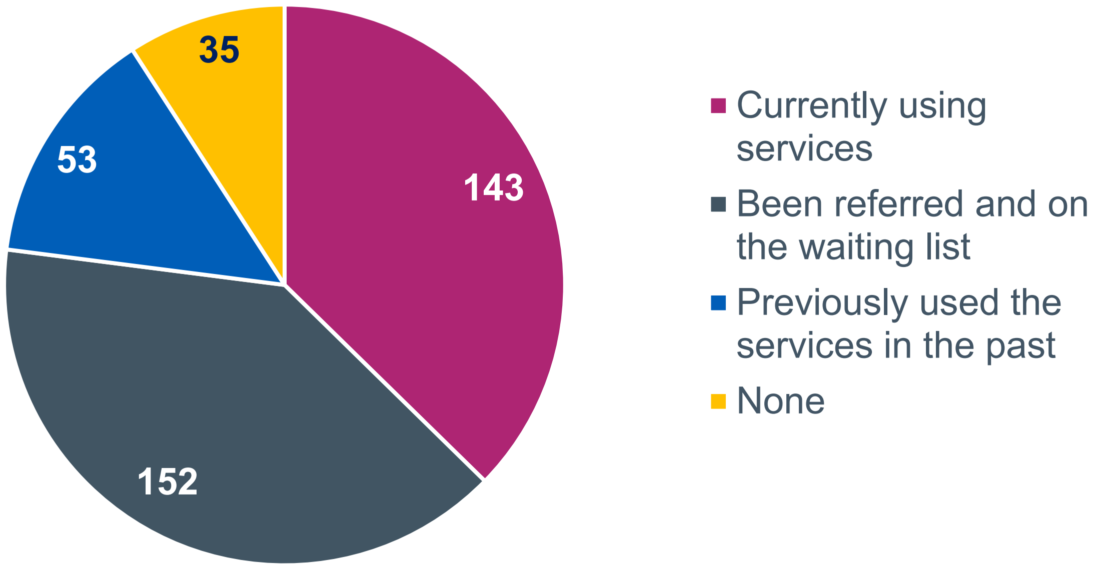


Chart 2. How people identified their current involvement with services



Partnership work

To enable us to reach as many people as possible to have their say, we reached out to numerous organisations and contacts. We provided information in numerous ways including a facilitator pack to deliver own sessions to engage, one to one conversations, presentations and generic emails. Whilst we don’t know what happened with all these organisations, we know that many of these contacts reached out wider to audiences they related to. The list can be seen on the next page.

Our Kids Eyes

Early Years teams

Colourful Minds

M9 Parent ADHD group

Healthwatch's

Schools

The Proud Trust

Youth Zones

Leigh Youth Hub

Primary Jigsaw

Kashmir Youth Project

Universities and Colleges

Respect for All

Kooth

Foster Carer Newsletter

Family Welfare Teams

Councils – all relevant teams

Disability Advisors

Carers networks

Parent Carer Forums

SPACE

First Point

Dare to be Different

Young Minds

Wigan Princes Trust

LGBTQ+ locality networks

Youth Cabinets

RNiB

Happy Smiles CiC

Greater Manchester Youth Network

To ensure the views and voices of children and young people themselves were heard during the engagement process NHS Greater Manchester commissioned Greater Manchester Youth Network to reach out to their wealth of networks and offer the many children and young people they work with the opportunity to have their say.

This way provided an accessible, experienced and trusted route for children and young people to engage. GMYN already delivers a range of development projects for Disabled and Neurodivergent (D&N) young people, so this was an obvious fit.

The involvement of children and young people via GMYN will exceed the duration of the engagement period. They will continue to use their perspective to comment on findings from the engagement period, they will continue to work with commissioners in relation to implementing changes to the ADHD service and will develop some tangible pieces of work for changing the narrative around ADHD.

To date there are growing numbers of regular members of the group and there has been some extensive qualitative feedback (mentioned in other parts of this report) from over 20 young people. This work will continue.

> "We are suffering and need help"
>
> Young person

> "We want to feel heard"
>
> "This is the only ADHD specific group I've ever come across"
>
> Young person

> "There is still too much stigma and misunderstanding, people expect you to be happy, excited, hyper all the time"
>
> Young person

Wider feedback

In the process of engaging and getting feedback on the service and the proposals, we have heard lots of wider comments of importance or for consideration, but that don't naturally have a home within this report. It is important that they are acknowledged and kept in mind.

Education

Lots of comments were made about challenges with the education system and schools. Whilst this is related and work continues with our partners in education, it is not within the scope of this work to change how schools offer support within school. These comments will be shared with relevant partners.

Survey

We had a very small number of people suggest that the engagement would have been better if families had been involved in designing it and the survey. We welcome all feedback on how we can improve our engagement. In reassurance, the engagement and survey were reviewed and signed off by a group including some parent and carer representatives.

Wider neuro-developmental programme

Some of the comments and reflections were on the wider neurodevelopmental pathways, including autism spectrum disorder and also adult ADHD services. These are outside of scope of the project, but the feedback will be shared.

All comments on these wider concerns that were raised will be shared with our partners across Greater Manchester so that they can be considered.

Section 2: Lived experience

Lived experience introduction

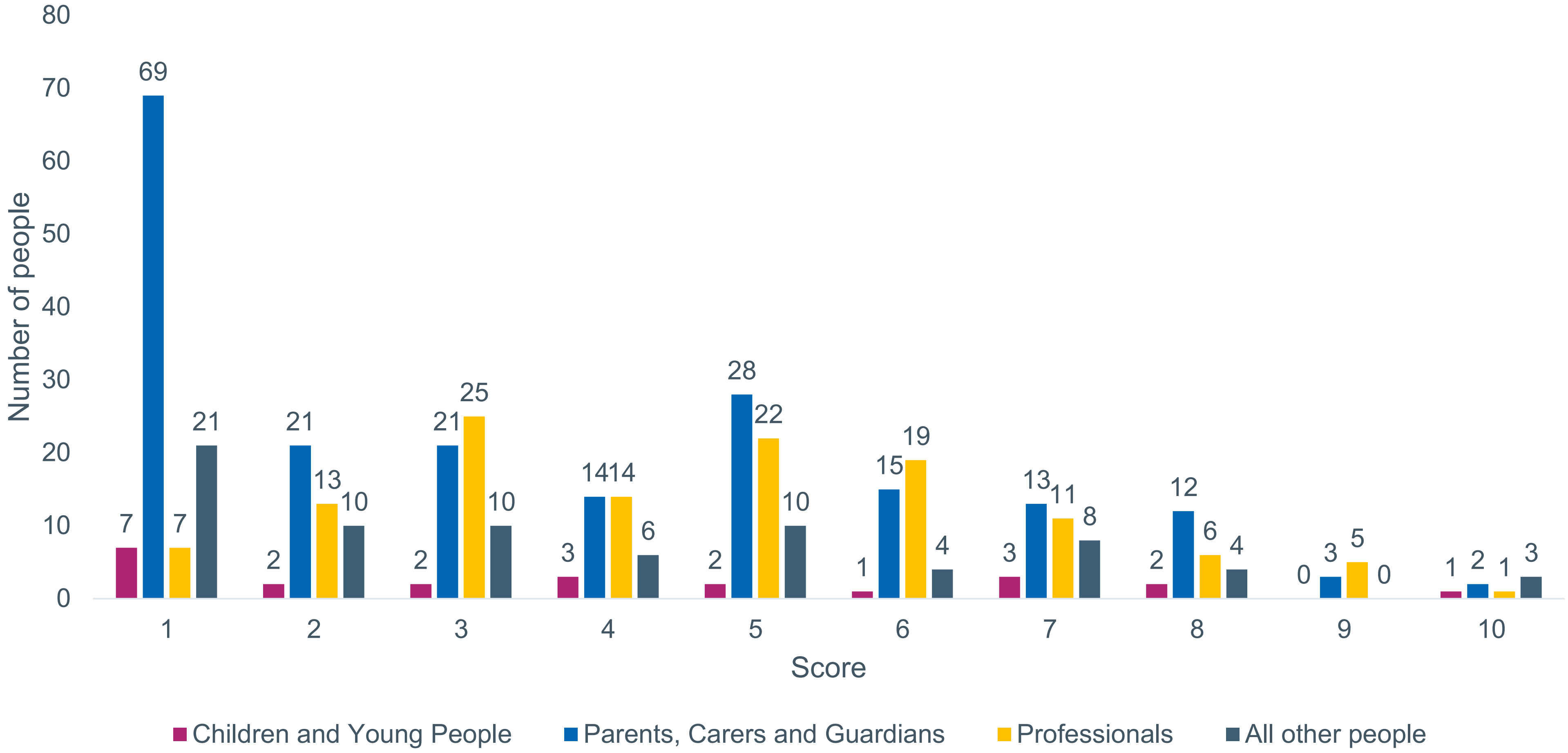
Many people shared with us their experiences and from this we have been able to build up a detailed view of the different journeys' children, young people and their families go on when they have symptoms of ADHD. This journey starts from point of referral through to post-diagnosis support. Find the themes on the following pages.

Many of the experiences shared with us were challenging and when asked to rate the support they had got from services (where 1=poor and 10=excellent), whilst the average score was 4, the most commonly chosen score was 1, showing that there is a lot of unhappiness about the service currently. People's scores can be seen in chart 3 on the next page.

All the different types of people who responded have scored the service in the lower numbers, demonstrating that there is a lot of unhappiness with the current services. This supports the need to change.

Professionals stood out as scoring predominantly within the middle section between 3 and 6 highlighting that professionals may experience the services differently than that of children and young people and their parents, carers or guardians.

Chart 3. How people rated their experiences of the services



The journey: referrals

There were a significant number of people reporting difficulties with the referral journey, particularly the pathway.

GPs were referred to as not always having the right knowledge to refer, however the process is seen as simpler and quicker than schools. Some felt that schools were cited as best placed to make referrals via the SENCO but others saw them as a gatekeeper or barrier to referrals which meant lengthy waits or a refusal to refer.

A significant number of people said that schools often didn't believe the parents, sometimes because of masking behaviour or that the school had lack of understanding and often blamed inadequate parenting for children's behaviour. This also led to children being labelled as badly behaved, resulting in a negative impact to the wellbeing of children and families. In addition, the capacity of schools to refer in a timely fashion was also cited as an issue.

On the whole professionals felt that whilst they the referral was easy to make there was still a need to improve the referral process and ensure referrers had adequate knowledge of processes and criteria and that paperwork was made more efficient and streamlined.

The variation in referral routes was also thought to be confusing and potentially creating inequalities.

> "…in Wigan GPs make referrals whereas in Bolton it is the school and the school can often take much longer or act as a barrier"
>
> A parent

> "Parent voices are lost in the process when schools gatekeep assessments. My child masks heavily in school so they refused to recognise it and told me I overanalysed my child."
>
> A parent

> "In Bolton referrals can only be made via school which is really difficult when child can behave well in school as many school staff don't deem them to have ADHD symptoms despite parents seeing much of it at home"
>
> A parent

The journey: referrals - age related factors and dual diagnosis

Barriers to accessing services due to age was also cited by a significant number of people. This is a particular issue for those under 6yrs and those aged between 16 – 18 yrs.

Some parents reported a lack of support for children under 6 years due to the minimum age of referrals. However, for some the hubs had supported younger children and these were found to be of great benefit. The impact for those between children's and adult services is a big concern for parents and young people who state that they are having to wait much longer due to transitioning from the children's to adults waiting lists and starting at the 'bottom of the list' for adult services.

People said that there needed to be a better understanding of the overlap between other neurodiverse conditions such as dyspraxia or autism as this didn't seem to fully be understood by professionals leading to delays in referrals or not being recognised. Parents also raised concerns about conditions such as autism masking ADHD and not being picked up earlier or referred for support or diagnosis because of this.

There are also concerns about separate referral pathways for comorbidities, particularly in relation to autism and ADHD. This is creating a delay in getting support and is having an impact on the person waiting, for example, one parent said in support and diagnosis for CYP with a dual diagnosis. Some professionals mentioned the disparity of funding between autism and ADHD and thought that there needed to be more funding to provide adequate support and reduce waiting lists.

> "The dual diagnosis my children hold make it difficult to seek the right support. I go round in circles. Everyone refers me to someone else."
>
> A parent

> "My child is too young for diagnosis but shows clear traits. The Neurodiversity hub and home start team in Rochdale has been so helpful in supporting her needs now"
>
> A parent

> "…since we know that CAMHS [Children and Adolescent Mental Health Services] are already supporting with the ADHD it seems unnecessary that we need to wait for autism assessment , this is impacting our choice of high school as we don't have clarity on a diagnosis."
>
> A parent

The journey: waiting

We know children are waiting a significantly long time for an ADHD assessment, survey responses indicated significantly improving waiting times was the single most important thing to all respondents to make their experience better. The responses indicated that it is not unusual for children and young people have been waiting more than 4 years with no answers or support. There were significant comments from parents, carers and children expressing genuine concern at the lack of communication during the time on the waiting list. Repeated mentions of having no indication if you have reached the waiting list, where you are up to on the waiting list, how long it will be before you see someone or an offer of any support whilst you are waiting. A suggestion of a commissioned text service for ''where am I on the waiting list'' and comments such as "*occasional texts or emails to say that you haven't been forgotten about, you're still on the waiting list.'*

This leads onto many comments relating to having a point of contact whilst on the waiting list 'being able to actually contact someone or at least get a reply via email or a call'.

Due to the lengthy waiting times respondents described seeking alternative routes through right to choose and the private sector. It is indicated that there is disparity in the right to choose offer and the private sector not being available to everyone due to a significant cost therefore this not being an equitable approach to assessing and treating children and young people.

Respondents also suggested there needs to be improvement within the capacity of staff to manage the waiting lists across Greater Manchester.

Lack of support whilst on the waiting list came through the majority of responses. Respondents felt strongly that an offer of support to manage symptoms is needed. There are many different reasons for respondents telling us this, as no support can lead to significant consequences for the child and sometimes the rest of the family.

Repeated comments around children developing significant mental health issues, attempted suicide, inappropriate school discipline, child being expelled from school, family breakdown, divorce, children becoming part of the criminal justice system, substance and alcohol usage and school not willing to support child due to not having diagnosis.

One professional said ‘’ I have seen children go to prostitution as a way of seeking the stimulus that the body is craving’’

One point which was mentioned numerous times by respondents was that young people aged 16 and over we're waiting more than two years to be seen and because they had reached the age of 18 before, they were seen, they then come off the children’s waiting list and start from the bottom of the adults waiting list.

“Waiting times are awful. I was forced to go privately to get support. The transition back to the NHS was complex and time consuming”

A parent

“We are still waiting for CAMHS to accept my son has a needs for assessment and the actions they agreed from the last consultation haven't yet been followed through. My son is developing significant emotional health issues because he hates the way his neurodiversity 'makes' him behave (he is very violent yet only 6 years old). He has talked on numerous occasions about killing himself because he doesn't deserve a family due to his behaviour. We of course reassure him but despite asking for support for his suspected ADHD, CAMHS don't seem to care.”

A parent

The journey: assessment and diagnosis

For many of the people who we engaged with, assessment and diagnosis were still to happen.

Diagnosis was seen as the gateway to help and support. It also served for some as a validation, but the gateway to support was the stronger feeling.

For those who had been through assessment and diagnosis, there were quite differing experiences of assessment and diagnosis though. Some reported a very positive experience whilst others reported challenges.

Key points people raised included:

- The diagnosis needs to take account of the parent and child experience, it was felt too skewed to the information provided by the school. There were specific comments about children who masked in school finding the emphasis on school experiences created a blocker to diagnosis.
- On the other hand, a small number expressed that the assessment was very comprehensive – it is possible that this difference is due to different approaches in different organisations.
- There were varying comments about online assessments, with some reporting that they were simple and helpful, particularly if they reduced the number of appointments, and others that they were too simple and were discriminatory against people with learning disabilities.
- A small number were experiencing assessments for both ADHD and autism spectrum disorder. One person had a very positive experience with both assessments being done at the same time as part of a pilot, but the others had difficulties because one assessment and treatment plan had to be completed before the other could start, and this was time consuming and meant years passed on two different waiting lists.

> “Once we got here the process was quick”
>
> A parent

> “Three appointments for one diagnosis is to much.”
>
> A parent

Key points people raised included (continued):

- There was evidence in the feedback that some people had been offered reasonable adjustments to help them manage and access the appointments, including being offered face to face or online appointments.
- A small, but significant number of people had chosen, or felt forced, to pay for a private assessment. Many of these then reported challenges getting this diagnosis accepted and acted upon.

- There were a lot of really positive comments about the staff from both parents and children, with a small number of people less happy. “Very knowledgeable”, “very helpful” and “engaged/communicated well with children” all coming up repeatedly.

A small number of people reported being told at assessment that their child didn’t have ADHD, but they felt that assessment was wrong – several of them had other children with ADHD or had ADHD themselves. After the assessment, they were left with no options or help to support the child and manage the behaviours that they were experiencing.

Feedback from professionals about diagnosis

Professionals offered lots of positive experiences of the diagnosis process. Including:

- Feeling that when children make it to the assessment, the clinics work really well, the appointments are high quality and the pathway is clear.
- Working in multi-disciplinary teams being extremely helpful.
- There is lots of collaborations across teams and information sharing allowing them to help the children and families.
- One service reported having a nurse-led pathway with psychiatry supervision and no waiting list.
- Other services report not having enough staff which causes the waiting times.

Lived experience of assessment and diagnosis

Lived experience 1:

My little one displayed difficulties and differences from a young age. He was referred for ADHD services at about 3-4 years old.

Services like ADHD, Speech and Language Therapy, Occupational Therapy and Autism Spectrum Disorder services are diagnosis pathways, not treatment and intervention pathways. This meant that when he was referred for ADHD assessment at about 3-4 years old, he was taken off the waiting list without being seen or listened to. It was clear to them he had ADHD, but he was under 6 and so too young for diagnosis.

If they had left him on the waiting list, he would have been seen at 6 years old, but he couldn't be referred again until he was 6. Instead, it took a lot of advocating for him and a Patient Advice and Liason Service (PALS) intervention before he was seen at the age of 7 and diagnosed at the age of 7 ½.

Lived experience 2:

Children and Adolescent Mental Health Services were awful and insisted he should be there whilst they shared information about medication and what a diagnosis meant in such a negative way. When he was diagnosed at the private clinic he was congratulated on his diagnosis and he was given a card with strengths on it, which my son still carries around with him. It was such a contrast of experience.

Please note that a few edits to the grammar may have been made to these stories easier to read.

The journey: accessing services

There were a significant number of comments and stories in relation to post diagnosis and accessing services including barriers to access. Professionals also commented on the way services operate including lack of integration and understanding of service user needs.

Receiving a private diagnosis presents a barrier to accessing post diagnostic support and services as this is not recognised by GPs. This means that some children and young people are not receiving the same post diagnostic support as those diagnosed by the NHS.

Whilst parents, carers and families thought that on the whole the changes sounded positive they wanted to ensure that they met the needs of individuals including understanding needs and making reasonable adjustments where required. For example, arranging appointments to suit individual needs such as after school or online. Professionals also commented on the need to make allowances for those that struggled to attend appointments and were likely to DNA.

People also talked about the need to make sure environments were ADHD friendly as this hadn't always been the case. Professionals also commented on this and had specific examples of where this isn't currently happening.

> "The hardest one is the lack of continuity in regards to the children being seen by many different people which is difficult for them to keep having to meet new people every appointment"
>
> A family member

> "I know that some families seek a private diagnosis due to NHS waiting times, and this costs them thousands, only to be told that the diagnosis wouldn't be recognised by the NHS."
>
> A professional

> "In the past, we have hosted clinics in school, supported parents in being there and the children have been engaged in the appointments because they feel safe and familiar there. This was something that CAMHS (Oldham) stopped doing a while ago and the DNA's have increased again as a result."
>
> A professional

Interactions with staff have not always been positive with people commented on the lack of understanding or empathy shown by staff. This was also reflected from professionals.

There were a significant number of comments in relation to services working together, particularly from professionals who raised concerns about the lack of integration and the impact on service delivery of service user experience. Parents and carers also commented on the lack of continuity of care and shared stories around 'being passed from pillar to post' and having to repeat their story to different services. Improvements in the way services share information to support this were advocated by professionals.

People also commented on the need to ensure that there are effective key performance indicators and that services are quality checked to make sure they are delivering high quality services that meet the needs of service users, families and carers.

> "The hardest one is the lack of continuity in regards to the children being seen by many different people which is difficult for them to keep having to meet new people every appointment"
>
> A family member

> “Need to improve data availability so other services can access and use the data to inform and improve their own delivery in support individuals, parents, carers’”
>
> A professional

> “I am concerned by the increasing number of private clinics offering assessment and diagnosis. I'm not sure how well regulated they are.”
>
> A parent

The journey: post diagnosis - support

Throughout the feedback there was a strong emphasis on the importance of support. However, it was also evident that for the majority they had received no support. Some parents felt once they received medication they were left to it.

This comment was also backed up by multiple people saying they had not had any reviews/follow ups etc once they had received their diagnosis.

Families often receive no support after a diagnosis, leading to feelings of abandonment and frustration. Immediate discharge post-diagnosis without follow-up care is a common issue.

There were many people who reflected on the wider impacts of a lack of support. Not all comments we received were negative with pockets of positive experiences being shared. There were several staff members across the system identified as being very positive and supportive of children, young people, and their families.

One parent shared a positive experience of a worker in Tameside who supported them, we have included this within the lived experience page for post diagnosis support.

There were multiple reflections on Children and Adolescents Mental Health services (CAMHS) stating the lack of support, communication and follow ups. It was also highlighted in some of the feedback that often Neurodiversity needs are stated as a cause to poor mental health and wellbeing and many people felt that this wasn’t always the case resulting in young people experiencing prolonged period of poor mental health.

“There is zero support through this process & I feel like I have to constantly battle to get any answers or support.”

“There is NO post-diagnostic support.”

“My son is developing significant emotional health issues because he hates the way his neurodiversity 'makes' him behave.”

“We are still waiting for CAMHS to accept my son has a needs for assessment and the actions they agreed from the last consultation haven't yet been followed through. My son is developing significant emotional health issues because he hates the way his neurodiversity 'makes' him behave”

There were groups that were identified as being positive support elements and outlets for enabling parents to have a voice. The Parent Carer Forums were mentioned e.g. the Bolton and Tameside group as were specific groups in localities such as First Point in Bury, Space in Stockport, The Hub in Rochdale, etc.

There were also suggestions for more peer support groups for children and young people, “There definitely needs to be ongoing support groups for children/teens, to give them a support forum with their peers.”

Many people shared that when they had reached out for support they had been placed on parenting courses or similar, it was reported to us that parents felt blamed or at fault for their child's needs or presenting behaviours. Whilst this was the case many people also shared pieces of training that they felt were useful in understanding their child. What parents wanted was support to meet their child's needs holistically and receive support form professionals who engage in their child's life.

There were reflections by parents that they had reached out for support to many organisations some of which they had been signposted to from professionals to then receive literature such as leaflets/self-help information. Many felt this wasn’t appropriate and identified they would like more substantial support offered with a preference of face to face or telephone calls; this is also evidenced in how people wish to seek support from Hubs.

“We waited 3 years for the referral to be seen. Then we were offered medication support services are limited and when not giving medication due to side effects your discharged.”

“My daughter is experiencing her own mental health issues from masking, and not living up to her potential. School just think she's quiet, and that her mediocre achievement reflects her ability.”

“There simply is no support. And I gave it a 1 for the TSO’s outreach worker. If I could have given her 10 I would, but didn't want it to be a leading answer. This is the only person from Tameside services who has supported my son and us as a family for the past 7 years. We need staff to lead with the same passion and conviction.”

“We have had no help! Just a bloody number for a service. They are awful. Rude. Want you off the phone.”

The journey: post diagnosis - medication

Throughout the responses there were many conflicting experiences and thoughts on the use of medication, what became clear was that people felt medication shouldn’t be the only answer or an answer on its own. "Very little help or support after diagnosis other than medication offer.“ Many people wanted support beyond being medicated this included through counselling, support in schools etc. “I feel medication - while helpful - should not be the first thing considering the side effects.”

Many others experienced challenge in obtaining medications due to the ongoing medication shortages with some reporting months of waiting and no interim support. Others who had accessed medications through a private diagnosis and were looking at shared care experienced lengthy waits, and many needed re diagnosis through an NHS provider.

“Her diagnosis led to trying medication, which made her autism symptoms worse and because she then wasn’t on tablets, the service took us off the list and left us too it”

There were several comments that highlighted the negative side of seeking medication and then prescription services. “Shockingly bad service. Understaffed. No replies or unable to contact for assistance. Prescription method for ordering and collection isn't efficient and isn't working.”

A lot of people shared their frustrations at the processes and the waiting for medication following diagnosis raising concerns over multiple waiting times throughout the process. There were multiple comments about the dosage given, and when this didn’t work it was changed usually without a review or appointment and if that then didn’t work one person reflected, they were told to stop the medication with no alternative.

> “Prescription service for medication is shocking, paper/email based with a 4 week lead time, have to be routinely chased up and are then often administered late meaning children are having to ration or go without medication and then dealing with side effects associated with starting again along with general medication shortages across the UK”

Some families stated that medications was their saviour and the impact on their child, the education system and family life was overwhelmingly positive whilst others shared experiences of being placed on multiple medications in a trial-and-error approach creating multiple challenges along the way: “being medicated has improved my focus and memory, reduced emotional dysregulation, meant that I no longer need antidepressants and I get on better with others.” There were also reflections about the impact of medication on enabling children in school, “The medication has helped him stay in the classroom at school” and, “Medication was a game changing for my son experience of school.”

There were also comments about how medication wouldn’t be required if settings changed to meet children and young people’s needs “…I think environments should adapt rather than forcing the child to change their behaviour” and specifically for a school setting one parent reflected: “schools also need funding to properly support as meds aren't a complete magic wand. And teachers need far more ADHD training - especially re girls.”

For many the post diagnosis support was only medication and for many people it felt like this was the end goal: “Medication is our last hope in trying to have a somewhat functional home life. Although the fight for diagnosis is ridiculous and stressful.”

There were 2 reflections on the NICE guidance in regards to treatment sequence and then medication: “Its important to offer the treatments recommended by NICE in the correct sequence…” and “The NICE guidelines state that support to manage symptoms should be offered as well as medication. It hasn't been.” This highlights that people are aware of the expected process and throughout findings we saw people sharing experiences where they have had to challenge processes and develop their own knowledge and this was also the case for medication, its processes and the journey through prescribing and accessing medication.

“waiting 18 months to be diagnosed with ADHD then we had to wait a further 11 months to start medication”

“…trying to sort medication out is a full time job. If my children don’t have medication we are talking serious problems - police, ambulances. Putting stress on all over services.”

The journey: post diagnosis - education

Education covered a number of aspects from the education setting of schools, key education courses that were supportive and others that were not and the needs to educate communities and parents with key strategies on how to best support their children.

Education Settings

This was the highest on peoples list was educators and the education system as many parents felt that their child's education, outcomes and future opportunities were being halted due to the system. Parents were also concerned over the impact of behaviours displaying in schools and the consequences of this:

“Because some children are more disadvantaged than others, and as we experienced, delays in care can cause permanent disruption to education and relationships, leaving lifelong scars.”

Teacher training and response from teachers was discussed a lot throughout the feedback and in particular there were some concerns over teachers understanding of the system and a child who is medicated.

Education Courses

It was reported to us that parents felt blamed or at fault for their child's needs or presenting behaviours. Whilst this was the case many people also shared pieces of training that they felt were useful in understanding their child. These are: IBasis (10month old – 2year olds), Riding the Rapids, Circle of Security, Incredible Years and PACT therapy. Where parenting courses and Webster Stratton type courses were seen as a negative in respects of not understanding the wider needs of the child, leaning towards a more parenting need emphasis which for many flet like blame of bad parenting.

A professional commented: "We see children who have diagnosis of ADHD and are able to manage their day to day lives effectively with support from family and school. We see too many pupils whose parents are not able to manage their behaviours and as such seek a diagnosis to justify the behaviours. Education for families is key."

Education for the community

To most people educating the community was a must, this was heavily placed on professionals needing training with school being a focus of attention. Especially around symptoms and early identification. This linked to people feeling school staff at times were gatekeepers to referrals/diagnosis and support given the emphasis placed on information received by schools as part of the process.

Strategies

Parents wanted to be educated on how best to support their child, this included during crisis, whilst they waited and throughout their life course. It was shared that many simply don't know what they need to do and try their best to support but without knowing and without access to key support strategies many felt helpless in their plight to best parent their child.

"Education around ADHD is important for community to support the patient and their family in their hard times and respect their individuality needs"

"…I'm not interested in anything but supporting my children to be able to recognise their challenges and develop strategies as the move into adulthood."

Lived experience about education

Lived Experience 3

"The understanding around ND and the acceptance needed to change things on a whole so our children can flourish, the world can grow, and people fully understand. The world would work much better if some strategies were a given rather than an intervention."

Lived Experience 4

"I think there is a big information gap in the school services, as some teachers don't seem to understand the condition...I think ADHD is more complex then people assume. I think there should be regular education around neuro diversity for teachers, school, nursery staff."

Lived Experience 5

"I have a son who is 15 years old. I was told by his nursery teacher he had ADHD when he was 2 years old but nothing could be done about this. He went all through primary school without support and was not referred for any kind of assessment, he had a difficult time at primary school.

"Schools themselves need support in this area as it is becoming unmanageable for them"

Lived Experience 6

"Education for the community and diagnosis are interlinked in my opinion as if the people involved in a child's life aren't aware of symptoms, how can they provide support in obtaining a diagnosis, especially for girls. They are quire often left to flounder, especially in an educational setting which can quite frankly be toxic. It can impact heavily on friendships which are so important to girls and they don't understand why they are left out of activities. Not feeling accepted or normal has an enormous impact on a child and their family which is why I've put getting help with symptoms first. However, may be it is the general lack of awareness around ADHD in girls that is the root cause of the issues these children face from primary school through secondary school and they need addressing alongside each other."

Lived Experience 7

"Education around ADHD is important for community to support the patient and their family in their hard times and respect their individuality needs"

The journey: living as a family with ADHD

"… [it's] hard to be a parent."

A parent

Whilst it wasn't a direct question that we asked through any of our engagement, one of the themes that came across very strongly from parents, carers and family members of the children and young people with or potentially with ADHD was how much the symptoms affected their everyday life. Many parents reported that it created anxiety, worry and stress for both the child and the family – including siblings, and reduced their ability to live a normal family life, for example, going on family day trips.

The was also serious concern that both the emotional impact long term on the child and the impact on their future and whether they would be able to achieve their potential. Children talked about the condition being very isolating and hard to talk about. Parents worry about the stigma. There are many references to struggles to get children and young people into school, and daily battles.

Some of the experiences shared about the emotional and mental health impacts on the child included significant self-harm, up to and including suicide. It was clear that in some cases families were struggling to cope, with people telling us of family breakdown and divorce due to the pressure of trying to support the child or young person and manage their behaviour. There were a number of references to ADHD attributed violence and assault, making the home unsafe for the family and siblings.

Links were even made to increased involvement in the criminal justice system, including county lines involvement and increased risk of the children and young people being involved in sexual exploitation and prostitution.

It was also evident through the language used throughout the responses that parents and carers had become experts in ADHD and the process, with many using what could be seen as "internal" NHS language, for example, referring to diagnostic tools by name, and talking about "dual diagnoses" and "shared care" arrangements.

> "…seeing your family member in need specially your own child and you feel yourself helpless, even though you are the part of NHS service it can't help your family, makes you feel miserable, and it does cause stress and anxiety in your life."
>
> A parent

“In school other kids would call my son a mong and this was awful for him, he hated being different. His self-esteem was really affected. He came out of school every day feeling like an awful person”

A parent

“…the lack of support for my SEN children makes my struggles much more worse. Therefore, I am tired and run down all the time.”

A parent

Lived experience of family life

Lived experience 8

“My daughter was put on a waiting list to be triaged by Bury CAMHS at the request from the GP.

“I found a separate CAMHS Eating Disorder Clinic which I could self-refer into (the GP did not know about this) which saw her within a week diagnosed her with an Eating Disorder and provided support from a nurse.

“We were triaged by CAMHS who put her on waiting lists to be assessed for ADHD and Autism. The waiting lists were over a year. We used Right To Choose to change the provider to one that had a shorter waiting list.

“The GP surgery failed to send the paperwork causing a delay.

“When we were about 1 month from having our appointment the ICB [Integrated Care Board] changed the rules about the standards that providers needed in place, and we were told we were no longer able to use the one we were waiting for. There was no process to transfer back to Bury CAMHS (at one point I was told we'd have to go back to the start of the waiting list).

“At this point, we went private to access both ADHD and Autism assessments at a cost of around £3,000. She received a diagnosis of ADHD. We needed medication but we were unable to get NHS medication until she'd been on a stable dose for 2 months as she'd had a private diagnosis.

“We went private. We spent around £2,000 on psychiatrist appointments, prescriptions and medication over 6 months.

“We have now transferred the medication responsibility to the NHS at Bury CAMHS ADHD clinic. I have had some awful experiences with Bury CAMHS and am wary of using them but have no choice if we want the medication on the NHS.

“I have made complaints there in the past when: 1. I received no support having contacted them in crisis as my daughter had stopped eating completely; 2. I have repeatedly had missed appointments from staff; and 3. I complained when told after a short conversation over the phone that my daughter 'probably has autism' sending me into a panic.

“The whole process is not visible, the timelines are too long and have all added to the stress of this situation.

“There is no support for me as a parent in all of this, luckily my work has been very flexible, and I have kept my job.

“There is no 'care' or 'compassion'. I was able to get this far as I am articulate, I have the capacity and the determination, but it has taken a toll on my mental health and our finances.

“The awful processes and continued 'fighting' has had a much more negative effect on the family than my daughter's eating disorder and ADHD, which are both manageable with the right support. It is important to note that added to this stress is the process to get a EHCP in place for my daughter at school - that is a whole other story.”

The journey: what would make your experience better?

From the survey responses people are aware of the NICE guidelines which talk about the offer of a more holistic offer of support and not offer just a medicated route of treatment.

The overarching response for the question ‘what would make your experience better?’ was to shorten the waiting times for assessment. This does not come as a surprise and is one of the significant reasons the service needs to change. In addition to this, there were many other comments from people to suggest other ways to improve their experience. These include:

- **Better communication** – most people who answered this question wanted better communication whilst on the waiting list, to know what to expect, to know where they were on the list and to be offered support whilst on the list knowing that the child's symptoms would progress without support. Answers were from parents/carers/guardians and the children themselves. ‘’Over 700 calls made one week and I still haven't had a reply to emails sent over a month ago’’

- **Education/school** – again this was an area which was commented on in high volumes. There is a consensus that there needs to be much better awareness and recognition of neurodiverse conditions within the education system. There were concerns from some parents that schools are completing forms inaccurately, they are not recognising symptoms and, they are not responding to parents concerns which is creating a feeling for some of schools gatekeeping access a referral/assessment.

  Children are experiencing a lot of negativity at school; this creates a highly anxious space for children where they are spending most of their day.

  Education has a huge role in supporting children with neuro diverse conditions and with this people would like to see more training for staff in schools to enable them to early identify children with ND conditions, to communicate with parents to signpost to support, to ensure children are supported in the appropriate way to learn rather than be labelled as naughty kids, this then leads on to impact negatively on the child's future. “School being more understanding, they are just waiting to see if he is diagnosed and then hoping he’s medicated. They don’t seem to do anything different for him even though the referred him, and he’s always in ‘trouble’ and has had suspensions.”

- **Support for children and young people** - The view is that a diagnosis can unlock the support for the child required which is not what people say is needed. There needs to be mentoring, coaching and workshops for children. “They could support families better, Workshops for children & parents if medication isn’t the answer. Would be a good thing.”

- **Support for parents/carers/guardians –** An offer of support should be available to parents/carers/guardians whilst on the waiting list. Examples of offers of parents/carers/guardians being put on courses for dealing with children's behaviour include things like ‘’the naughty step’’ but these are the wrong courses and not aimed at parents/carers and guardians with neurodiverse conditions, they just add to the overwhelming feeling of blame.

- **Parents voice to be heard** – People state that parent/carer/guardians need more of a voice when trying to access support/diagnosis. They want to be believed their voice should have a significant place, a child can present differently at home and many examples explain there are “explosions of violence’’ when children get home. for support and referring children and young people and not allow “school to play god.” Parenting courses are needed but not for naughty children, for neurodiverse children. “My child masks heavily in school so they refused to recognise it and told me I overanalyse my child.”
- **Family diagnosis** – People feel it is important to consider whether other family members have had a diagnosis when considering a referral for a child. This may get the child seen quicker and be offered support sooner.
- **Early Intervention** - it came through the survey results that early intervention was required, in the same way as other health conditions, not leaving a child to reach crisis point before any support is given.

A parent shared their struggle with getting their child assessed for ADHD. Despite clear signs and struggles in school, the process was prolonged due to high demand and lack of prioritisation, leading to significant stress and impact on the child's education and self-esteem. The parent described feeling frustrated and helpless as they navigated the system.

Section 3: Support to help manage symptoms

Support after diagnosis

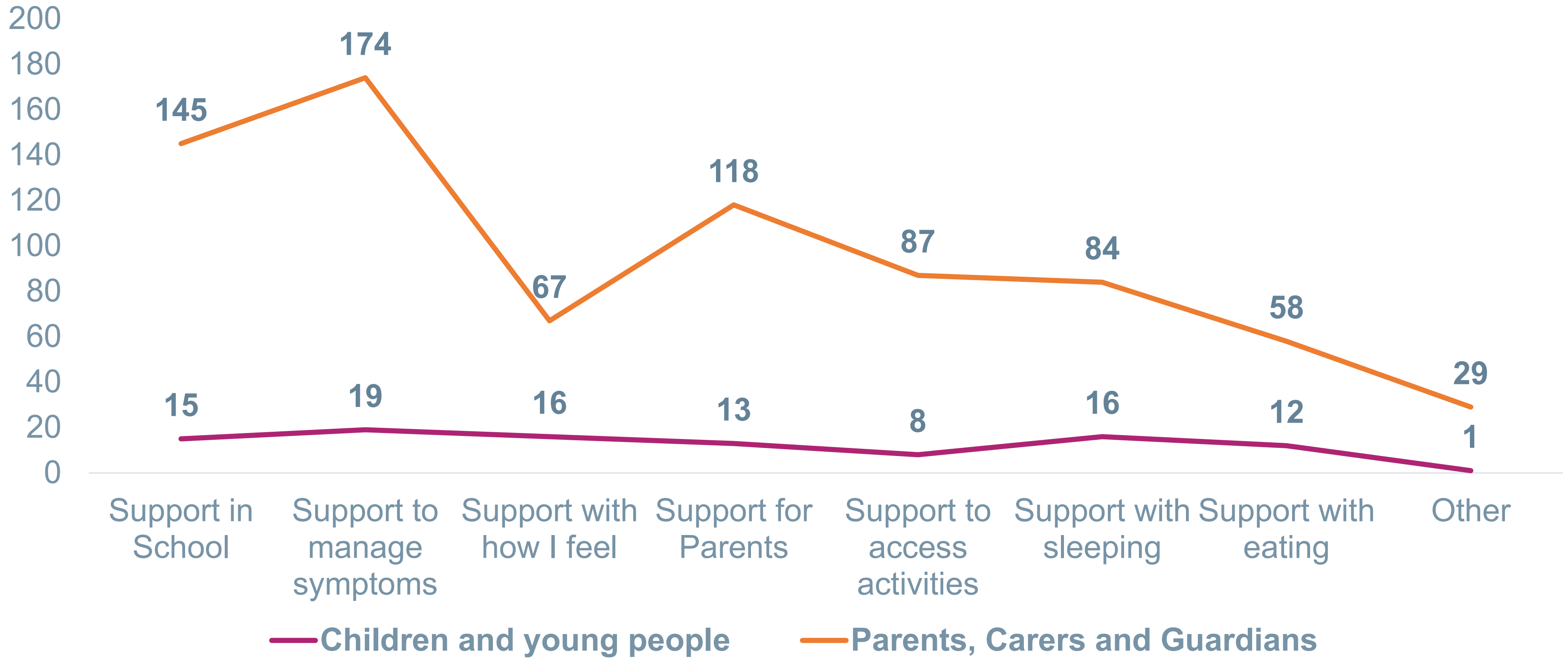
As already set out, people shared many negative experiences around the support that was offered, mainly that it took too long to get and the offer was too limited – mostly just medication.

When asked to consider what support would be helpful, people offered a number of suggestions.

- Support to manage the symptoms was the most important offer for children and parents – particularly around the impact on mental health
- They want this support as early as possible to stop symptoms worsening
- The support should be meaningful and individual to the needs of the child young person and their family
- Support should be offered in schools for the children and families, but support should also be offered to schools to help them manage and improve their offer
- Support should also be offered to professionals and referrers as there is lots of pressure on the system
- Most people wanted to get support face-to-face, but they then preferred online support to telephone support
- Parents also wanted support to help them cope, and support for the siblings in the family too with specific sibling support groups suggested

Types of support people said would be most useful

Chart 4: Support people would find most useful



Both parents and children placed “support to manage symptoms” as the most useful form of support needed. Parents felt less urgency around support for themselves in respects of how they felt. Whilst this is expected we noted that many parents shared with us that their anxiety, poor mental health and issues around illness was a factor form the processes they were undertaking. Many identified as needing to strongly advocate and challenge the system to get what they needed. Children and young people and parents also felt that support in school was high on their list of needs, and this is further reflected throughout the report. Lots of people commented on the importance of support to get the diagnosis in the first place and how this was essential to accessing any other support options.

Types of support: the top 3 types of support wanted in hubs.

Top 3 answers

1. CAMHS (191)
2. Educational Psychologists (180)
3. Psychology/psychiatry (169)

It is important to note that Children voted psychology and psychiatry the highest priority above CAMHS support.

As part of the survey, we asked which services people would find most helpful in hubs and the top 3 answers are in the blue box.

Some did state ‘other’ as a suggested support type within the hubs and some of the ideas people had included:

- Weekend activity / outings for children with ADHD
- General support with organising things such as medication reviews, prescriptions etc
- Resources that people could use to access information relevant to them
- Specialist nurses

We also asked people how they wished to access support, specifically focused on the new hubs model where support would be available at point of need of services.

The graph on the following page showcases that there was a preference for face-to-face interaction. This seems to be a consistent theme throughout the findings that people find it better to talk, interact with people face to face. There is also reflection that this is a better approach for children with ADHD who can struggle with other methods of communication.

How do people want to access support from hubs?

We asked people how they would most like to access support from hubs, and the responses can be seen in the chart below. All types of people would like to see a face-to-face offer, with an online offer also important.

People had the option to suggest their own ideas, and the suggestions included:

- Social Media, for example, Tik Tok
- One person asked that they were “not given another padlet”.
- Some wanted Microsoft Teams or Zoom meetings

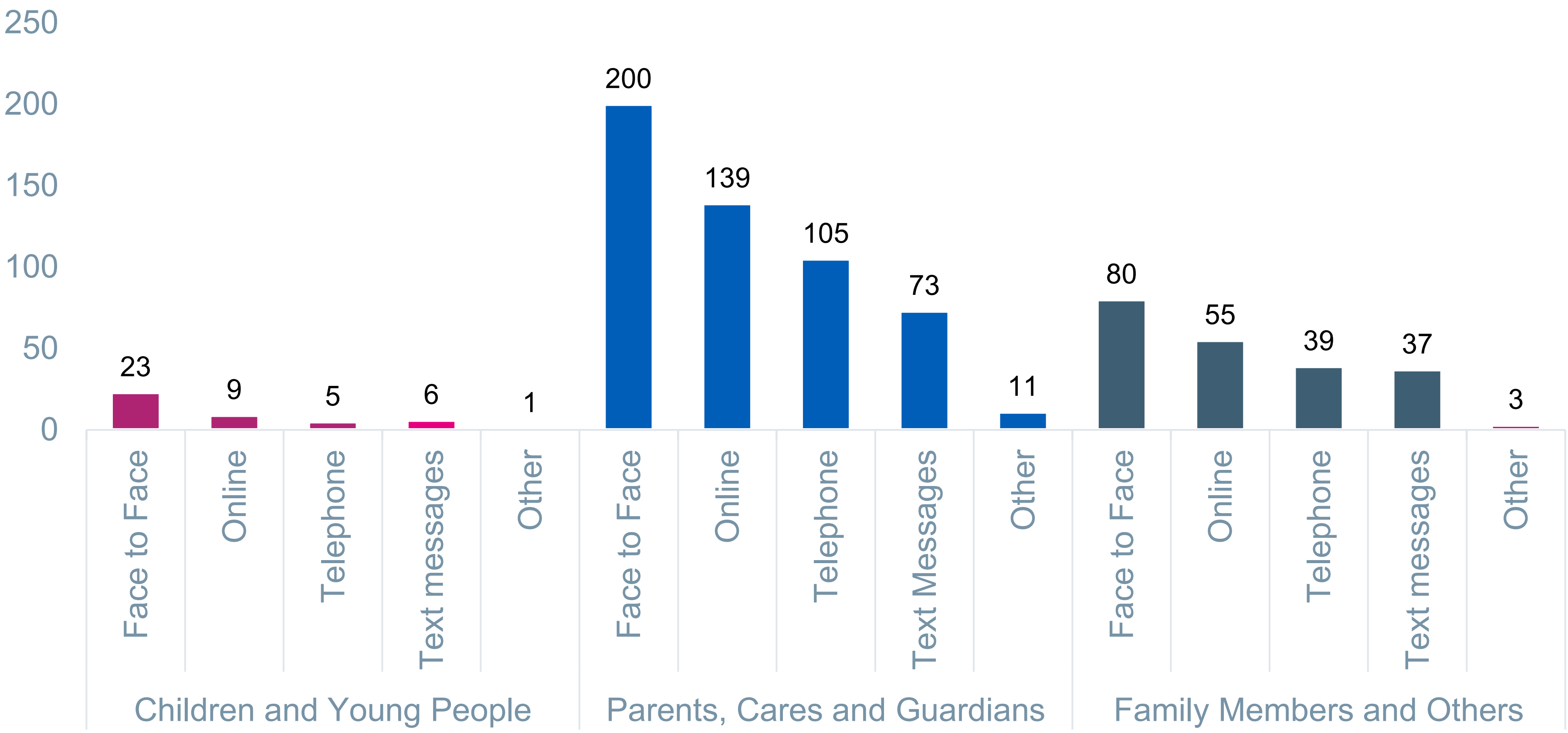
Some examples include more other communication methods such as:

- letters
- email newsletters

With a few people suggesting:

- home visits or school visits would be better

Chart 5: How people want to access support from hubs



Section 4: Assessment and diagnosis

The importance of assessment and diagnosis

One of the things we wanted to explore in the engagement was whether diagnosis was important in its own right, or whether diagnosis was mainly important because it meant getting support.

It is clear from the feedback and conversations that diagnosis is seen as the gateway to help and that this is the most important element. For some, however, the diagnosis itself is validating and is seen as helping the child or young person understand themselves.

Currently diagnosis is the only way to get to support for most children and families. However, there is support for early intervention and those families that have had access to support without a diagnosis have found that hugely helpful and the diagnosis becomes less important.

Reducing waiting times, offering more early intervention and providing practical tools and support that help children and family manage everyday life are all themes that have come strongly out of the engagement.

> “He is only 7, he doesn't understand why he doesn't feel the same as everybody else, and if you could just have that coached in to get him to see why his brain does certain things. I just think the diagnosis would be the icing really.”
>
> A parent

How people felt about the introduction of referral criteria for assessment

In the survey, we asked people how they felt about the plan to introduce referral criteria for ADHD assessments. We gave them a scale of 1 to 5, where 1 meant that they strongly disagreed with the proposal (or it made them very sad) and 5 meant that they strongly agreed (or it made them very happy).   Overall, more people were supportive of the plan than not, but there was a significant number who sat in the middle and weren’t sure either way. This was true for all the different groups of people.

The charts below show both the scores added up for all groups (Chart 6), and the scores split for type of person as a percentage (Chart 7).

Chart 6: Total number of people

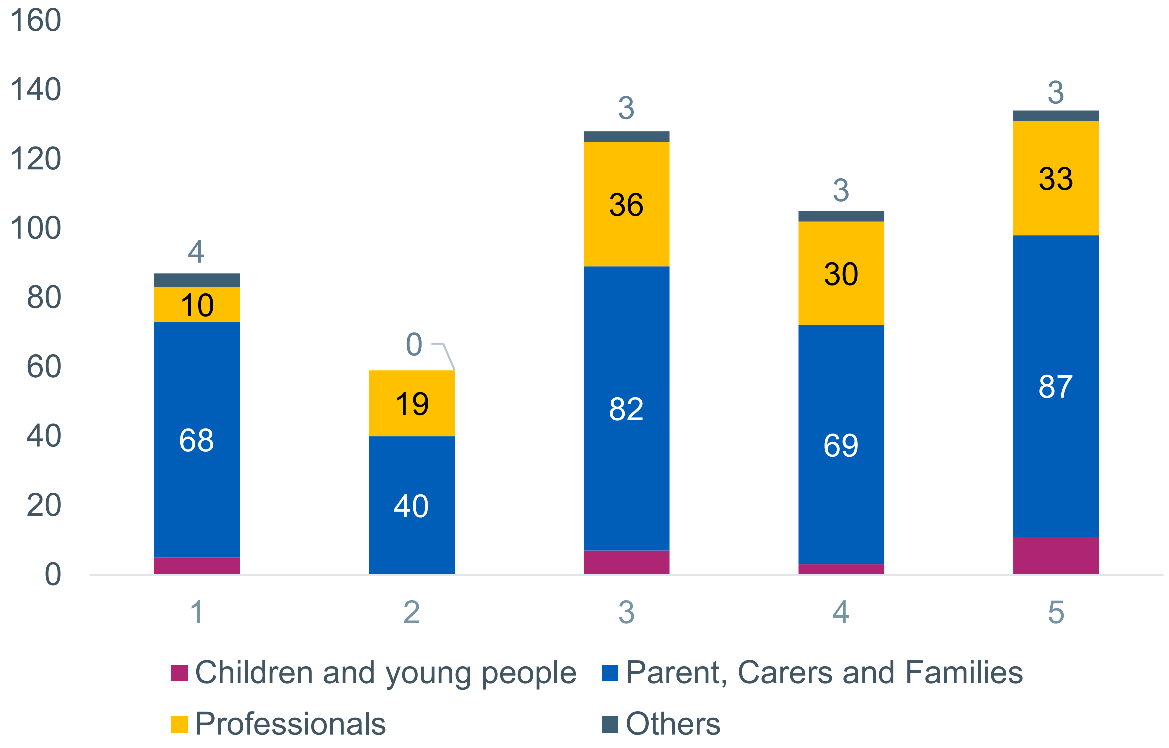
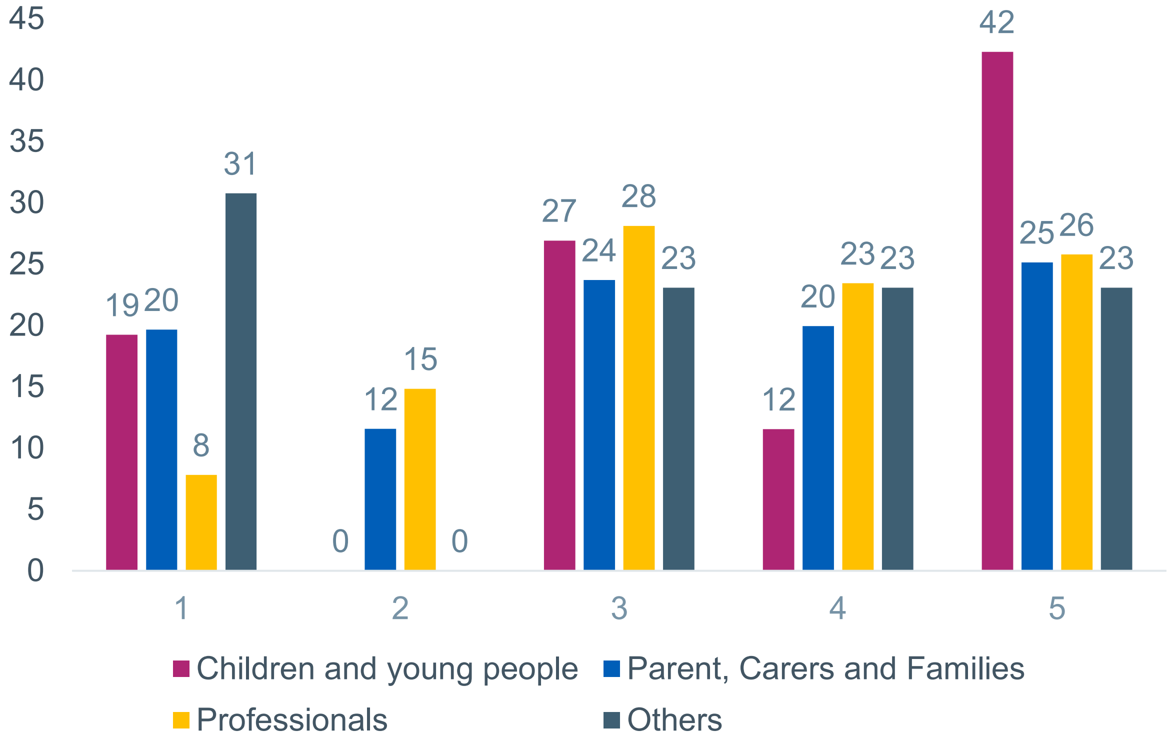


Chart 7: The percentage of people by their type



Feedback on the referral criteria

The suggested referral criteria is:

- The symptoms severely impact on their ability to live and function daily, and/or
- The child or young person also has severe mental health conditions, and/or
- The child or young person also has co-existing physical or complex conditions.

People were asked if there was anything they would change or add to these criteria.

Whilst there were a number of people who expressed satisfaction with this as a suggestion, there were also a large number of people who offered improvements, ideas or felt that referral criteria should not be used at all. A particularly strong theme was that every child and situation was unique, and it is important that we listen to the child or young person.

General feedback on the criteria:

- This is a medical model and doesn't fit for neurodiversity. There is particular reference to the need to consider children who have more than one neurodevelopmental condition.
- There was concern about the threshold of "severe" being too high and "moderate" would be better.

Feedback on ability to live daily life criteria:

- The impact on daily life was considered the most important criteria by many and was strongly welcomed. However, it should also include the impact on the family.
- There was concern that this wasn't very specific and so could be interpreted differently. A comment from one parent or carer whose comment was very reflective is in the speech bubble.

Feedback on mental and physical health criteria:

- There was less consensus on both mental health and physical health.

- For mental health, some felt it was very much connected to this, but more people felt that waiting until the child had severe mental health wasn't a great approach.
- There was some push back on the inclusion of physical health by some as it was felt to be unrelated, but others supporting its inclusion.

> "The wording needs to be adjusted to include - difficult for them to live day to day life at home or school, and not reaching their personal potential."
>
> A parent/carer

Alternative ideas for referral criteria

As well as feedback on the criteria, people shared concerns about the process in general and ideas for improvement.

Ideas for criteria:

- Include the impact on the family and family life.
- Emotional wellbeing is important too and the effect on confidence and self-esteem.
- The impact on outcomes and education should be specifically included.
- There was concern that vulnerability wasn't included in this, particularly children in care. The safety of the child also worried some.
- The life stage of the child should be considered – are they changing school, family changes, etc, can all mean that more support is needed.
- The family history of neurodevelopmental conditions and ADHD should be considered as part of the criteria.

Concerns about how it is delivered:

- The word "severe" is subjective and will be difficult to make sure it is applied consistently.
- The voice of both the parent and the child should be listened to – not just the school.

- This doesn’t fit with the plan for earlier intervention and could cause future problems for children, families and services.
- Some children, including many girls, mask their symptoms and so are less likely to meet the criteria, despite potentially needing it.
- There was a specific concern raised about children with learning disabilities who it is felt are currently discriminated against. Online assessments do not work for these children.

There were a small number of people who felt that referral criteria should not be introduced at all, and this was consistently raised in all groups of people including parents and carers and professionals with concerns that it was rationing and creating a service to meet resource rather than needs.

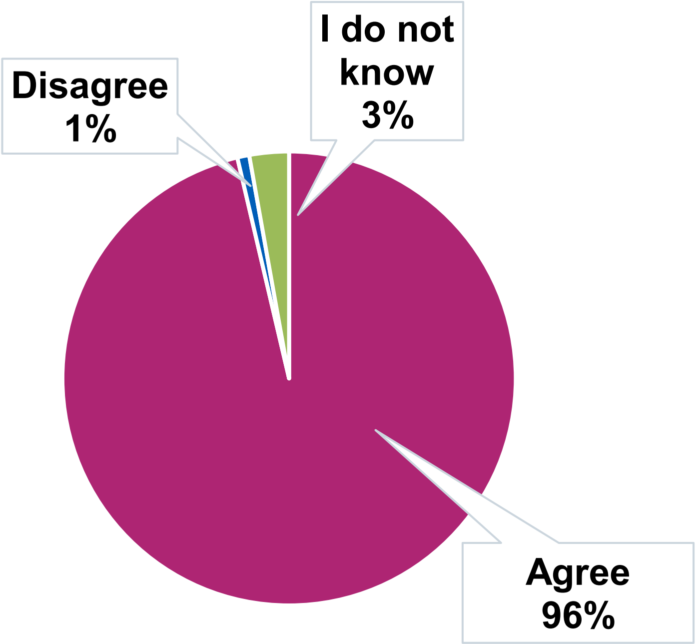
The most common reasons for this was that all children who have symptoms or ADHD deserve a diagnosis and parents and schools wouldn’t request a diagnosis if it wasn’t having an impact. There was also the suggestion that the diagnosis and “label” can be helpful in its own right to help children understand themselves and so it is essential in its own right.

The use of non-CQC accredited service providers for assessment and diagnosis

Within the survey we asked whether people agreed, disagreed or didn’t know about the following statement.

“We think it is important that the people who run ADHD services are checked by an official body whose job it is to make sure that they are safe, good and managed properly.”

Chart 8: People agreed or disagreed with the statement that providers should be CQC qualified



A clear majority of people agreed with this. “I am concerned by the increasing number of private clinics offering assessment and diagnosis. I'm not sure how well regulated they are.”

It was important to people that they felt their provider services were part of the system,

There were multiple reflections within the findings around Right to Choose Services, private providers and sharded care.

It was reflected that a small number of people felt this question inferenced the reduction in “right to choose private providers” and was simply a money saving exercise.

Section 5: Prioritisation

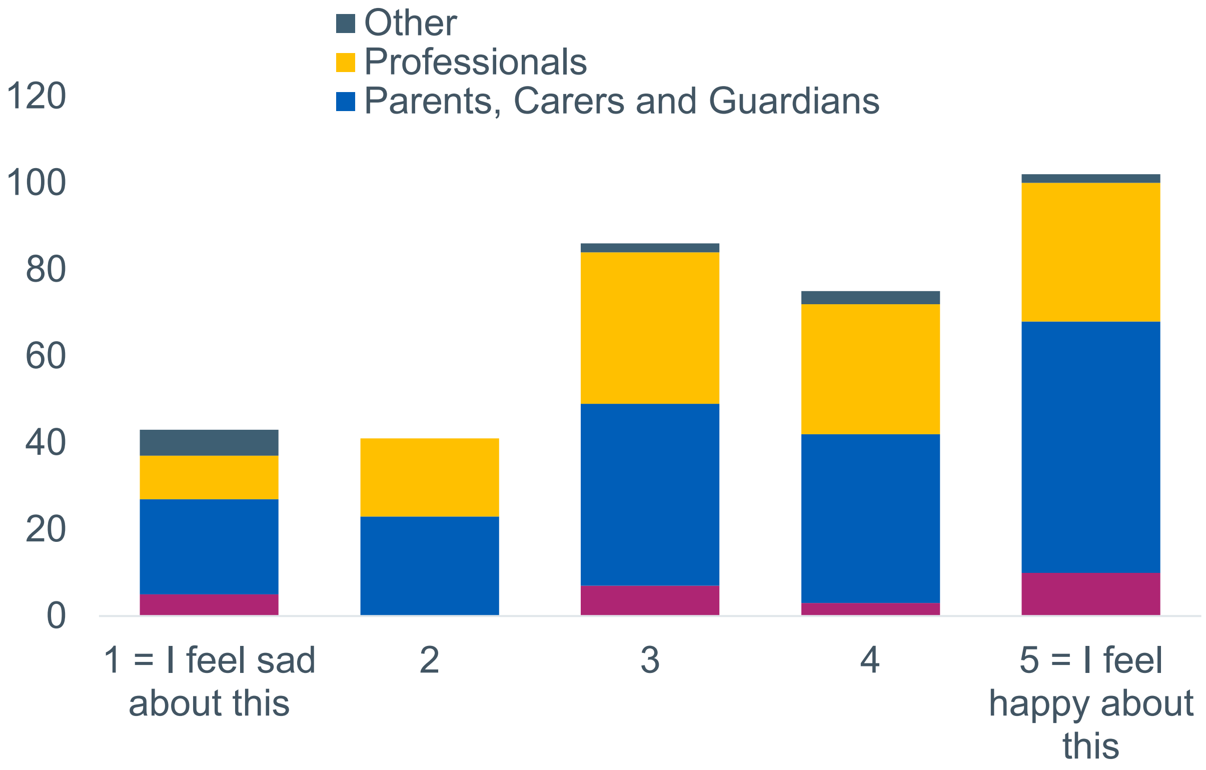
Prioritisation criteria

We asked people what they thought about prioritisation criteria. We gave them 3 things we were thinking about including:

- whether the symptoms make it difficult for you to live your day to day life.
- whether you also have mental health condition that affects your day to day life.
- whether you also have a physical condition that affects your day to day life.

We had a mixed response on how people felt about this and the graph showcases people's response. What we saw however was that whilst in general people were happy and saw the need to prioritise as a positive, there were lots of mixed feelings on the criteria that will be used to create this process.

Chart 9: What people thought about the suggested prioritisation criteria



Many people felt that the above didn’t go far enough to recognise the needs of individuals whilst others did comment to say they did not feel prioritisation was fair for those that “cope or manage better than others” some people shared that this would impact on children in later life should they experience challenges throughout their life course. It was important to people that they understood the process.

There were linked comments around prioritisation and other aspects of the report such as education and how education settings act as gatekeepers to services and diagnosis sharing information and the challenge those who mask or cope could face long term. Parents have also shared how they already feel not listened enough to in the process.

Why do people want prioritisation and what needs to be considered

Why people want prioritisation:

- People want prioritisation because ADHD symptoms can severely impact daily functioning, affecting academic performance, social interactions, and family dynamics. Early diagnosis and intervention can prevent escalation of symptoms and associated problems.
- Prioritising ADHD assessments helps address co-existing mental health issues early on, reducing the risk of more severe mental health conditions developing.
- Addressing ADHD symptoms promptly can prevent secondary mental health issues caused by ongoing struggles and lack of support.
- ADHD can significantly hinder a child's ability to learn and thrive in an educational setting. Early assessment allows for tailored educational support.
- Preventing suspensions and exclusions through timely interventions helps maintain educational continuity.
- ADHD symptoms affect not just the individual but also their family, including siblings and parents. Early diagnosis can alleviate family stress and improve overall family functioning.

- Understanding and managing ADHD can lead to a more harmonious household environment.

What needs to be considered:

- Assessments should consider the child's overall life context, including socio-economic factors, family dynamics, and the presence of other conditions.
- Criteria for prioritisation should be inclusive, accounting for variability in how symptoms present across different settings.
- Streamlining the referral process and ensuring GPs and other referrers are well-informed about ADHD.
- Clear guidelines and training for referrers so help can be identified in cases that need urgent attention.
- Ensuring that all children, regardless of socio-economic status or additional conditions, have fair access to assessments and support.
- Addressing potential biases that may lead to certain groups being underrepresented in ADHD assessments.
- Implementing preventative measures and support systems in schools and communities to help manage symptoms early on.
- Using clear and accessible language in criteria and communications about ADHD to ensure families understand the process and requirements.

Things that people wanted to be considered

As well as the survey responses there were numerous other suggestions in relation to how we prioritise the children and young people on the waiting list, these include:

- School exclusion or those at risk of exclusion – *“he has been excluded from school on a number of occasions due to no support as no diagnosis”*
- Age of child – this included children who were accessing curriculum thresholds and who may be going through exam periods or transition from primary to secondary education. “*The service needs to close the 16-18 year old ‘no man’s land’ gap*

which prevents young people from accessing support during these 2 critical years.”

- Dual Diagnosis (Autism) – *“Consideration for wider diagnosis of autism at the same time & that the pathway should be together.”*
- Looked after/Adopted children – *“I feel that adopted children should be given priority for assessments, as so many have ADHD and they are also suffering from trauma too.”*
- Those children and young people at risk of ending their life by means of suicide – *“My son attempted to take his own life at 15 as a result of being on a waiting list. He could have lost his life because of the length of the list.”*
- Family breakdown
- Other family members having a diagnosis
- Masking – *“She's masks it so well in school and has a full meltdown at home. I'm really worried about her.”*
- Criminal justice system – *“Our child has been arrested and sexually assaulted and NOBODY cares!”*
- Emotional Based School Avoiders

There was also feedback from some people that prioritisation in the way we have suggested could cause challenges. For example, if those masking and or achieving academically at school are not prioritised there could potentially be mental health issues building as a result of managing their condition themselves.

Section 6: Health inequalities

Inequalities

People reported inequalities in relation to access and experience of services for specific groups. These barriers prevented some people from accessing services in the same way as others or when using services, they felt that their needs were not considered or that they were not treated fairly.

Age

The strongest theme around barriers to access was in relation to age and specifically for children under 6 and young people between the ages of 16 – 18. The minimum age for referral is 6 and some people reporting not being able to access support because of this, however in some localities, particularly where hubs were in place support was available and people felt very positive about this. Young people aged 16-18 were experiencing longer waits than others due to being moved from children’s to adults services and being placed on the bottom of waiting lists despite have already waited up to two years.

There are also many accounts of school aged children not receiving the support they need in schools for example reasonable adjustments for exams meaning an inequality in their ability to achieve the same outcomes as their peers.

Mental health

People experiencing poor mental health are often struggling to access services and are not being provided with reasonable adjustments. For example, some people experiencing anxiety around attending face to face appointments are not offered alternatives and if they fail to attend are removed from the service.

> “Stop blaming ADHD symptoms on other diagnoses such as Autism or mental health issues, you can have these conditions and still have ADHD as well.”
>
> Young person.

> “The service need to close the 16-18 year old no mans land gap”

Dual diagnosis

Those with a dual diagnosis also reported difficulties in access. For example, children an autism diagnosis and currently receiving support are not being identified as having potential ADHD because of masking or professionals attributing symptoms to autism. This is the same for other neurodevelopmental conditions. Similarly, children and young people with learning disabilities are often overlooked due to professionals and schools attributing symptoms to their LD.

People on low incomes or living in poverty: people reported an inequity around waiting times and support for those who could not afford to pay for private providers. People also felt disadvantaged due to system barriers such as having to attend face to face appointments but not having the funds to access childcare for siblings, this was particularly true for single parent families.

Gender

There were many reports of barriers to accessing services or understanding of professionals in relation to gender. This was particularly true for females who are much more likely to mask symptoms and as a result some are not referred for diagnosis or support as quickly as males. The children and young people's lived experience group reported that young people felt that girls in particular can struggle in silence for a long time - due to masking well.

It was felt that professionals and in particular schools are not knowledgeable about the gender difference. This is also the case with gender identity where young people report difficulties with staff understanding their symptoms or needs due to their gender being different than at birth.

"There needs to be ease of accessibility, some people may find certain places and situations overwhelming".

A Professional

"My gender identity does not match my sex at birth and having ADHD assessments that are based on the male brain is not a true reflection of how ADHD in the female brain works"

A young person

Ethnicity

Some feedback indicated a potential stigma attached to children and young people from a community experiencing racial inequalities (CERI) the feedback suggested that the child was labelled as bad behaviour and symptomatic behaviour was not recognised or supported. It was suggested that there is an inequity in recognition, diagnosis and treatment dependant on ethnic background

Looked after children and adopted children

Looked after children who experience adverse childhood experiences (ACE’s) can display neurodiverse needs including ADHD. It was felt this needs to be recognised and included as part of the prioritisation criteria given the wider impacts on the child.

Complex family circumstances

we heard examples of families who need support but cannot access it due to their family circumstances or wider impact. This included families who had parents with an ADHD diagnosis or other neurodiverse condition and families where domestic abuse had occurred.

People on low incomes

People also told us that services weren’t responsive to the needs of families on low incomes e.g. difficulties in accessing online offers or attending appointments due to not being able to afford childcare.

> “I feel that adopted children should be given priority for ADHD assessment as so many of them have ADHD and experience trauma too”

Section 7: Key points to consider and next steps

Key points for commissioners to consider

From the engagement, there are a number of key points that have emerged for the commissioners to consider.

- Waiting times are currently too long for access to diagnosis and support, so any new model need to consider how they can be reduced.
- The offer of support for many people is currently limited to medication, but there is a need for a broader offer of support.
- Consider how additional factors such as gender (e.g. masking), dual diagnosis, vulnerability and family circumstances might impact on eligibility for assessment and diagnosis.
- Consider how we reduce the gap in relation to wait times between those who are not able to pay for private diagnosis and those who are.
- Consider how access to support can be improved for specific groups where there are known gaps due to age, including under 6's because they are too young, school age transitions, and 16–18-year-olds who are either being dropped off the children's waiting list at 18, or being told to wait until they reach the adult age to go on that waiting list.
- When developing the hubs, think about accessibility and the different range of ways people need access, including both face-to-face and online opportunities.
- There were concerns raised that limiting access to assessment might create future crisis points for both the children and young people, and also for NHS mental health services. When developing the model, consider how this may be mitigated or managed.
- There were lots of suggestions for how the prioritisation criteria could be refined. Review these suggestions when updating the criteria.

- Consider how we can ensure consistency of application by professionals of the criteria for either referral or prioritisation, particularly given the subjective nature of the word “severe”.
- When developing the new model, consider that for some people diagnosis is about more than just access to support (e.g. validation and helping them understand themselves).
- Consider how we can work with schools to improve knowledge, awareness and capacity.
- Stigma and misinformation impacts on negatively on people with ADHD and we should think about how the NHS can address or reduce this.
- When reviewing services and the new model, look at ways to improve communication throughout the whole patient journey, particularly whilst people are on the waiting list.
- Recognise the impact of the condition on the whole family (e.g. parents and siblings) and offer appropriate support and intervention.
- Consider the balance of parent and school voices and experience throughout the pathway journey, particularly when getting evidence of impact for referral or diagnosis.
- When developing the new model, integration between services is important to make the pathway run more smoothly for families.
- Many professionals and teams would benefit from more information and training about the condition and pathway to enable them to support people and implement the pathway consistently

Next steps

This report will be shared with the people responsible for commissioning and delivering services

Commissioners will use the information to check their proposals for change and ensure they reflect what people have told us.

We will also update the equality impact assessment using the feedback and the things we have learnt.

We will continue to engage people when developing and evaluating services including any new models that are proposed

We have a 2 lived experience groups that will support us to decide who and how to engage further

The report will be published on our website and shared with those directly involve through focus groups etc, along with regular updates on what has changed as a result of the engagement.

If you would like to be kept up-to-date, or get involved in the next steps, please contact us:

Email: gmhscp.engagement@nhs.net

Ring, text or WhatsApp: 07786 673762

Section 8: Glossary and Accessibility

Glossary

ADHD

Attention Deficit Hyperactivity Disorder (ADHD) is a condition in children and young people that makes it more difficult for them to focus, sit still, and control their impulses.

Autism

A lifelong condition that affects how people communicate, learn and behave.

Diagnosis

The process of identifying a disease, condition, or injury from its signs and symptoms

EHCP

An education, health and care plan.

Neurodiversity

A term used to recognise the diversity of different brains.

NICE

National Institute for Health and Care Excellence

People

Those who took part in the engagement including residents, patients, carers, families and professionals.

Accessibility and translation

If you would like this information in another format, or translated into a different language, please email gmhscp.engagement@nhs.net

如果您希望以其他格式获得此信息，或将其翻译成其他语言，请发送电子邮 件至 gmhscp.engagement@nhs.net

Jeżeli chciał(a)byś otrzymać te informacje w innym formacie lub w innej wersji językowej, prześlij wiadomość na
adres gmhscp.engagement@nhs.net

Pour obtenir ces informations dans un autre format ou dans une autre langue, veuillez adresser un e-mail à gmhscp.engagement@nhs.net

إذا كنت ترغب في هذه المعلومات بتنسيق آخر، أو مترجمة إلى لغة أخرى، يرجى
إلى الإللكتروني بالبريد رسالة gmhscp.engagement@nhs.netإرسال

ਜੇਕਰ ਤੁਸੀਂ ਇਸ ਜਾਣਕਾਰੀ ਨੂੰ ਕਿਸੇ ਹੋਰ ਫਾਰਮੈਟ ਵਿੱਚ, ਜਾਂ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿੱਚ ਅਨੁਵਾਦ ਕਰਨਾ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ gmhscp.engagement@nhs.net ‘ਤੇ ਈਮੇਲ ਕਰੋ

اگر کسی اور فارمیٹ، میں یا کسی اور زبان میں ترجمہ شدہ آپ کو یہ معلومات چاہیے، تو براہ
gmhscp.engagement@nhs.netکرم پر ای میل

Haddii aad rabto in aad macluumaadkan ku hesho qaab kale, ama lagu soo turjumo luqad kale, fadlan farriin iimayl u dir gmhscp.engagement@nhs.net

Dacă doriţi aceste informaţii în alt format sau traduse într-o altă limbă, vă rugăm să trimiteţi un e-mail la gmhscp.engagement@nhs.net

আপনি যদি এই তথ্যটি অন্য ফর্ম্যাটে বা অন্য ভাষায় অনুবাদ করতে চান, তাহলে অনুগ্রহ করে এখানে ইমেল করুন gmhscp.engagement@nhs.net

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Section 9: Appendices

Appendix 1: Survey Equality Monitoring Data

Chart 1: What area of Greater Manchester (GM) People live in

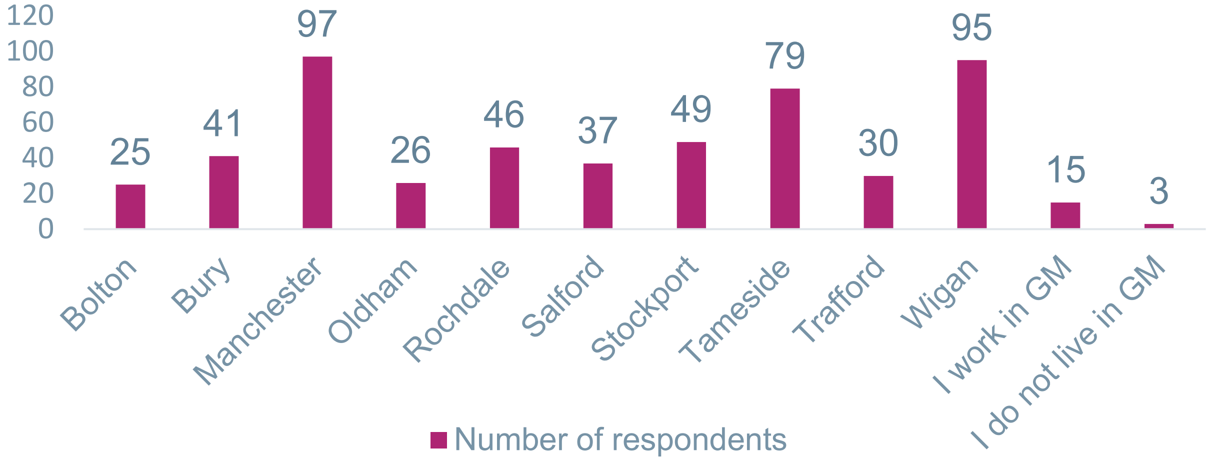


Chart 2: Age

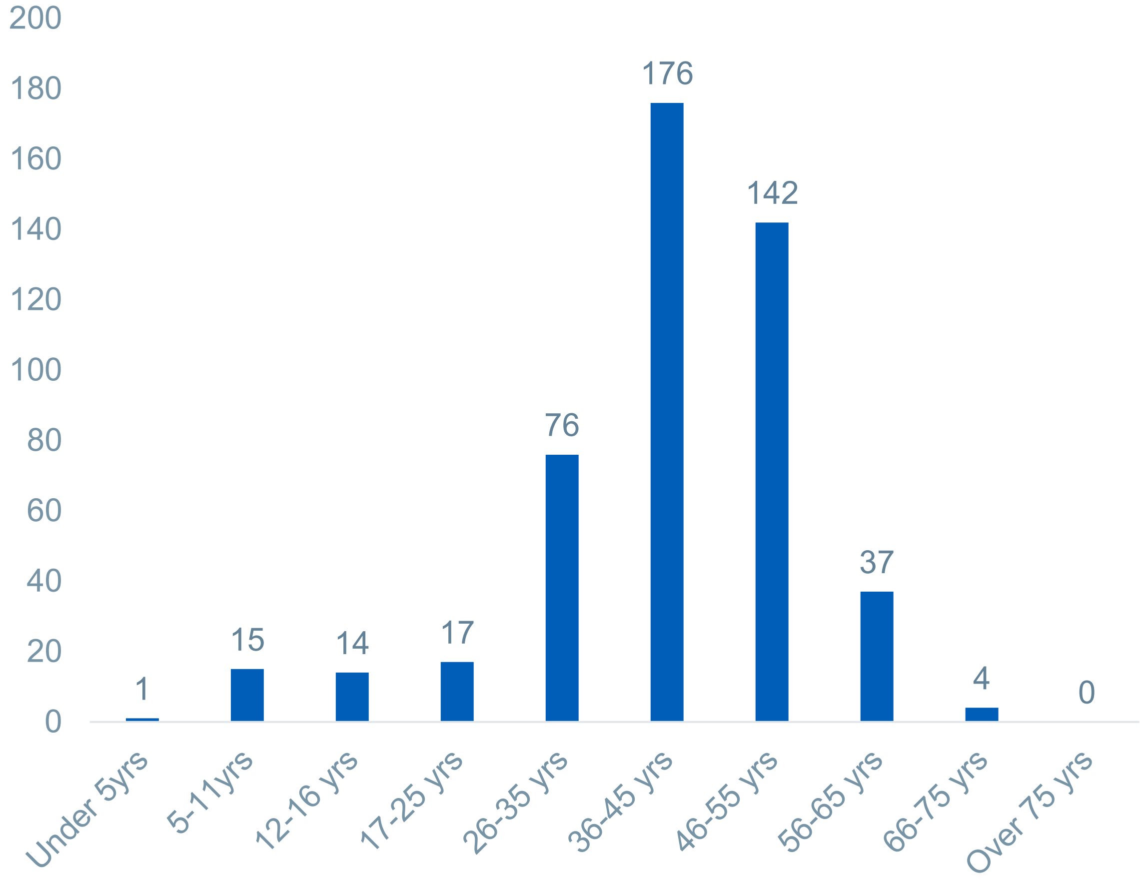


Chart 3: Ethnicity

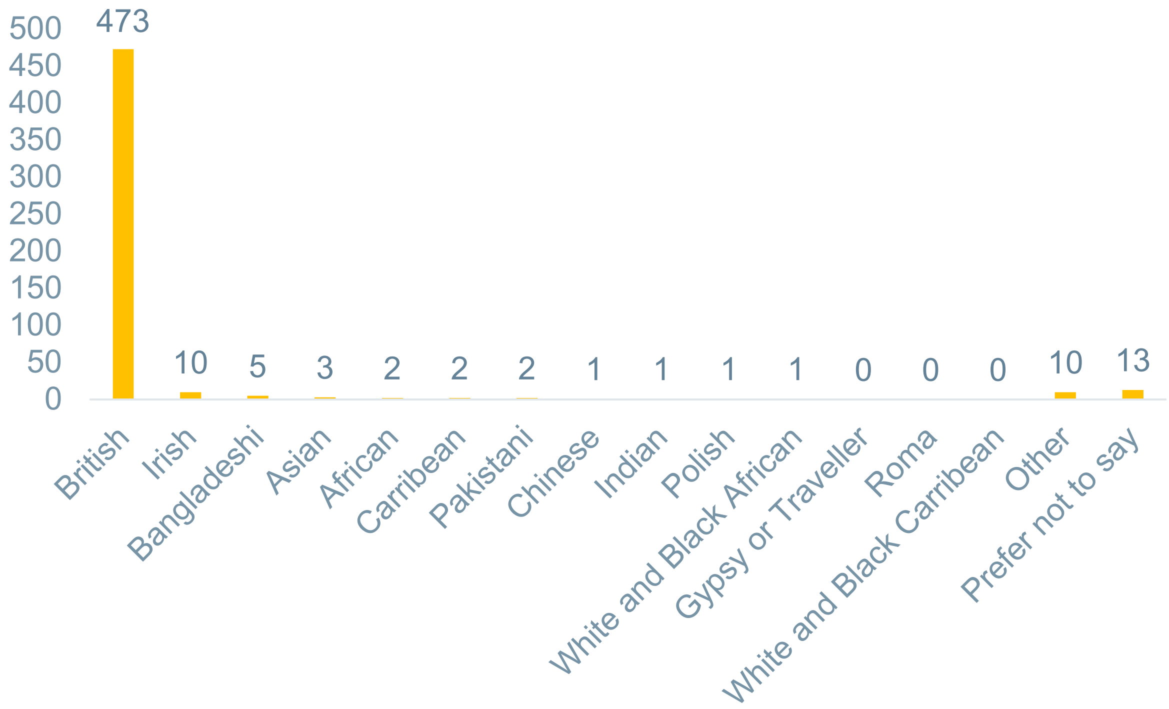


Chart 4: Gender

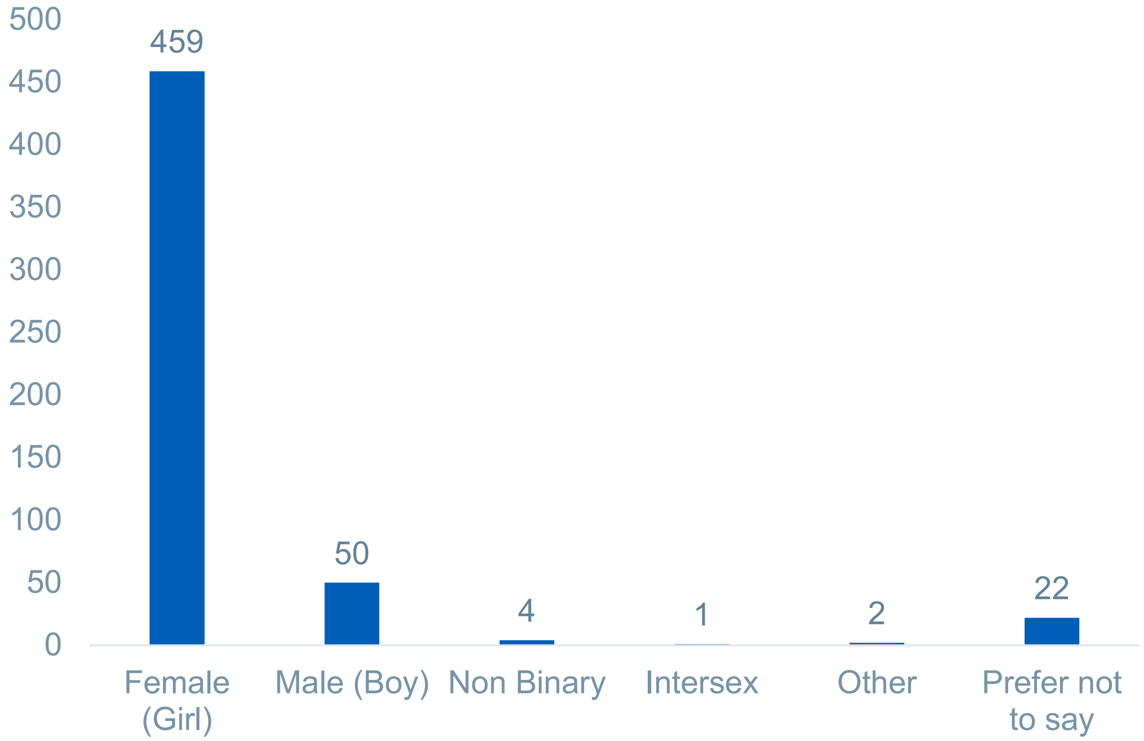


Chart 5: Gender the same as described at birth

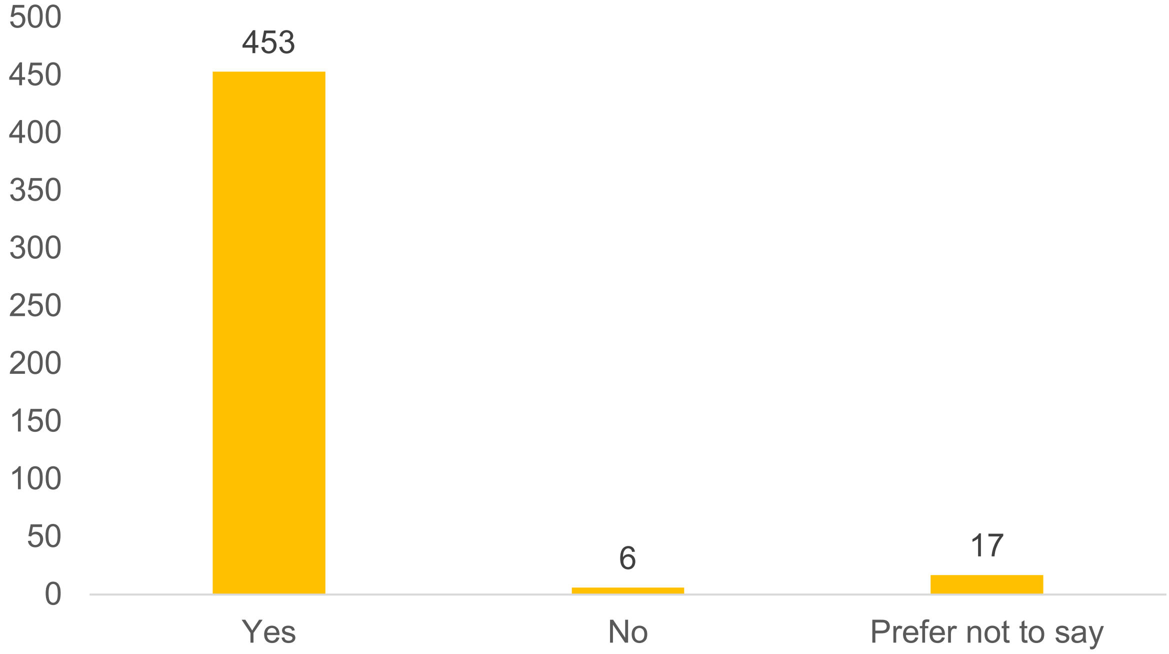


Chart 6: Relationship status

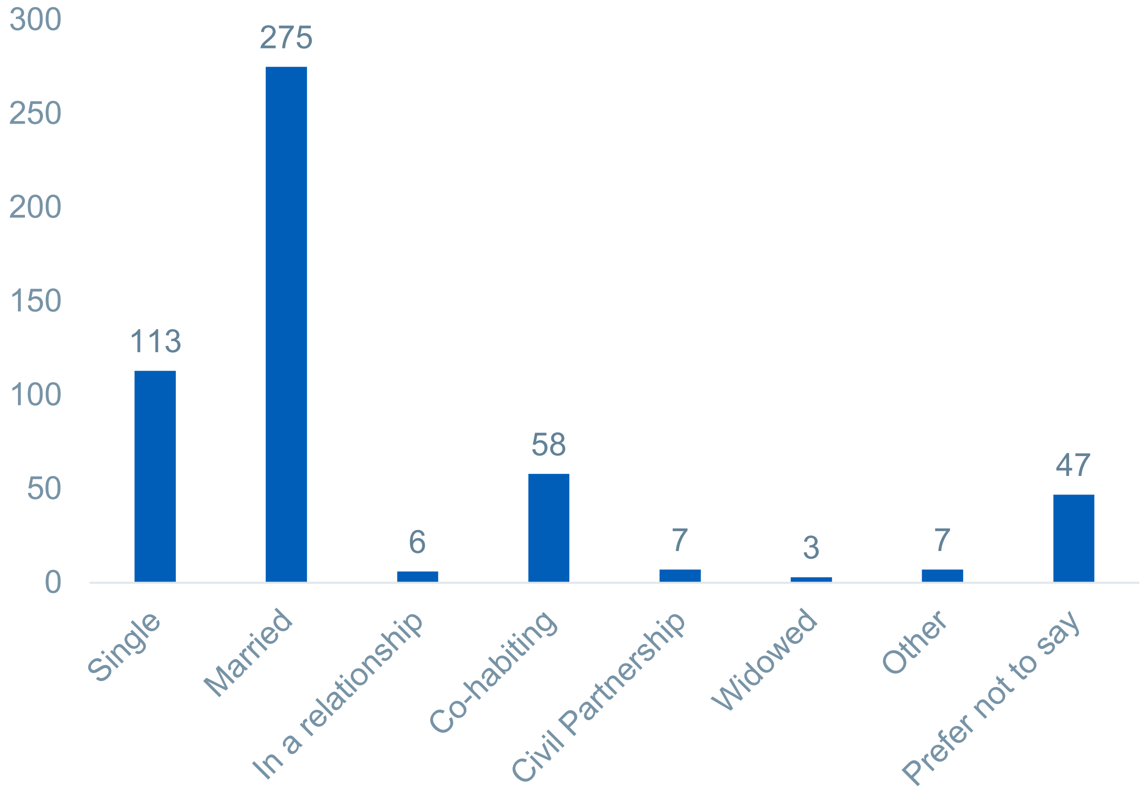


Chart 7: Faith

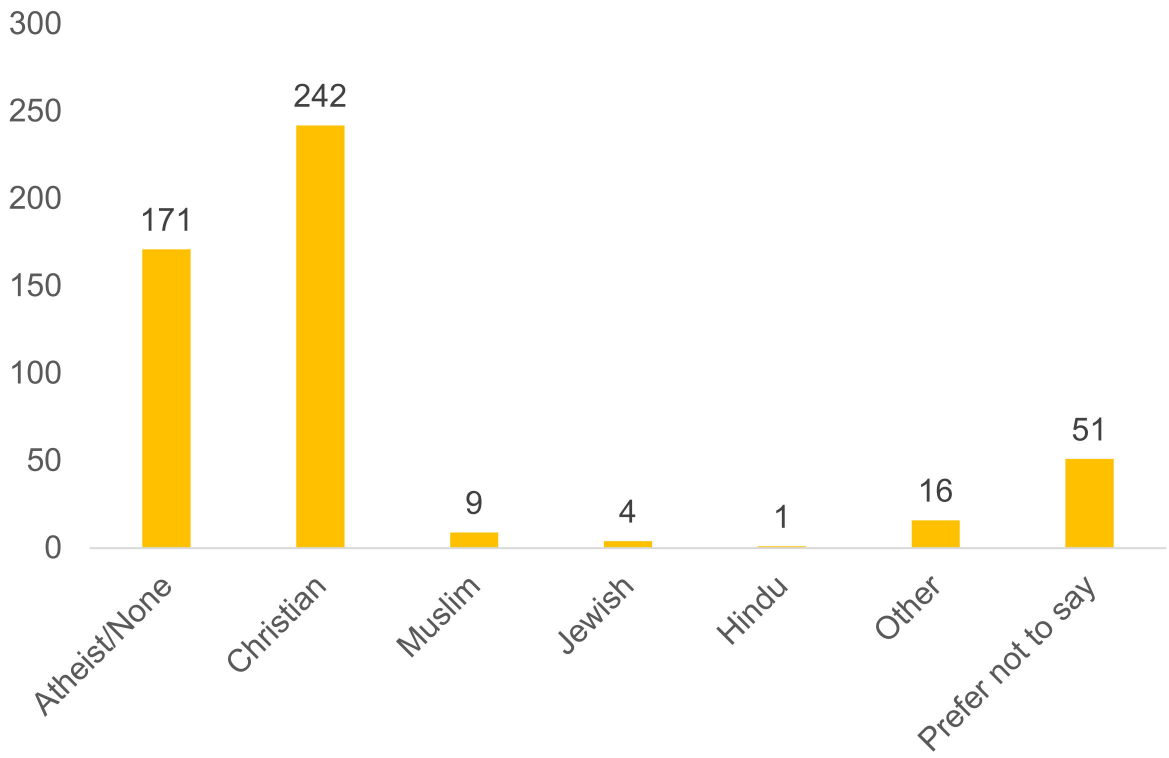


Chart 8: Sexual orientation

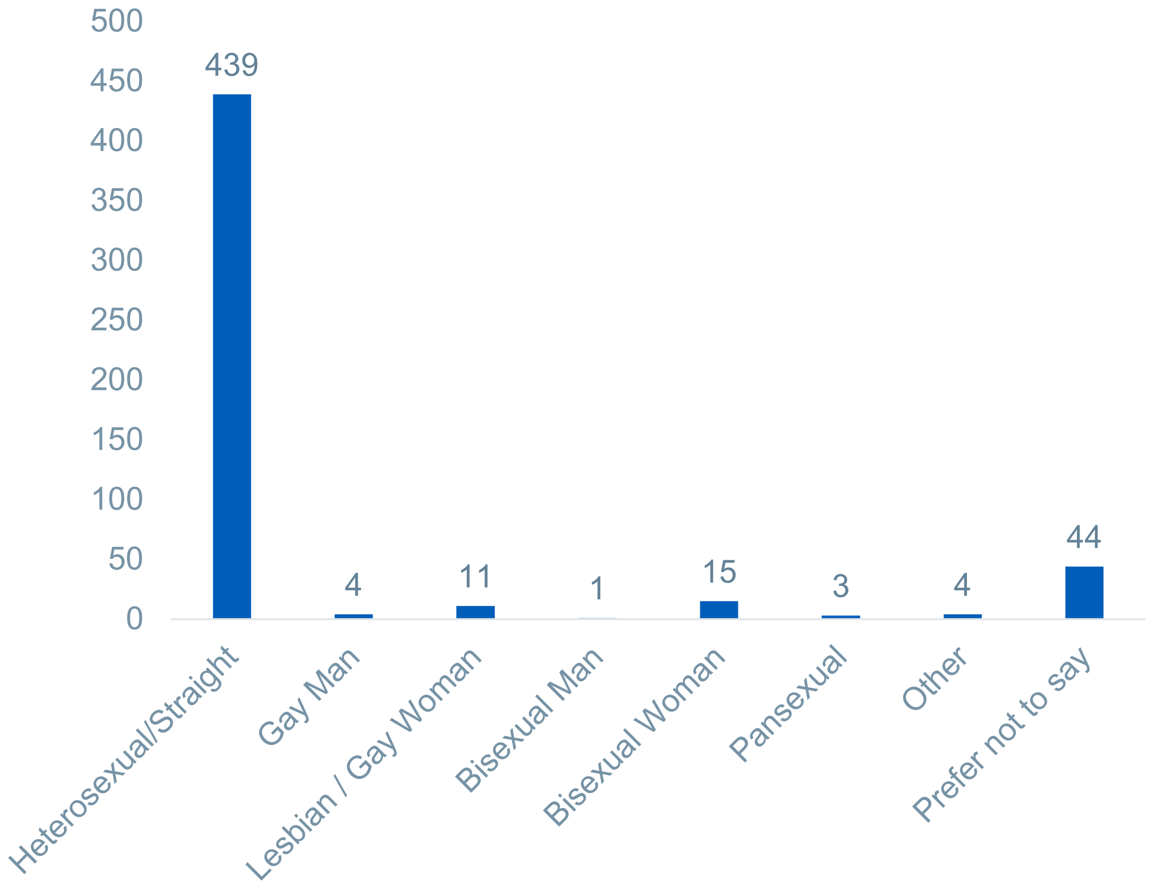


Chart 9: Employment status

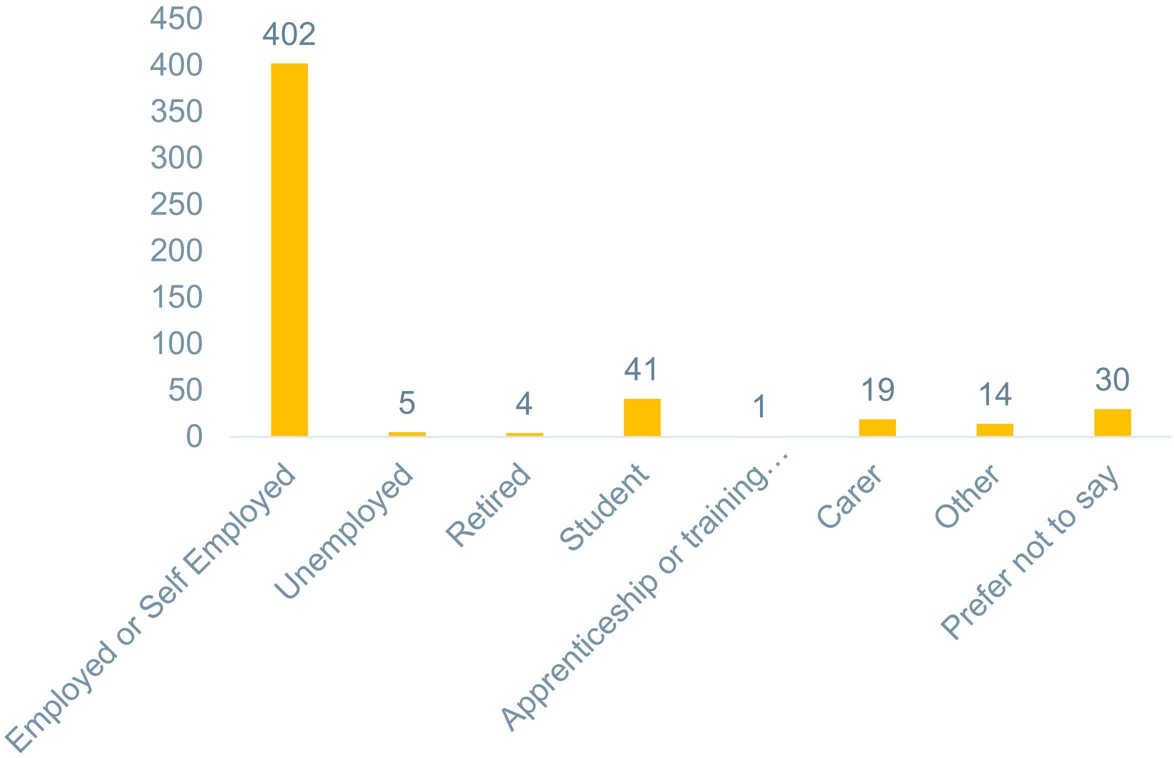
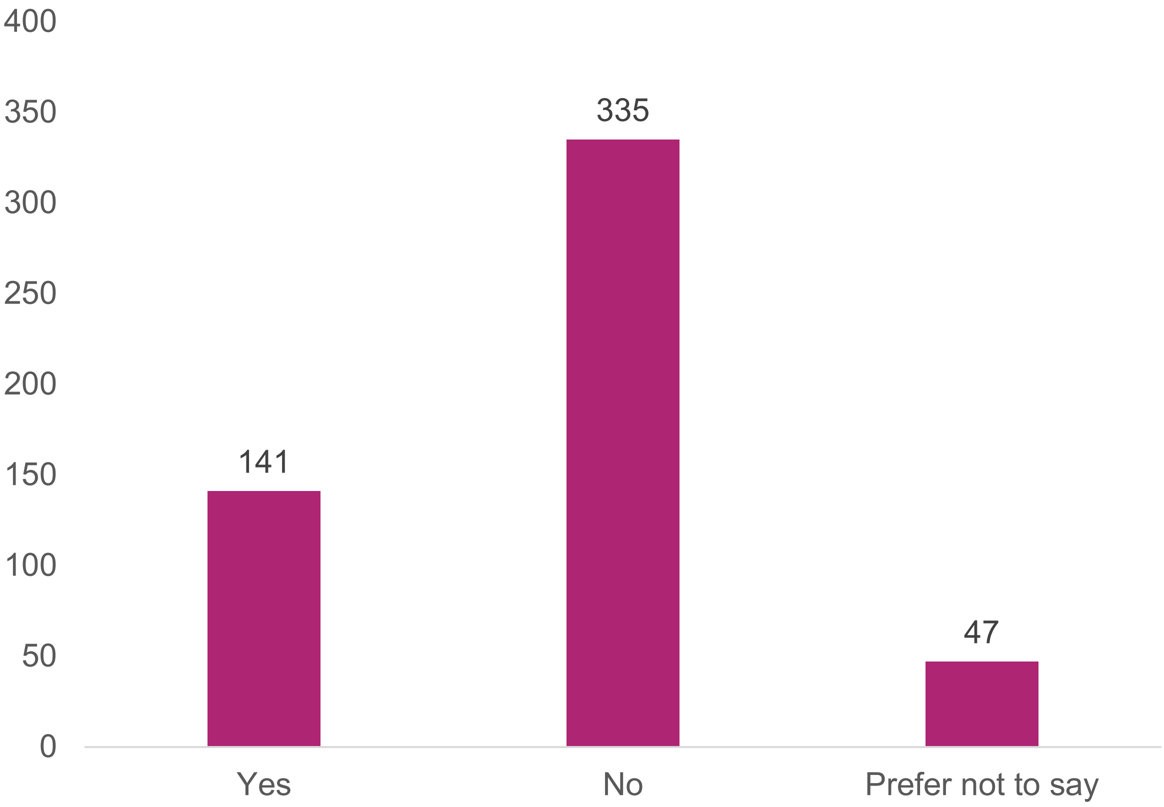


Chart 10: Disability



Of those who said “Yes,” 117 shared further information:

- 32 identified with ADHD
- 21 identified with Autism
- 19 said they had a physical disability or needs
- 10 with Mental Health conditions
- 5 stated they had chronic health conditions

Chart 11: Armed forces (currently serving and veterans)

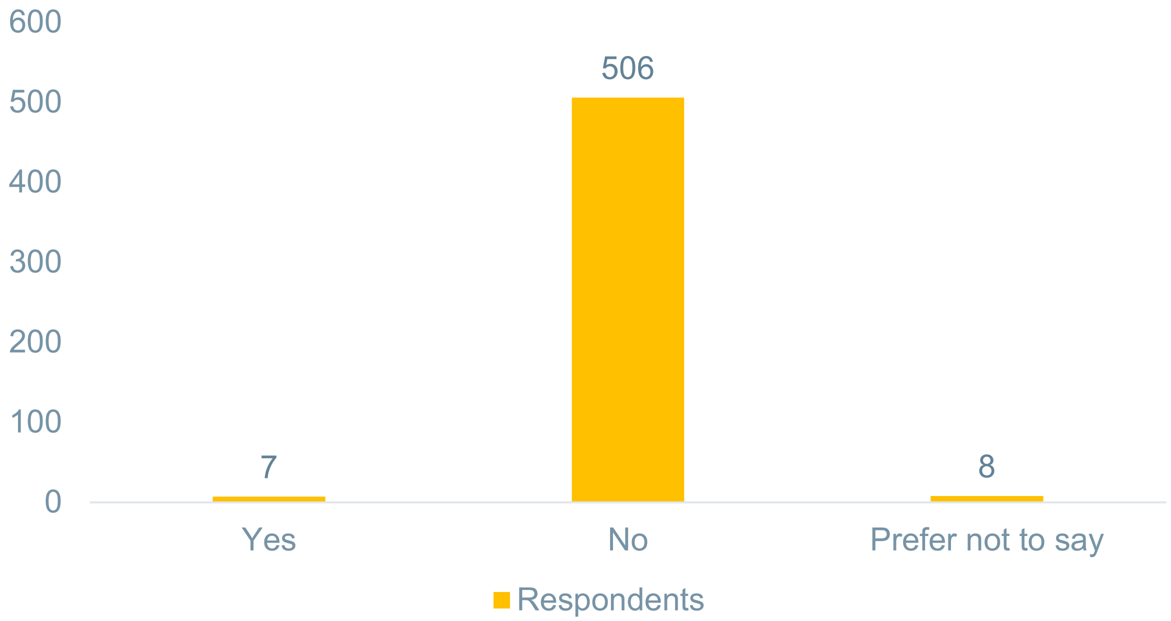
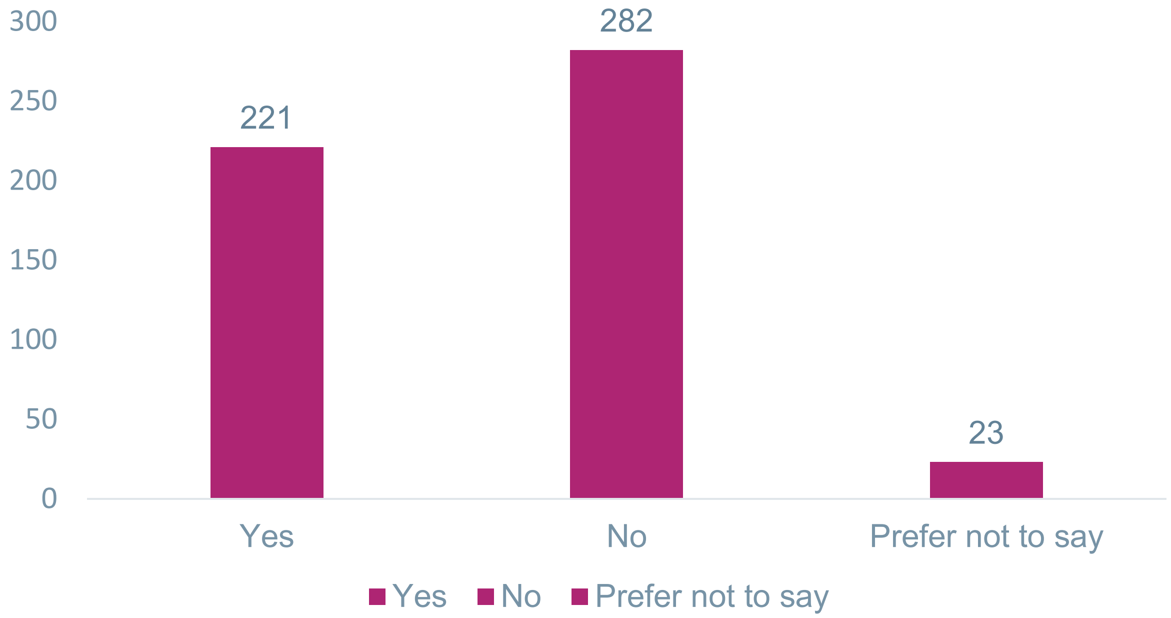


Chart 12: Carers



Some reflections from carers feedback.

What works well?

The overall sentiment is mixed, with a considerable number of negative experiences overshadowing the positive aspects. While the quick diagnosis process, effective medication, and supportive staff were appreciated by some, the predominant issues included long waiting times, lack of engagement, inadequate support beyond medication, and poor communication. The inconsistency in the diagnostic process and the feeling of being let down by the service were significant concerns for many families.

What could make your experience better?

The predominant sentiment is a need for improvement in accessibility, communication, and support. Parents desire a more holistic approach that goes beyond medication, with shorter waiting times and better resource allocation. Consistency, reliability, and comprehensive involvement of parents are key areas highlighted for improvement. Reducing administrative hurdles and providing timely, compassionate support would significantly enhance the experience for families dealing with ADHD and related conditions.

Appendix 2: Focus groups

First Choice Focus Group, Thursday, 5th December 2025: Participant feedback

Person 1

- School didn't agree so it took a long time to get on NHS Pathway
- Young person wants and update, but mum can't answer
- Lack of communication
- Found out about First Point after months of trying.
- Before lockdown it was still difficult
- 2 ½ years 2014 – straight away
- Schools not having awareness.
- Masking is real.
- Girls present differently
- Children self-harming due to lack of support
- Children to adults transition was really difficult
- First point and social worker difficult
- Social worker turnover in Bury is extremely high.
- Young person disengaging due to inconsistent staffing

Person 2

- Pulling things together
- No co-ordination
- Right time, right place
- No communication
- Specialist provision
- Local college
- Empowering family members and young person
- County lines

- Stereotyping and inequalities
- Stigmatisation
- More experience from ethnic minorities

Person 3

- Education
- Baseline level and mindset, not assume and write off families/young person
- Girls’ masking
- More openminded/curious
- 14-year-old, mental health
- ‘My time is done’
- Behaviour escalated
- No pathway
- Risk taking behaviour
- Several tier 4 admissions
- Medication not from someone who knew young person
- Tier 3 GMAC is not tier 4
- Not sustainable how we were living as family
- Young person sectioned
- Mum need things to change
- On ward 4 months and needed medication to change
- College panicked and wanted to take action however not understanding the issue
- Changed college
- Moved to adults ADHD clinic – in Bury CAMHS
- Psychiatry for medication
- No social care input – despite significant risk-taking behaviours
- Trauma

- High anxiety
- Parents live like this

Person 4

- Education
- Naughty child
- Being judged as parent
- Not enough resources
- Needs people to understand child better
- Child in school 3.5 hours a day as school can’t cope with him for full day
- Schools need education
- Resilience as a parent as the system blames and judges
- Being positive
- Impacts the whole family
- CG is a parent and doesn’t have own identity
- Severity of symptoms need to be prioritised
- Mum feels medication might help this is based on past experience with older child
- Who would be assessing/prioritising?
- MDT approach
- Don’t know what child is doing in school
- He is not having enough education
- He is extremely difficult to engage

Appendix 3: Case studies

Case study 1

Background

I have just received the email regarding helping out further to shape the future of the services for Neurodiversity. I am happy for our life to be used as a case study,

I am a parent to 3 boys aged 17, just diagnosed with ADHD. Aged 12 diagnosed autistic at 6 along with sensory, anxiety and selective mutism. And Aged 11, diagnosed privately with ADHD after reaching desperation, later confirmed via CAMHS and also diagnosed autistic, sensory, selective mutism and ARFID.

Each story is completely different, each bit of help also completely different, yet all seen by the same services.

What support have you and your family had that was useful?

The most helpful support that I have had has come from the occupational therapist, they have been the lynch pin that has held everything together. They have been a great advocate for the children, made sure that they have had everything they need to cope at school. All the children seem to be really good at masking.

My youngest child was getting punished for being naughty, it took the OT to explain why this wasn't helping and what the school needed to do instead.

The main issue has been that because the children have not displayed the worst behaviours at school but only at home, school said there is not an issue but when they child comes home after a day of masking I get the full meltdown.

My eldest child was one of the schools best students until the exams started and then he couldn't cope and they finally witnessed what I have been dealing with all the time.

Because he had no focus, he failed all his mocks. The week before his GCSE's he was diagnosed prescribed medication and was able to get grade 6 in his exams.

If they could have acted sooner, he would not have had to suffer first.

Parents should be listened to and believed not dismissed because the school don't see what they are seeing. No one takes you seriously unless professionals have witnessed what you see, others need to see it before you are believed.

What support do you feel would have helped but wasn't there?

People think that getting a diagnosis brings with it loads of help and support but that is simply not true. It gives you a reason something to explain to the child. It can also lead to medication, but it is just a label.

There needs to be some form of interim support while you are waiting for your child to be seen and diagnosed. There are many issues that could affect your child's behaviour, having a triage early on in referral could mean that some who have a different issue get the support they need earlier rather than wait to be told ADHD is not the issue.

My youngest child has extreme issues and has run in front of a tram and jumped in the canal and nearly drowned. I knew then they needed help so went private to get a diagnosis and now has medication privately. Again, professionals need to see it before a parent is believed.

I was told that knowledge is power, educate yourself. I have done every course and webinar I can find to equip myself with the knowledge I need to support my children.

A parent also needs to learn to step back and reflect, why did that happen? what was the trigger? what could have changed the response? what could I have done to stop the escalation?

My son goes to a therapy to help him cope with his feelings and behaviours but my son is not a talker, so he is not getting anything out of going but I still take him to every appointment.

What are your views on what factors should be taken into concertation when prioritising how quickly people should be seen?

If a family is having a major problem they will keep chasing, not wait in a corner for something to happen. A parent knows when their child is in crisis, not every crisis means self-harming.

I knew my child would not cope in high school, but I was not listened to. He started school, we could be in the car park for several hours trying to get him to go in. He then went down to 3 days a week then he stopped going altogether. He is now finally in a special school. For 6 years my voice didn’t matter, I knew the school won’t work.

If there is a difference of opinion, parents should be listened to over the school. If my child had been seen earlier, he may not have needed the meds he is on now.

Is having a diagnosis for your child important? Why?

It depends, it gives you something to say to the child, this is why you feel like you do. This is why you this happens, this is what we can do to help, this is how it may affect your life in the future, but it won’t stop you doing anything you want to do. It is important to be honest with the child.

The diagnosis is for the school to get understanding and support because without they are just a naughty child and are offered no support. The SEN should be about the behaviour not the diagnosis but it’s no diagnosis no support! even if teachers can see it they can’t do anything without it.

What are your thoughts about medication?

The medication can be life changing for the family and the child. I have always sat on the fence about it as there are a lot of side effects, but it has made a difference to the child.

I do give the children the choice, I ask if they would like a break from it as it is school holidays, they may say yes, but then they come to me later to say, can I have my medication as my brain is running around in my head. He realises he can cope with life better on the meds. He says it isd like being on a train that has slowed down.

Currently there is a shortage of meds, we live in Manchester, but I have had to drive to the other side of Yorkshire to get the medication.

I feel judged for having my children on the medication, but I know it helps them, my eldest can go to college and my youngest is calmer which means he can be managed and as a family we are calmer and less on-guard.

Before the medication I would not have dreamed of taking my children on a plane to Florida, I struggled taking them anywhere in the car.

As a parent of children with ADHD I have had to grow a thick skin.

Anything else you want to us to know?

There should be interim support while people are on the waiting list.

There needs to be a hub or drop-in, not in the daytime or during school hours but when working people can get there.

I don’t want a coffee morning where I go to listen to parents talking about the bad behaviour of their child and how bad life is, what are we doing about it? How can we make it better for our child?

The drop-in hub should have OT’s, Dietitians, psychologists, people that can help you set strategies and have things in place to help you and the child cope better.

The forms that you have to fill in are not helpful, they haven’t seen your child the just go of the form you filled in but if you don’t know the language to use, the right words to say or how to describe behaviours in the right way you are not believed and not taken seriously.

There needs to be education on what to look for, what are the signs and what language you need to use to be believed.

EDUCATION: Education for the kids - Education for the parents - Education for the professionals.

As a parent, nothing is getting better or going to change unless you make it happen.

Case study 2

Background

I have a son who is 15 years old.

I was told by his nursery teacher he had ADHD when he was 2 years old, but nothing could be done about this. He went all through primary school without support and was not referred for any kind of assessment, he had a difficult time at primary school.

He then went on to secondary school where it was picked up pretty soon that he has ADHD symptoms. At this time there was no SEN worker but he was referred for some TOGS mind sessions as his mental health was becoming really concerning and he was drawing pictures of how he would end his own life. He needed so much more support.

SENCO then recognised he needed an assessment; this was in year 9 which was a relief that eventually he had been acknowledged. We waited and waited with no communication.

Schools themselves need support in this area as it is becoming unmanageable for them.

As a parent I have tried to access support for my son and would do anything I can to help his condition. It is really hard as a parent, and we too need support coping.

I recently went to an event hosted by a charity called OKE (Our kids eyes) where there was a guest speaker for children's mental health, I made it my mission to share my sons story with her and she told me she was in charge of CAHMS in Tameside. The lady agreed to follow up where we are in the system, and we have now been fast tracked for a full assessment on 20th November. This was by pure chance I went to the event and obviously should not happen like this.

What support have you and your family had that was useful?

He then went on to secondary school where it was picked up pretty soon that he has ADHD symptoms.

What support do you feel would have helped but wasn't there?

Schools themselves need support in this area as it is becoming unmanageable for them.

I think prioritising kids with mental health conditions, suicidal thoughts and those in significant school years (exams etc) should be seen sooner. This is what escalates quickly into crisis.

The GP told me about right to choose but said CAHMS would need to refer us. CAHMS said the GP would need to refer us so we didn't know what to do, the process should be clear to all who need to know.

For parents too as they have no clue what the process should be, better communication is needed.

As a parent I have tried to access support for my son and would do anything I can to help his condition. It is really hard as a parent, and we too need support coping.

Being heard is so important, CAHMS is a faceless service.

What are your views on what factors should be taken into concertation when prioritising how quickly people should be seen?

I think prioritising kids with mental health conditions, suicidal thoughts and those in significant school years (exams etc) should be seen sooner. This is what escalates quickly into crisis.

His impulsiveness is so dangerous and has put him at risk many times.

Is having a diagnosis for your child important? Why?

I agree a diagnosis is not important for everyone, but my son needs it and needs to be on medication, of this I am certain. His impulsiveness is so dangerous and has put him at risk many times.

What are your thoughts about medication?

My son needs it and needs to be on medication, of this I am certain. His impulsiveness is so dangerous and has put him at risk many times.

Anything else you want to us to know?

I think having a service where needs are assessed sooner sounds like the right way to go.

Thank you for hearing me.

Case study 3

Background

I have been diagnosed with ADHD this year and strongly suspect that at least one my children, my middle son also has ADHD. I also believe that my eldest son has some form of neurodiversity.

I am a primary school teacher and do have experience working with children (and staff members) who are neurodiverse.

What support have you and your family had that was useful?

For me the support I got from our GP practice when I first raised concerns. The GP responded really quickly on the same day.

After that the right to choose pathway, I thought was a really good idea, it was better than just sitting on the NHS waiting list. I had considered paying for my own diagnosis but in the end the right to choose pathway was best.

What support do you feel would have helped but wasn’t there?

Once I had a referral to a mental health practitioner I was seen really quickly. The practitioner agreed that I needed anti-anxiety meds but in order to get them prescribe them. It would be more efficient if the person you see first has the ability to prescribe. I understand that this may need further training, but I was quite frustrating once a decision is made to then have to wait to see someone else, not very efficient.

That being said my journey so far has been quite efficient.

What are your views on what factors should be taken into concertation when prioritising how quickly people should be seen?

That’s a really difficult one, it is highly possible that some people would over play their symptoms and their need in order to get seen quicker while other may downplay their symptoms and effect on their life as they will assume that others need the support before them. It needs to be a professional decision based on a professional assessment, a professional needs to make contact to give a professional assessment. It needs to be an external, third-party decision.

Is having a diagnosis for your child important? Why?

I think this is a really individual thing. I didn’t have a burning need to get a diagnosis but once I realised, I was concerned about what having a diagnosis would mean.

For myself, if I didn’t have a diagnosis would I be caging myself from talking it, now I am freed up to talk about it with people, how things affect me, why I react like I do to things, the fact that sometimes I need more time.

For my children, I would like to be able to explain to them help them to have an understanding of themselves. My middle especially I think it will help him understand himself.

My eldest son, I think he will be able to manage better and be more self-aware.

I think that having my own diagnosis will help me to better support my sons as best as possible.

What are your thoughts about medication?

I think that once we accept diagnosis medication becomes an option. I think I am fearful and sceptical about it. I don’t want to change who I am and for the children who they are.

I think now I am open to try and see what would happen. It would help with executive function to be able to keep focus etc.

It would be a matter of getting the right dosage, for myself, as a schoolteacher I would be worried about taking meds and having to function as a teacher.

For my sons, I think it is different to make that decision for someone else. I can see how it would help my middle son but for my eldest son I think it would be a big leap for him to take medication.

Anything else you want to us to know?

To repeat my satisfaction with the GP and the good job they did at getting back to me and the situation regarding the mental health support.

The right to choose pathway is a very good way of getting past the NHS waiting list, I realise it’s a privilege.

Is there a way that a professional makes contact with the person to make a professional assessment to prioritise them to where they go on the waiting list.

Case study 4

Background

Lives in Bolton has two sons the youngest is diagnosed is 8 and has a diagnosis of autism, the elder son is 13 and has ADHD.

What support have you and your family had that was useful?

What has been useful is having to EHCP in place. I had to apply for this myself with no support from the school, I kept asking for support, but they said no. The support I got to apply for the EHCP was from an advisory service in Bolton. There needed to be support in place for my son to enable him to cope with a full school day.

What support do you feel would have helped but wasn’t there?

What would of helped is a point of contact, maybe someone at CAMHS I could call. There are periods when things are stable and doing okay. Services sign you off and you are left alone, then when issues start again you have to go back to the beginning, back to being referred and put on a waiting list meanwhile things are getting worst.

There needs to be quicker opt back in to the process for people already in the system, not starting again from the beginning. This is especially true now that my son is a teenager. He can see now that he is different, and no teenager wants to be different. This triggers his mental health issues.

Because of his behaviour he his vulnerable, he will follow what his peers are doing, he will do what they tell him just to fit in. He is at risk of being led into breaking the law or getting hurt.

There should be more 1-1 support in schools but instead all they want to do is get rid of the naughty kid. If you don’t have a diagnosis no one wants to know.

There needs to be more sensory space in mainstream schools, he gets no release or relief all day so when he comes home, he just has a meltdown. The school says he gets a break walking between classes but that is just not enough, there is so much noise and chatter, smells and colours.

He needs a sensory space to let off steam, all they offer him is a cupboard with a broken strip light with a beanbag in it, what he needs is to run and spin. He was part of a sensory processing disorder support pilot in Manchester, he had access to the most amazing sensory space, but it was decided not to fund the project in our area and it all stopped.

What are your views on what factors should be taken into concertation when prioritising how quickly people should be seen?

I definitely think age should be a factor. As a teenager he is at a time when things are difficult anyway and he is vulnerable to what others want him to do, he will do anything to fit in. He could end up being led into something that would affect the rest of his life if he is not properly supported, all just to fit in and not be different.

There are other medical factors too. He has a cyst on the brain so has to be physically careful but if I try to manage his behaviour, discipline him or say no to him he head butts the wall which could cause him major problems.

He wanted to go to the Trafford Centre with some mates, but I had to say no, he is hard to manage at home I can't imagine what would happen in the Trafford Centre with other teenage boys egging him on. Because I said no, he went upstairs and started banging the shower screen, it is glass anything could have happened, I tried to explain to him how dangerous it is.

Parents need to be listened to; School never sees to full picture and parents get labelled as lying. If schools say they don't see it than the system says is not happening, so you get no help. When professionals have come to the house and seen what he is really like they are shocked. When he was in nursery, they said that he needed treatment or he was just going to get worst as he gets older. If his nursery school could see it why can't a senior school?

What I don't think is that services, schools and professional understand the toll that masking puts on a child, the pressure can build, it's not fair. Just because they don't believe parents.

Is having a diagnosis for your child important? Why?

Diagnosis is massively important. The professionals say it doesn't matter and it's not important to have a diagnosis but without it no one listens to you.

Bad parenting is what you get told, I have been on so many courses for parenting because people just assume your child is 'naughty' because of you.

My son is extremely good at masking and keeping it in at school to fit in which means all hell breaks loose when he gets home as it is a released. The school would say, 'we don't see these issue he doesn't behave like that at school.

When it comes to assessments and forms, what the school says carries more weight, but they don't see what is really going on and I get labelled a bad parent. Once you have a diagnosis people listen to you, and you can explain to people what is going on.

If a diagnosis is not important like the professionals say, them why is the question about diagenesis always on every form? If a diagnosis is not important, why does it make a difference to the benefits you are able to claim or how you are treated at the hospital?

What are your thoughts about medication?

They tried him with one lot of medication, and he had side effects, it raised his blood pressure and he stopped eating. They did some tests and said that he was not getting much benefit from the meds and the side effects were too severe so they took him off that drug but wouldn't try any others so he has not been on any medication since, even though I have asked.

When my son was seen by a psychiatrist, he said that they should have tried him on other medications not just given up after one. So, we now have to start again on the referral prosses.

Anything else you want to us to know?

- I try to explain to my son that being different is not a bad thing, no one is the same.
- School have been trying interventions, he works well on a one to one but in the class he struggles.
- We went to see a psychiatrist once, all he kept saying was, my son is just like that when he has coke. My son doesn't drink coke, he won't drink anything fizzy. Because he is so sensory sensitive, he can't bear the feeling of a fizzy drink on his tongue.
- My son also has dyspraxia, he has a very poor memory. I am trying to get him into Ladywood for a learning disability diagnosis. Hopefully this will get him more support and he will be able to focus more. He now has a laptop to support his learning, but he always forgets to pick it up, he has to be reminded everyday It makes him look different from the other which he doesn't like.

- I worry about what kind of life he is going to have, he wants to be independent, and I want him to be independent but he is vulnerable and I worry.
- I go to meeting on meeting, but my hands are tied, everything has to come from a professional. They place way too much emphasis on what the school says.
- The only time I get a break is late at night when the children have finally gone to sleep. Then I have to be up early to get them into school.
- The length of the waiting list is shocking.
- I really wanted to attend the last online event, but my other son had to have surgery so couldn't make it. I want to help improve services for children with ADHD in Bolton.