Autistic Voices

Local people's health and care experiences

healthwatch Cambridgeshire

healthwatch Peterborough

Autism Focus Group 2021

Autism – is a lifelong developmental disability which affects how people communicate and interact with the world. Like all people, autistic people have their own strengths and weaknesses.[1]

Autism affects the way in which a person understands, functions in and interacts with the environment in which they live. It can cause social communication and social interaction challenges; repetitive and restrictive behaviour; over or under sensitivity to light, sound, taste or touch; highly-focused interests or hobbies; extreme anxiety and meltdowns or shutdowns.

It is thought that autism affects one per cent of the population.

Background

In Cambridgeshire and Peterborough, the local authorities and health commissioners are developing a new All-Age Autism Strategy. To prepare for this, an important needs assessment has been carried out over recent months to understand the characteristics and health needs of autistic people of all ages across our area.

Local and national sources were studied to find out how many autistic people there are and how these numbers are predicted to change with time. Current services were reviewed and, with the help of the views and experiences of service users and their carers, any gaps in services and support were noted. Good practice was also identified from other areas of the UK. All this information has been used to develop recommendations and to help inform an All-Age Autism Strategy for Cambridgeshire and Peterborough.

One of the recommendations from the needs assessment was to set up a multi-agency All-Age Autism Board for Cambridgeshire & Peterborough to manage the work going forward. One of the Board’s responsibilities has been to further develop an All-Age Autism Strategy for Cambridgeshire and Peterborough together with autistic people and/or their family members/carers.

Other recommendations covered how services would be paid for, getting help sooner for people with autism, getting a diagnosis, numbers of staff and their training.

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[1] National Autistic Society (2021) What is Autism?

Our Healthwatch held a focus group for autistic adults in February 2021 to find out their experiences of using and finding services for autistic people. Almost all those taking part were 18 and over. The feedback from this focus group will feed into the All-Age Autism Strategy work to help develop services that work well for autistic people. This report also includes further feedback we have received since starting this piece of work.

We asked partner organisations to promote our focus group with a poster and a social media toolkit – and many kindly did so. We had a lot of interest and the 13 people taking part were a mix of male and female autistic adults and carers. The discussion covered several areas of people's lives that can be affected by autism.

Common themes in the group's feedback

- People say it is hard to get a diagnosis for autism and the path is long.
- It should be easier to find support after diagnosis.
- A need for more support is clear. This ranges from help in coming to terms with a diagnosis to help with social skills, advice on training and employment opportunities, benefits, independent living, and where needed, a support worker to guide and encourage people in their daily lives and help them reach their potential.
- Healthcare workers and the wider community should have a better understanding of autism, especially autism in women and girls.
- Mental health services should have a good understanding of autism and the needs of autistic people, so that reasonably adjusted and effective care and treatment is always provided.
- People want better and easier access to services with communication options such as emails and text.
- People want clear information about autism, local services and support.

Challenges in getting a diagnosis

Everyone in the group, except for one who was awaiting an assessment, had been diagnosed with autism. They all agreed that getting a diagnosis was very difficult.

There were various reasons for this including: lack of understanding of autism; misdiagnosis by healthcare staff; and not knowing where to send someone for assessments. It can be especially difficult for women, as autism can present differently from the way it does in men. People may not be aware that women can be autistic.

In Cambridgeshire and Peterborough, there can be very lengthy waits for assessments which can be between three and five years.

A person may already be in a service – mental health services for example - before their autism is recognised. So the service may not be appropriate and treatment is not necessarily helpful – and can just delay the possibility of any diagnosis.

Gender diagnosis gap

One person had been diagnosed for ten years but explained that it was hard when people think only males can be autistic. They said that they had been misdiagnosed in the past with a Personality Disorder.

> "It is hard as a woman. People don't understand you can have female Asperger's or autism. People just skip over this. Trying to get a diagnosis for a woman can be terrible!"
>
> - Autistic adult

Another woman explained that she had been in mental health services for 12 years and only now was the possibility of her being autistic being considered.

Autism and mental health

One young adult told us that they had lived a long journey of trying to gain support for their mental health difficulties. They had many times of crisis and had been diagnosed with different mental health conditions. It was only at the age of 24 that a local voluntary organisation suggested an autism assessment. An autism diagnosis followed and all their past then made more sense.

> "I was under multiple doctors, Children and Adolescent Mental Health Services (CAMHS), admitted to mental health wards, attended a special school and yet I went completely under the radar."
>
> - Young adult

A parent carer expressed their concerns around complications with autism and mental health difficulties.

> "I believe that a lot of mental health conditions spring from being misunderstood, leading to secondary behaviours that lead to further punishment and issues."

Overseas diagnosis

One person told us how they had been diagnosed in Europe but that their diagnosis had not been recognised in England. They had been trying to get a diagnosis for two years and were still waiting. Three GPs had given three different pieces of advice which had been very confusing. One GP told them that they would need to get a diagnosis in England to access any support. And one way to access support was to present with anxiety due to the pandemic.

Older autistic people

We have heard from several older people asking for more awareness about autism in older people and the importance of earlier diagnosis. Some said that they have only recently had a diagnosis after years of suffering. Others say they have not had their symptoms recognised or had any help or diagnosis when they feel they should have. As a result, they have suffered in silence for many years.

Some older people had concerns that autistic people or people with Asperger Syndrome may need healthcare in a care home for example, where their needs may not be met because their condition had not been recognised previously throughout their lives.

Misdiagnosis can mean people are referred to the wrong service, such as mental health services in many cases. As well as taking up valuable NHS time, resources and money, this leads to more stress and frustration for patients.

Support after diagnosis

> "There has been absolutely no support whatsoever that I have received (from the NHS)."
>
> - Young adult

One person explained how they were initially diagnosed with anxiety and depression until they pressed for a possible autism diagnosis which was confirmed a couple of years ago. Their journey to a diagnosis, from start to finish, took about three years.

After this, they were told that the only appropriate service to support them was to self-refer to the IAPT (Improving Access to Psychological Therapies) service for an eight-week course of CBT. However, early in their therapy they were told that their needs were too severe for the service.

Now they need to find other support for their mental health needs. This person was assigned an adult autism support worker (from the county council's Adult Social Care Team) following a recommendation from the service where they were diagnosed. But they found it was not always easy to contact the support worker when needed.

They also found it difficult to get reasonable adjustments made at work. Some changes were made which meant they were able to stay in work and that was incredibly important for them.

It was pointed out that support workers could not help if one then moved to another county. There seems to be no transition for this in place.

> "It is really very difficult for an adult with autism."
>
> - Young adult

One parent carer explained how they had tried very hard to gain support for their teenage autistic child, who was now 18. The family had sought help and support for their child five years ago when they were in school and had just been diagnosed with autism.

After about a year, the parents attended an information course and learned that there should have been a referral through a special educational-needs co-ordinator (SENCO). This would have allowed their child to have autism outreach support in school but this link-up to support was missed initially.

In previous feedback to our Healthwatch, a parent told us that their child had been given a diagnosis for autism after a two-year wait. After this there was very little support for adults with autism in their area.

> “We were given a few website addresses to contact and given information on an app that would cost £90 a month but would offer ongoing support. My [child] needed help with coming to terms with the diagnosis, and general information around working, university etc. I also felt they could benefit from having a support worker, but this was not available in our area.”
>
> - Parent carer

Accessing services

There have been long and difficult journeys to the right service for some of our participants.

One young adult told us about their experience with a local mental health service. They had been advised to self-refer and had told the service that they were autistic.

It took a year to access this virtually. Then, soon after starting therapy, they were told they could not be helped because their needs were too complex.

The staff admitted that they did not know enough about autism. Private therapy had to be found.

> “I have been in and out of therapy for more than half of my life and I am still trying to find somebody who not only has an understanding of autism, but also knows how autism can affect your mental health, your daily life. Being told just to let it go, is not how it works, not at all.”
>
> - Young autistic adult

> “People are told they need specialist Cognitive Behavioural Therapy (CBT) but there is no one in Cambridge who provides this”.
>
> - Autistic adult

Feeling dismissed, excluded and misunderstood

Another person explained the many barriers to getting help for autism and that it took them ten years to be diagnosed.

Previously, they were diagnosed with various mental health conditions including borderline personality disorder. It had been very hard to get the support that they felt they needed. They felt dismissed by staff at times and were discharged from various services over time, sometimes when still unwell.

Once diagnosed, an adapted form of CBT was recommended which should have been accessible through a local mental health service. When the self-referral pathway was added for this service, they applied in the hope of accessing therapy. This took several attempts because of concerns over previous diagnoses they had been given in the past which were felt to be too complex.

Eventually, CBT therapy was accessed through the service, but it was a very difficult road – leading to feelings of being excluded and misunderstood regarding their autism.

Our Healthwatch has also received previous feedback from people who tried to access services but found these were available only in certain areas – and not theirs.

The need for healthcare support

We heard that a person with Asperger's had needed support due to being anxious about going into hospital but they did not know how to access this help.

Someone else had also needed support to go to a hospital outpatients' service. It took several contacts with many people to enable reasonable adjustments to be made to support this person to go to appointments. Eventually they learned there is a Matron in the hospital who is an "autism champion" and this helped enormously.

> "There really should be a clear, defined, accessible way to request adjustments (for autistic people) for all healthcare."
>
> - Young autistic adult

This person is still unsure how they would be supported if they needed any inpatient care. They said there had been times when healthcare staff have not understood autism at all - even in mental healthcare services.

Our focus group highlighted:

- People want healthcare services to assess autistic people in a more holistic way.
- There is a real wish for mental health services to be able to support autistic people's specific needs.

Accessing CAMHS

One parent carer told us that their child had become suicidal with frustrations with their autism and still this was not enough to gain access to CAMHs (Children and Adolescent Mental Health Services). They were told to ring their GP or NHS 111 option 2 if the situation got worse.

> "How bad does it have to get? Feel totally let down by the service."
> - Parent carer

The focus group agreed that there might be several agencies offering up different services, such as support in seeking employment, but people are not aware they exist. People can be signposted back and forth before they end up in the right place, if at all.

Experiences of CLASS

A few people have told us that it would be ideal if there was better support following a diagnosis in the Cambridgeshire Lifespan Autism Spectrum Service (CLASS). Some have tried all avenues for help and support, including access to social services, personal payment plans, supported living and mental health services but have not got the help they need.

We heard how someone had tried to access the CLASS service for about five years but had felt GPs had not taken this need for referral seriously.

People agreed that it is even harder to gain support when there is more than one condition other than autism, such as autism and mental health conditions.

Being involved in service planning

No one seemed to have tried to access any specialist service in the county such as a speech and language therapist or help for social skills. One person talked about having had a social services package and had been living independently with support. Another person was trying to find out information to do this.

The group agreed the importance of involving autistic people in planning of services was very important.

Making services more accessible

A participant explained that they have problems with understanding information over the phone. Often, contact with banks and other services, such as making a doctor's appointment, is by telephone. They had had problems with organising a healthcare appointment in the past.

The service had left a voicemail message at their home with a telephone number to call back on. But because the person had auditory processing difficulties, they hadn't understood it and were not able to call back. This call was never followed up.

Finding easier ways to communicate

They explained that it takes an enormous amount of energy trying to follow information that is given verbally. A non-verbal contact option - such as email or text - would make their life much easier.

Other people agreed that a chat option with a GP via messenger or voice texts might work better for some autistic people.

And other people also mentioned that they would prefer face to face conversations as opposed to telephone.

This shows the importance of being flexible and giving individual support to people when accessing healthcare. Indeed, services have a duty by law to be more easily accessible to everyone. The Accessible Information Standard 2016[2] "aims to make sure that people who have a disability, impairment or sensory loss get information that they can access and understand, and any communication support that they need from health and care services."

Support from community organisations

One person said they had been helped by some carers from the National Autistic Society a few years ago but this sadly came to an end. They had struggled for a while before gaining carer support through mental health charity MIND. This support has been so important and had meant they could live independently.

Support in schools, colleges and universities

Some families told us that schools could have been more supportive to their autistic children, while others were more positive about help offered by their colleges and universities.

One family told us the school their child attended had not understood their sensory needs.

A young autistic adult explained they had been diagnosed with autism at pre-school age. As a child even in a special school, they felt some staff did not really understand autistic children. They still remember this as an adult.

They felt that staff in schools need to understand that these children may not adapt to the norms that other children might do. This person now attends a college where they have support and feel much calmer and more understood. They feel it can be a real struggle for autistic people to be understood.

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[2] NHS England (2016) Accessible Information Standard

One parent, whose child was reaching school leaving age at 18, talked about how important it is to have a good transition into adulthood. Their child was already feeling much anxiety around this.

> "When transition goes wrong for young people with high support needs, this can result in extremely expensive provision, therefore early planning is essential."
>
> - Parent carer

One parent carer explained how certain conditions make coping difficult for their child and therefore they need more support.

> "Sensory processing disorder and dyspraxia have a massive implication on my child's ability to cope."
>
> - Parent carer

Another person explained that they had had more support from the local university they attended, than they had received in the community. They were helped with their confidence and studies by a disability worker. The university also had an autism support group which they attended virtually, which had been very beneficial for them.

Training, employment and Covid-19

One parent carer explained their child was doing a course at college that supports young people into work. The plan was to gain a possible internship in a store which could have eventually resulted in paid work. But the pandemic has interrupted this. Now they will just be hoping for some voluntary work of some other kind to gain work experience this summer.

> "It was always going to be hard (for the child to find work) but Covid-19 has made things much harder."
>
> - Parent carer

It was also highlighted that once in work, there needed to be support in place so that people could stay in work.

> "The pandemic is particularly hard for people with autism."
>
> - Young adult

One participant told us their child had been incredibly anxious throughout GCSEs and had not studied so much due to this, but still had very good results. They had been able to remember much information anyway and did very well, despite the anxiety, due to having an incredible memory.

It was suggested that for young people with an Education and Health Care Plan (EHCP), employment and training planning should begin in good time – before 16 or 18 years old - so that the support they need is in place.

Valuing people's skills and abilities

We heard how a young adult had a photographic memory which was very useful in their work with data. They highlighted that they knew autistic people who were very talented in areas like the arts or science for example, but these people needed support for their social needs.

> "Support for these social needs (for autistic people) would be much appreciated."
>
> - Young autistic adult

> "Autistic people can be an asset to companies as long as we have reasonable adjustments made if needed."
>
> - *Young autistic adult*

People agreed that autistic people can be very talented and clever. Some have a good eye for detail and a superb memory.

Including autistic people in decisions within a workplace situation to ensure their needs are being met was also seen as being very important and necessary.

Independent living and Covid-19

One young adult said they were still living with their parents but would like to explore independent living options. They were not sure what was available in Cambridgeshire or how to access this.

Covid-19 has also affected people who previously had carers coming into their home, but when the pandemic came, support was stopped due to the risk of spreading the virus into people's homes. One person told us that this had meant them moving back in with their parents, affecting their possibility for independent living at this time.

Autism language

There were concerns over certain words and language used in relation to autism.

The words *high-functioning* and *low-functioning* were interpreted differently and not liked by many.

> "Perhaps 'high functioning' can be used to deny support and 'low functioning' to suppress potential (talent)."

> "The term ‘high functioning’ implies we don’t have issues or difficulties and ‘low functioning’ implies they aren’t capable of living a normal life or are not intelligent”.
>
> - Young autistic adult

One person pointed out that one can be thought to be high functioning in terms of intelligence, social ability and communicability, but still have high needs.

> “My child has been described as ‘low functioning’ as they are non-speaking, but he is still working at GCSE level in some subjects. It is a very disparaging way to describe a human being.”
>
> - Parent carer

A preference for *high support needs* and *low support needs* as opposed to high functioning or low functioning was expressed.

Previous feedback to our Healthwatch mentioned further language concerns involving how an autistic person is presented.

> “‘I am autistic’ not ‘I am a person with autism’. This is because autism should not be seen as a disease or something separate to the person that needs to be fixed or cured. Equally many autistic people don’t like the term ‘on the spectrum’ because it all too easily leads to phrases like ‘we are all on the spectrum somewhere’ which is a fallacy and demeaning.”
>
> - Feedback via Healthwatch in Cambridgeshire and Peterborough Facebook page

Other difficulties

Someone mentioned that “there was a lot of information on the county council website, but it is very hard to navigate and not specific to autistic needs. To know which benefits to apply for or help for supported living is very difficult.”

A concern was raised about the high level of use of prone restraints in the UK when autistic people were struggling with coping.

There was a feeling that there are some harmful stereotypes about autism that are not helpful to autistic people.

In an ideal world…

People were asked what they would like to be able to do in an ideal world. What would make life easier?

One young adult said that since being diagnosed, it had helped them understand the type of help they might need. Their main wish was for people to have a greater understanding of autism and to be more empathetic towards them.

> "In an ideal world, I would like to get rid of the stigma (around autism)"
>
> - Young adult

One person explained that autistic people have strengths such as paying more attention to detail. They would like people to see the strengths rather than the negatives and that employers should see also see the benefits of hiring a diverse workforce.

Information for autistic people

People in the group wanted clear, online information about autism, including what services were available and how to get support.

However, not everyone has access to a computer or internet access. So information about autism services and support should be available offline and in other formats.

Searching the Keep Your Head website

Autistic people may have developmental and emotional issues. In Cambridgeshire, we have a county website called Keep Your Head which was originally developed so that mental health information could be in one place for children and young people. It has since expanded to include a website for adults and another for professionals.

We searched the site for information specifically on emotional support available for autistic people. There was nothing easily found on the children and young peoples' website. On the adults' website, we typed "autism" into the search engine and it returned a page explaining autism, how one can be diagnosed and information on two organisations to support autistic people.

If this information is to remain here, these websites would need to be updated with service information and changes on both the adult and children and young people sites going forward.

However, the Keep Your Head website focuses on mental health and wellbeing information, not autism. So consideration could be given to a 'one-stop' county-wide website specifically for information on autism, services and support that can be shared through local organisations, schools, colleges and universities to reach autistic people.

Our recommendations

1. Local authorities and commissioners develop and enable a pathway of services, including voluntary sector and community organisations, which meet the needs of autistic people. Within this-
    - Make the diagnostic service more accessible for all ages.
    - Shorten waiting times for assessments and diagnosis.
    - Ensure through awareness raising and training that children and young people's and adult mental health services provide excellent care and treatment for people with autism and co-occurring mental health conditions.
    - Ensure healthcare staff have autism training to understand the needs of autistic people, with a lead person who is specialist trained.
    - Identify and properly treat mental health problems that many autistic people may have - such as depression, anxiety, obsessive compulsive disorder (OCD), epilepsy, learning disabilities, attention deficit hyperactivity disorder (ADHD) or dyspraxia. These should not be thought of as a part of the autism spectrum.
    - Improve understanding and awareness of female autism.
    - Open up access to specialist services such as speech and language therapy or social skills development.
    - Offer more support and advice post autism diagnosis, for example, support regarding coming to terms with diagnosis, advice on training, university, employment or support to stay in work, and help for independent living.
    - Ensure good transition planning and support for young people moving from childhood to adulthood, with better integration of services.
    - Develop a ‘one-stop’ countywide website for autistic people offering up to date information on autism and any service changes (statutory and voluntary sector organisations).
    - Give autistic people information they need, engaging with them to understand these needs. Ensuring other ways of accessing this information for those who do not have digital access will be important.

2. Ensure these services are accessible across the whole county to avoid a “postcode lottery” of unequal provision across different geographical areas.
3. Develop a system which will recognise a diagnosis for autism for people coming from another country.
4. Ensure school, college and university staff are well trained to understand autism and the potential needs of autistic young people.
5. Improve understanding and support in workplaces for autistic people and involve them in the planning. Perhaps a local campaign could be developed to help with education and positive messaging on autism. This could also help reduce any stigma or harmful stereotypes.
6. Ensure healthcare services comply with the Accessible Information Standard, flexing to meet people’s individual communication needs, making it easier for autistic people to access care. This should be the case for anyone with a disability, impairment or sensory loss.

Contact us

The Maple Centre
6 Oak Drive
Huntingdon
PE29 7HN

Email: enquiries@healthwatchcambspboro.co.uk

Call: 0330 355 1285 or text 0752 0635 176

Web: www.healthwatchcambridgeshire.co.uk

Web: www.healthwatchpeterborough.co.uk

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