

Thinking outside of the box

How those with Autism access Mental Health Services in Hull



healthwatch
Kingston upon Hull

About us

Who are Healthwatch Kingston Upon Hull?

We are the independent champion for people who use health and social care services in Kingston upon Hull. We exist to make sure that people are at the heart of care. We listen to what people like about services and what could be improved, and we share their views with those with the power to make change happen. We also help people find the information they need about services in their area.

We have the power to make sure that people's voices are heard by those who commission (pay for) services and those running services. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them. Our sole purpose is to help make care better for people.

Disclaimer

All the views, opinions and statements made in this report are those of the public who participated in our research across Hull. Any quotes within this report are written verbatim to fully capture the meaning, tone and emotion of the person sharing their experiences. Feedback is not verified for factual accuracy.

- Support for the whole family, not just the individual with a diagnosis of autism
- A more one to one personalised experience for individuals accessing their services
- Assistance with navigating the referral systems and processes
- More options for assistance, less of a one size fits all approach

People with autism faced the following issues and barriers when interacting with mental health services.

- The waiting times while being referred, and support whilst waiting for an assessment
- The services provided weren't always suitable for those with autism. i.e. group sessions, being too generic to help anyone.
- Individuals that access services feeling as though there were too many 'hoops' to jump through.
- People felt that their mental health concerns are either not extreme enough or too complex to be taken seriously by services.

Aims and Approach

Aims:

The aim is to understand the barriers faced by people who have autism, and their loved ones when trying to access support for mental health. We aimed with this project to highlight areas of both NHS services and specialised services that demonstrate positive aspects of working alongside those with a diagnosis of autism, as well as identify areas for improvement within those services.

Approach:

We cast a wide net for our engagement for this project, contacting both NHS based and independent services to gain a varied perspective. Our engagement took place over 4 months, in various formats, including face

of autism. We spoke to **20** individuals during our time with TIC. It was very clear to us through our visits that this service is vital to those in the area with various diagnoses and their families, not just as a professional service, but a peer support system for those living with someone with Tourette's and in many cases, a diagnosis of autism.

Special Stars

Special Stars is a not-for-profit registered charity. Their focus is to *'improve the quality of life for people with significant learning and physical disabilities and their families across Hull and East Yorkshire'*. They provide a range of support, training and advice for those with these disabilities and their families, supporting just over 3000 families across the region. Special Stars also owns a very expansive, wheelchair accessible sensory room equipped with a mobile hoist to maximise accessibility. When visiting special stars for their input in this project, we spoke with **8** individuals.

AIM Higher

Aim Higher is a registered charity in the Hull and East Riding area, who are dedicated to providing neurodiversity, mental health, and educational support for families of children and young people aged 0–25 years. With a special focus on autism, they strive to create an inclusive and supportive community where every individual can thrive.

This support comes in many formats, including:

- Providing inclusive activities, events, support groups and more
- Campaigning to increase awareness, acceptance and inclusion
- Signposting service
- Workshops, training and fundraising events
- Promoting neurodiversity and inclusion in the workplace
- Community engagement, school and college visits

We attended one of Aim Higher's support groups to engage with their attendees about this topic and spoke with **10** people.

Parent Carer Forum

Hull's Parent Carer Forum are an independent group of parents and carers of children and young people with special educational needs and/or disabilities in Hull. Their mission ensures that families voices are heard by decision-makers and planners. They work closely with Hull City Council and our local Integrated Care Boards as strategic partners to ensure this mission is carried out.

We have attended several engagement events alongside the Parent Carer Forum where we directly engaged with them and their attendees. We spoke to **20** people each time we attended the Forum. Our engagements with the Parent Carer Forum allow us to gain the perspective of those caring for someone with autism and mental health difficulties, in turn allowing us to understand the impact that the difficulties of accessing and using those services have on not only the individuals requiring the assistance and their families.

Newbridges Acute Inpatient Unit

Newbridges Acute Inpatient Unit is a 16 bed, all male unit that provides a 'A safe, therapeutic environment for males suffering from any form of mental illness who need to be in hospital'. Healthwatch Hull first attended Newbridges in March 2024, to discuss the protocols they have regarding their care for any individuals that are admitted to them that have a diagnosis of autism. We then set up a recurring engagement at Newbridges every 4-6 weeks to maintain a consistent level of engagement. Across the course of our engagements for this project we spoke to **3** individuals accessing the services at Newbridge with a dual diagnosis of autism and mental health.

Townend Court

The inpatient service at Townend Court provides assessment and treatment for people with learning disabilities across the Transforming Care Partnership (covering Hull, East Riding, North Lincolnshire, and North East Lincolnshire). The service has 14 beds, split between Lilac Ward (6 beds) and Willow Ward (8 beds).

Findings

Throughout our engagement we spoke to a total of **79** people in Hull who had a diagnosis of autism and had required support from mental health services or had a child who had required support. We spoke to an additional **10** stakeholders from organisations who support people with a diagnosis of autism and/or mental health need.

Survey Data

We gathered **16** responses to our Autism and Mental Health online survey. Our respondents ages ranged between 22 and 60 years of age and all live in the Hull area. The respondents all have experiences with autism and mental health services.

What services were accessed

Name of Service	Number of attendees
Andy's Man Club	1
CAHMS	1
Let's Talk	7
Mind	4
Matthews Hub	2
Other	4

*The total number of responses to this question being higher than responses to the survey overall is explained by some respondents accessing more than one service.

How would you describe accessing these services?

x = response

	Very Poor	Poor	Neutral	Good	Very Good
Andy's Man Club	x				
CAMHS		x			
Let's Talk	x		x	xxx	
Mind			xx	x	x

to our survey surrounded accessibility and reasonable adjustments. One individual stated:

'Maybe to have a city centre location with wider halls/doorways (for groups and 1 to 1 sessions) to make it easier for wheelchair users to get in and out of as when I attended the Beverley Road location it was a tight fit for my electric wheelchair and I banged it up a few times and had a plastic wheel cover break off trying to manoeuvre into the therapy room'

Another respondent commented:

'It didn't help at all. Let's Talk made me do group sessions online which weren't suitable for my needs especially as I was working at the time it wasn't always possible for me to attend the online appointments as I'd be out in the community'

One person stated that there needed to be a better understanding of those with autism from those working within Let's Talk:

'The call handler didn't understand that as someone with autism I couldn't receive calls, and a callback would not help. They told me it couldn't be that serious if I wasn't going to answer the phone. The service was overwhelmed, and the waiting times were obscene. Create check-ins, if you are waiting then maybe someone keeping you up to date and informed to let you know they haven't forgotten about you'

Mind

We had 4 responses related to Mind for this project, with all responses being relatively positive. The only improvement that was suggested was for the service to be more aware of autism, and how those with autism would benefit from minor changes to how the service is delivered.

'Mind tried very hard to help me with my social anxiety and depression via graded exposure therapy. I found it very taxing as I didn't respond well to it. I got my autism diagnosis late in life and I believe a lot of my social anxiety stems from being on the spectrum. Perhaps if the treatment was tailored more to those with autism it would have benefited me more.'

Waiting Lists

We asked respondents if they were on a waiting list for the services they accessed. **11** responded that they had been placed on waiting lists to receive support from the services. **5** responded that they had not. Of these respondents, **2** responded that they did not know/remember how long they had been waiting, **1** reported that they had waited a **few weeks**, **3** reported a **2–5 month** wait period, **1** responded a **7–9 month**, **2** respondents communicated a wait time of **1 year** and **1** reported that they had been waiting **since 2019**.

‘Everything is a battle, I was waiting 3 years for a diagnosis then when we finally got one, it was another battle again to get a psychiatrist’

In an informal conversation with one of our stakeholders, the idea of ‘waiting well’ was raised, this was in response to both the waiting times experienced for those wanting a diagnosis, and to the courses that certain parents discussed with us whilst attending the Parent Carer Forum.

‘We know people are waiting a long time for diagnosis. We want to make sure “people are waiting well” (In regard to the courses for parents whose children are autistic). It offers a “how to parent” in these circumstances but neurodivergent parents aren’t helped by this resource, because we know that neurodivergent people tend to research things a lot, so they probably already know this information. ’

Referral Systems

We asked those responding to our survey if they were referred by their General Practices or not. We also asked them a follow-up question that enquired about how they were referred.

Of those that answered, **10** confirmed that they had been referred through their GP practice, **6** responded that they hadn’t.

'It (the wait times) is impacting me immensely. To know that there could be something available for me that could help me and not have access to it is cruel and ridiculous'

'It heightens my depression, to the point of feeling suicidal'

'This affects my everyday living, my ability to study or engage in meaningful activities that require any degree of focus'

'It makes everyday a challenge; I am constantly exhausted'

Treatment within services

We asked those responding to our survey; 'Do services separate your diagnoses of Autism and Mental Health?'. This question was asked following a background sentiment that said people felt as though services were viewing patients as either autistic, or in need of mental health assistance, not both. **6** individuals responded that **Yes**, the service does separate the two diagnoses, however **8** respondents stated that **No**, this was not the case.

'If I go to the doctors as an autistic person and say I'm feeling depressed, they turn around and say, no that's just a symptom of your autism, like both can't exist at the same time.'

'Feeling like you have an active agency in your own care, that your care is happening with you and not to you'

This sentiment was shared at many of the engagements we took part in while gathering views for this project. Particularly from parents/carers of young people with autism. These carers told us that their child's needs were deemed 'too complex' for services to handle.

When we spoke to parents at Aim Higher, it was reported to us that their children are referred to CAHMS for support but upon admission at CAHMS, they are told that their child's mental health needs are due to their autism diagnosis and are therefore released from the service.

'It started really well, we got the diagnosis a lot faster than if we'd have waited in the NHS queue, and for the first lot of medication we paid NHS prices, when we went to renew them the bill was nearly triple what we originally paid, when we asked why they said there was a breakdown in shared care but didn't say when it would be sorted, so we had to pay the extortionate price anyway.'

Consistency of Provision

One of the recurring challenges facing many mental health services are the workforce challenges. This, combined with the lack of knowledge of the number of autistic people in Hull potentially requiring support due to the gap in recording of their diagnosis, presents significant challenges to the delivery and future planning for these services. It was stressed by several individuals with lived experience within the services that a consistent approach to care impacted their experience whilst using services in a positive way.

Patients receiving treatment from mental health services recounted the positive impact of structure throughout their treatment:

'I discharged myself from care 2 weeks ago, I came back because I realised I still needed the structure and stability of seeing the same faces helping me with my eating and my medication etc. Certain places can feel like the staff are just there for the money and they disappear as quickly as you meet them. I'm looking forward to getting back into my own routine, knowing that if I need them for some stability the staff at ** are always on the end of the phone'***

Improvements already in progress

Trauma Informed Care – Hull

In 2022 Hull City council alongside Humberside Police, Humber and North Yorkshire Integrated Care Board (Hull Place), Humber NHS Teaching Foundation Trust, Forum and An Untold Story – Voices, engaged in a

The Oliver McGowan training aims to:

1. ensure services are accessible and acceptable to autistic adults
2. support access to meaningful activity
3. facilitate timely access to autism assessment, when clinically indicated
4. use evidence to guide intervention choice for those with autism
5. assess and proportionately manage risk
6. monitor and minimise the use of restrictive practices
7. support cohesive transitions
8. consider the physical health needs of people accessing mental health services

To achieve this, all ICBs should:

9. develop a local commissioning strategy to ensure appropriately adjusted and tailored mental health provision is available for autistic adults, informed by local and national statistical data
10. develop and maintain a well-trained workforce

A point raised by one of our stakeholders was that even when adequate training and adaptations are made, such as the provision of the Oliver McGowan training, issues experienced by those with autism and mental health difficulties, certain professionals still lack the deeper understanding to make decisions for the benefit of the individual.

‘A great example of this would be the screening questions used to gauge if someone is going into crisis. Autistic people answer with a different framing than neurotypical people so MH services may not pick up that they are in crisis. However, on the other hand, the call handler may not know unless the caller says they are autistic.’

‘Services have to be open to the routines and unique habits that autistic people have that calm them down, even if those things may not be conventional and neurotypical.’

that will help make my stay better' and include several aspects of a person's care needs. CHCP also provide several 'Communication Boards' that provide more opportunities for communication between providers and those using the service.

Culture of care

Culture of care is a programme created by NHS England, aimed at inpatient services. It is a part of the Mental Health, Learning Disability and Autism Inpatient Quality Transformation Programme, created to support cultural change across all NHS funded mental health, learning disability and autism inpatient settings.

Humber NHS Foundation Trust has nominated 4 wards for this programme, including Townend Court and Newbridges Inpatient Unit. The programme supports positive outcomes through encouraging co-production on existing examples of positive care. It aims to ensure that all care is autism friendly, anti-racist and trauma informed.

The positive initiatives observed by the programme will be rolled out on a wider basis. The idea behind this programme being that staff will be trained and mentored on these positive initiatives so it can work from the ground up to improve how autism is seen within services, including Trauma Informed Care principals.

In addition to these initiatives, there is also a wider push by the Humber Teaching Foundation Trust surrounding the understanding of autistic people within the context of healthcare. This included steps such as respecting peoples avoidance, not making neurotypical assumptions and adapting their ways of working to suit those with autism.

Conclusion

To conclude, there are many areas within the health services that work with those with a diagnosis of autism and mental health difficulties that work well for those accessing them. There are also steps being taken to adapt these services to make them more accessible to those with autism. Despite these steps however, there are some measures that need to be

NHS Humber Foundation Trust:

- Should prioritise co-production and co design with autistic individuals who've experienced mental health support, empowering them to shape support and training that is offered by the Trust
- Should ensure staff continue to complete the Oliver McGowan Training.
- Should Adopt a more person-centred approach when caring for those with a pre-existing diagnosis of autism and mental health support needs, by involving them in decisions about their care and utilising Health Passports, and continued implementation of the Culture of Care programme principals both in inpatient settings and other mental health services.
- Should ensure that all staff with autism and mental health services are trained in trauma informed practice
- Should utilise the lived experience of people with autism to co design and create information leaflets to inform patients about terminology and processes. This could included ;
 1. 'Waiting well' – what this means and looks like, how long the wait is expected to be and where people can get emergency help if needed.
 2. Shared care – Ensuring a better understanding of shared care protocols within individual's accessing services that include the protocol and any limitations.
 3. Support Groups – What is available, where it can be accessed, how to contact and any criteria for attendance.
 4. A breakdown of the services available – what each area is in place to do (GP, Hospitals, MH services, autism services), what can be done by those services and what can't, to limit the possibility of being in contact with the wrong service and improve public health literacy.

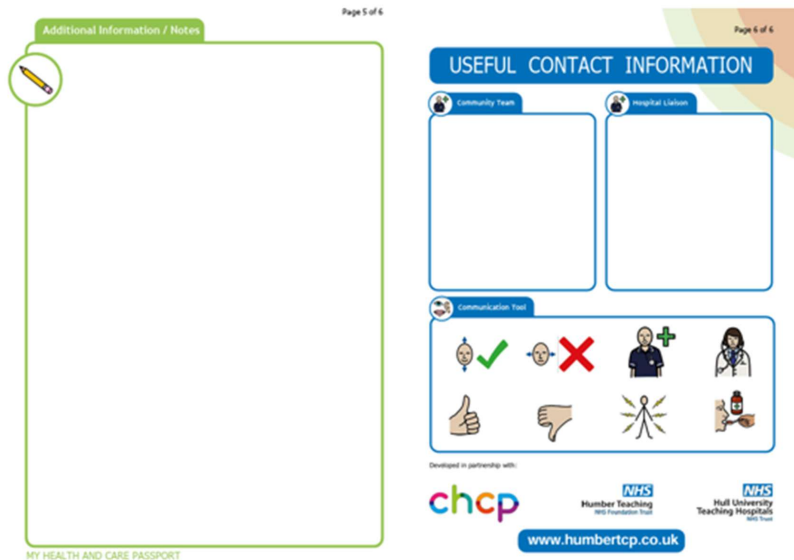
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11. City Health Care Partnership 'Patient Passport' [Internet]
<https://www.chcpcic.org.uk/chcp-services/wellbeing-primary-care-liaison-service/pages/patient-passport>



Examples of Communication Boards



Reasonable adjustment flagging communication board



If you are using NICE Clinical Frailty Scale (CFS) or NEWS 2 Score to assess me, please note that a diagnosis of learning disability or autism alone is NOT a reason to place a DNAR/CPR.

I am autistic. Please do not assume that I do not have mental capacity.

The Human Rights Act means that staff in the NHS must respect and protect my human rights when making decisions about my care.

All decisions must be made in line with the Mental Capacity Act.

The Mental Capacity Act has five key principles:

1. Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise.
2. People must be supported as much as possible to make a decision before anyone concludes that they cannot make their own decision. If a lack of capacity is established it is still important to involve the person as far as possible in making decisions.
3. People have the right to make what others regard as an unwise or eccentric decision. Everyone has their own values, beliefs and preferences which may be different to other people. They should not be treated as lacking capacity for that reason.
4. Anything done for, or on behalf of, a person who lacks capacity must be done in their best interests.
5. Anything done for, or on behalf of, people without capacity should be the least restrictive of their basic rights and freedoms.

Information on the Mental Capacity Act is available from www.publicguardian.gov.uk

About autism

Autism is a lifelong disability which affects how people communicate and interact with the world. There are more than 700,000 autistic adults and children in the UK.

Autistic people see, hear and feel the world differently to other people. If you are autistic, you are autistic for life; autism is not an illness or disease and cannot be 'cured'. Often people feel being autistic is a fundamental aspect of their identity.

Autism is a spectrum condition. All autistic people share certain difficulties, but being autistic will affect them in different ways. Some autistic people also have learning disabilities, mental health issues or other conditions, meaning people need different levels of support. All people on the autism spectrum learn and develop. With the right support, all can be helped to live a more fulfilling life of their own choosing.



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Example of Autism & Mental Health Questionnaire

Autism & Mental Health Questionnaire

Healthwatch Kingston Upon Hull is the independent voice for the people of Kingston Upon Hull, helping to shape, challenge and improve local health and social care services. We are charged with collating the views and experiences of the people receiving care, friends and relatives. If you would like your views to count as part of this process or to share your views at any time with regards to any Care/ Residential or Nursing Home, please complete the following survey. It would be extremely helpful if you would answer the questions below and return the completed survey to a Healthwatch representative on the day of our visit or post back to us at our freepost address. This will assist us in having a better understanding of the service. It will also ensure that we hold the most up-to-date and accurate information possible. All responses are recorded and collated anonymously. If you require any further copies please contact using the details at the end of the survey.

How would you rate the communication between yourself and the services? 1 being no communication, 10 being perfect communication.

Were you on a waiting list for your service?

Yes

No

If yes, how long were you on the waiting list?

Do your autism services and mental health services work alongside each other?

Yes

No

If no, how could the services you access work together for your best interests?

Did your GP refer you to your Mental Health Services?

Yes

No

If no, what was your referral method?

having autism or mental health? Tell us about the experience

Do you feel there is the need for a new provision that specifically supports mental health and autism (and other neurodiverse conditions)?

Yes

No

Further Comments