Healthwatch Greenwich

Autistic spectrum condition (ASC) report

Contents

1. Executive Summary

1.1. Introduction

Following feedback from autistic people and their families/carers, Healthwatch Greenwich conducted a study into autistic spectrum condition (ASC) specialist services for children and young people (ASC is also called autistic spectrum disorder, ASD). Following the initial report, Healthwatch Greenwich expanded the scope of this research to include specialist services for autistic adults as well as children.

1.2. Findings

Through our online survey, focus groups and one on one interviews, we identified six major themes surrounding people's experiences with the services:

- Long waiting times for assessment and diagnosis
- Varying experiences of service quality across the borough
- Lack of communication and information sharing among different health, social care and educational services
- Lack of acceptance and understanding of ASC experiences by professionals in these services
- Difficulty locating and accessing support services without an official diagnosis
- Difficulties in transitioning to adult services.

1.3. Recommendations

- Pre-diagnostic support services should be more widely communicated.
- Information and signposting should be easily available throughout the borough.
- ASC awareness training should be comprehensively implemented across all services in health, social care and education.
- More support services are needed for ASC adults.
- Improved information sharing is needed among services.
- Independent oversight is needed of school special educational needs coordinators (SENCOs).

2. Introduction

2.1. About Healthwatch Greenwich

Healthwatch Greenwich is an independent, statutory organisation representing people who use health and adult social care services in the borough. We collect patient and public feedback and push for changes needed to improve services. Our vision is for Greenwich to have high quality services, consistent levels of public engagement and an excellent service user experience that meets patient need and preference. To achieve our vision we listen, we act, and we influence.

2.2. Summary

Healthwatch Greenwich has spoken to autistic people and their carers and families about their experiences in accessing diagnosis, care and support from specialist services in the Royal Borough of Greenwich. They told us that autistic people experience a range of barriers to accessing the services they need within health, social care and education.

2.3. What is ASC

Autism spectrum condition (ASC) is a developmental condition lasting throughout a person's life, causing them to perceive and interact with the world around them differently to their non-autistic counterparts (often referred to as neurotypical people). ASC is also called autistic spectrum disorder (ASD). Autistic people, as a result, experience difficulties with social interaction and communication among their peers. They may also struggle with processing and filtering information from their surrounding (known as sensory processing disorder, SPD), which can result in information overload and perceived loss of control over their environment. These difficulties can outwardly manifest as mental health issues such as anxiety and depression, and behavioural issues including meltdowns, restricted and repetitive behaviour, social isolation, behaviour considered to be socially inappropriate, and speech and language difficulties. While no two autistic people are the same, they can experience any one or more of these difficulties in their daily lives to a greater or lesser degree of severity.

Autism is not an illness and cannot be cured; rather, it should be considered as a variation in the structure and development of a person's mind – in the autistic community, this is referred to as neurodivergence. Autistic people can mitigate and manage the difficulties they face by receiving appropriate support, adjusting their environment and having the understanding of people around them.

2.4. National picture

According the National Autistic Society (NAS), over 1 in 100 people in the UK are diagnosed as being on the autistic spectrum, which includes the diagnoses of autism, Asperger's syndrome and pathological demand avoidance. Taking parents, relatives and carers of autistic people into account, NAS estimates 2.8 million lives are affected by ASC.[1] Nationally, demand on ASC services – particularly diagnostic services – has significantly increased, far exceeding capacity. Overstretched services have a profound effect on the lives of autistic people with many families experiencing long delays, up to 4 years, for a diagnosis.

Approximately 70% of autistic children and young people (CYP) have at least one co-occurring condition, such as epilepsy, general anxiety disorder or another learning difficulty such as dyslexia. As a result, autistic CYP and their families require support from a range of services but often find them difficult to access due to the varied presentations of ASC and the lack of understanding by professionals across sectors and services.

Research by NAS in 2011 found 63% of parents with an autistic child did not feel they were in an educational setting which best supported their needs. Nationally 17% of autistic children have been suspended from school (48% of these three or more times) and 4% have been expelled from more than one school, and not receiving the support needed to stay engaged.

School exclusions, barriers to accessing services, and a general lack of understanding have a detrimental effect on a child's life. Their ability to manage day-to-day challenges in adolescence and later life can be significantly improved with support and intervention in the early stages of life. As such, the development of ASC services for both children and adults has now been listed as a key priority in the NHS long term plan.

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[1] National Autistic Society https://www.autism.org.uk/about/what-is/myths-facts-stats.aspx

2.5. Key legislation: CYP 0 to 25

ASC services for CYP aged 0 to 25 come under the umbrella of special educational needs and disabilities (SEND) services and are jointly commissioned by the borough and Greenwich NHS Clinical Commissioning Group (CCG). The Children and Families Act (2014) specifies that local authorities must ensure collaboration between education, health and social care to provide support services to meet the needs of children and young people aged 0 to 25 with SEND. The SEND code of practice specifies that they should adopt a “key working approach” to the design and delivery of services, centred on the individual child or young person, keeping their views and wishes as well as those of their families at the forefront of decision-making. A key aspect is the provision of a single point of contact for the individual and their family to ensure holistic and well-coordinated access to services.

The Children and Families Act requires Local Authorities to ensure cooperation between children and adult services so that young people are able to transition smoothly from children’s to adult social care, and are not left without support. This is crucial for autistic young people who may require extra support to enable them to live independently as adults.

Finally, the SEND code of practice states that both local authorities and CCGs must have arrangements in place to ensure accountability for commissioning SEND services with clear understanding of who is responsible for delivering each service. In addition, providers must be able to make clear decisions about how they will meet the needs of CYP with SEND in each case.[2]

2.6. Key legislation: Adults 25+

The Autism Act of 2009 requires the local authority and local NHS to ensure a clear pathway to assessment and diagnosis for adults, and to ensure that service users have access to the support services they need both during and after assessment.

Specifically, the act specifies that local service providers must have an autism diagnostic pathway for adults including those who do not have a learning disability. They must ensure

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[2] SEND code of practice, Ch 1 pp23-28, Ch 2 p35; 2015 https://www.gov.uk/government/publications/send-code-of-practice-0-to-25 accessed 10/2018

there is a clear mechanism to notify individuals of their entitlement to an assessment of needs and access to local authority adult services.

NICE guidance and the NICE quality standard on autism represent best practice when developing diagnostic and related services. CCGs and NHS England should:

- Establish, maintain and promote autism diagnostic pathways, working with partners in local authorities. This includes giving appropriate post diagnostic advice and support;
- Promote NICE best practice (e.g. where people seeking an autism diagnosis have a first appointment within 3 months of their referral) as set out in the NICE Quality Standard on autism [QS51].
- Ensure people with autism are aware of the right to access a needs assessment (for the adult) and a carer's assessment (for the carer).
- Needs assessment process should align with the diagnosis process and be offered at the diagnosis stage and a referral made if needed.

In addition, local commissioning plans should set out how local authorities ensure that adults with autism are able to access direct payments (where appropriate) and benefit from personalisation of health and social care. Local partners should have a local autism partnership board, which brings together different organisations, services and stakeholders and adults with autism and their families to set a clear direction for services. Autism partnership boards are a highly effective means for stakeholders to shape and monitor local delivery of strategy and statutory guidance. It is therefore essential for partnership arrangements to be established in areas where they are not currently in existence.

3. Local context

3.1. Autistic CYP in Greenwich

The population of CYP under 18 years has been steadily increasing in Greenwich, rising to 14% (8,300) since 2011 and is estimated to rise by another 3% (2,300) by 2021. CYP currently comprise about 25% of the population of Greenwich, approximately 69,800 children.[3] The number of children with a confirmed diagnosis of ASC in Greenwich has more than doubled between 2007 and 2016, from 308 to 719. However, feedback we have received from residents suggests many difficulties and delays in getting a diagnosis, making it difficult to construct an accurate picture of the true number of families living with autism in Greenwich.[4]

3.2. Ofsted/CQC joint report

In July 2017, Greenwich SEND services received a joint inspection by Ofsted and the Care Quality Commission (CQC)[5]. Inspectors spoke to CYP with SEND, their families and carers, and also visited local services and spoke to staff, leaders and school governors about how SEND policy was being implemented. Their report was positive, highlighting strong leadership:

> *"Senior leaders in the local area have interpreted the reforms skilfully when planning improvements in the provision for children and young people who have special educational needs and/or disabilities."*

> *"Leaders have ensured that arrangements for joint commissioning are effective. Leaders from health, education and social care services work together efficiently when planning and budgeting for services. The co-production of services, advice and guidance (a way of working where children and young people, families and those that provide the services work together to create a decision or a service*

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[3] Profile of Children and Young People in Royal Greenwich; 2016 https://www.royalgreenwich.gov.uk/info/200164/about_the_royal_borough/1873/childrens_services_performance_and_statistics

[4] SEND Information and Advice Support Service (SENDIASS) annual report

[5] Joint local area SEND inspection Royal Borough of Greenwich 07/2017 https://files.api.ofsted.gov.uk/v1/file/2724531

> *which works for them all) is well understood by local area partners, young people, parents and carers."*

They also reported positive feedback from staff and professionals:

> *"People working in the local area report feeling supported, well trained and able to influence change."*

> *"Education, health and social care professionals collaborate well. They understand one another's work. This allows timely and effective working to improve outcomes for children and young people."*

However, there were areas requiring improvement, including long delays within the services:

> *"Children and young people referred for autistic spectrum disorder (ASD) assessments wait too long to complete the assessment process (12 months). Although waiting times have been halved over the last year, there is still further work to do. The local area has realistic plans in place to reduce the waiting times further, including accounting for the rising numbers of children and young people referred and diagnosed with ASD."*

> *"The process of transfer from statements of educational need to EHC plans has been too slow. Changes in leadership and the use of inefficient software systems to store and organise information have held up timescales."*

It was also noted that Greenwich was lacking a designated medical officer (DMO) responsible for overseeing the health services that form a part of SEND:

> *"There is currently no DMO or DCO in Greenwich. This means that oversight of health practitioners' contribution to the SEND reforms is limited. The clinical commissioning group is committed to recruiting to the post."*

There were also significant issues with service users not being made aware of the local offer, as well as CYP and families reporting feeling poorly supported and struggling to access the services they needed:

> *"Not enough parents and carers are aware of the local offer and other services such as the local independent information, advice and support service and Greenwich Parent Voice. A number of parents say that they do not know what support is available to them. Some parents think that the location of some services prevents them from accessing assessments or support because they live too far away from where this is provided. Some parents who speak English as an additional language say that there is little support or information for them to access in their first or second language."*

> *"Some children and young people are poorly prepared by health services for adult life. Practice is not underpinned by a locally shared vision and policy, and, as a result, preparation does not consistently start early enough."*

3.3. ASC Adults in Greenwich

While there is some data on the prevalence of autism in adults at a national level, the pool of research remains small. The National Autistic Society estimates that about 1 in 100 people are on the autism spectrum in the UK. We have not been able to locate any data on the number of adults in Greenwich with a confirmed ASC diagnosis.

3.4. Greenwich specialist services

The Royal Borough of Greenwich has a statutory responsibility for SEND services as laid out in the Education act 2011, Children and Families Act 2014 and the Childcare Act 2006 and 2016. It works in partnership with the CCG and local schools to provide a range of support services including but not limited to:

- Early years inclusion team
- Speech and language therapy (SALT)
- Occupational therapy

- Community equipment service
- Greenwich Child and Adolescent Mental Health Service (CAMHS)
- Continence service
- ASD Outreach Service
- Sensory service
- SEN assessment and review service, which manages individual educational health care plans (EHCPs)[6]
- Short breaks.

Services for CYP in Greenwich are accessed either through primary care services, or via SENCOs at the child's school. School SENCOs are also responsible for providing support to the child or young person in school while they are in the process of being referred for a diagnostic assessment.

The SEND Information and Advice Support Service (SENDIASS), which assists young people, parents and carers in navigating the services, has seen a rapid increase in referrals, reflecting the increasing pressure on SEND services in the borough. Between 1 April 2016 and 31 March 2017, there were 243 referrals to SENDIASS, an increase of 30% over the previous year's total of 186.

The Oxleas adult assessment service offers ASD assessments to adults over 18, without a learning disability, who are registered with a GP in Bromley, Bexley and Greenwich. The service offers ASD diagnostic assessments to adults who have not previously been assessed or received a diagnosis in childhood. It is accessed via GP referral, or by referral from other specialist services. However, after completing the diagnosis process, Oxleas is not commissioned to provide ongoing support to adults with ASD.

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[6] Royal Borough of Greenwich children's services business plan 2018-2020
https://www.royalgreenwich.gov.uk/info/200222/policies_and_plans/756/childrens_services_plans/2

3.5. Initial research

Healthwatch Greenwich received multiple feedback from service users dissatisfied with their experience in accessing specialist ASC services before, during and after diagnosis. We explored, with autistic people and their families, how well the processes of assessment for autistic spectrum disorders is working, how effective receiving a diagnosis is in accessing health and social care services and SEND support, and the impact that waiting list delays have on individuals and their family’s ability to access support.

3.6. Expanded scope

After completing our initial research, we found that many of the issues present in the services for CYP are also experienced, in many cases to a far greater extent, by individuals accessing adult ASC services. As a result, we extended the scope of our research to include the experiences of adult ASC service users. In conjunction with ASC residents and their families, we looked at the structure of SEND services in greater detail to understand where they worked well and where improvements could be made.

4. Findings

4.1. Survey results

We invited autistic people and their parents and carers who had contact with specialist services to complete our online survey. We had a total of 65 responses: 79% were parents or carers of autistic CYP; 13% were autistic adults (18 or over); 7% were parents or carers of autistic adults. Most CYP were reported as being in mainstream education with some being home educated or in SEN specialist schools.

When asked to rate their satisfaction with the SEND services in Greenwich, two thirds of residents told us they were unhappy with the service received (28% “very dissatisfied”, 38% “dissatisfied”) and a third had either no opinion or were happy with the service received (20% “neutral”, 6% “satisfied”, 8% “very satisfied”).

4.2. Themes identified

Residents told us about a range of issues with specialist services across the health, social and education sectors. We have grouped these into six themes:

- Lack of support before diagnosis
- Waiting times to access services
- Inconsistent service experience
- Poor communication between services
- Lack of understanding of ASC
- Lack of services for ASC adults.

4.3. Lack of support before diagnosis

Residents told us that few services are available before receiving a confirmed ASC diagnosis. Long delays in the diagnostic pathway makes this especially frustrating for many families. Parents describe asking for help, being refused, and being left to cope without any support while waiting for an assessment. One parent told us how her child found school a difficult and unhappy place and struggled with attendance, but as there was no official diagnosis her son was labelled as truanting.

> *"Can't get a diagnosis and can't get services without a diagnosis. School attendance is poor due to illness, which is normal for ASD, but because diagnosis isn't in place yet, school attendance officer is now involved."*
>
> Focus group participant

Without support, and prior to diagnosis, parents and CYP feel isolated and lost. Many report a downward spiral in their child's behaviour and a negative impact on family life. One parent described how even though her son was under the care of the Evelina London Children's Hospital, as a result of difficulties relating to ASC, the hospital was unable to offer referrals to specialist services due to his lack of 'official' diagnosis.

> *"[My son is] under Evalina who feel he is autistic, but they can't give support or refer him until he gets a diagnosis."*

4.4. Waiting Times

A common issue, identified by both service users and earlier in the 2017 Ofsted/CQC report, is the long delays between referral, assessment and diagnosis. Our survey shows that despite most parents and carers noticing potential signs of ASC in their children at an early stage (67% between ages 0-4 and 15% between 4-6) 33% waited for 1-2 years for a diagnosis and 26% waited for over 2 years. Individuals accessing adult assessment and diagnostic services via Oxleas often face an even longer wait – 20% waited 1-2 years to get a diagnosis and 40% over 2 years.

Parents in our focus groups describe feeling frustrated by the delays and unsupported during the waits. Well aware of the importance of the first 5 years of a child's life in terms of development, they were frustrated at how delays in diagnosis blocked access to the early years intervention service, leaving their child significantly behind their peers.

> *"The lack of access to ASD support and long waiting lists led to massive stress for our family; it has impacted on our marriage and our other children as he takes all our time and attention. My son's behaviour and condition has also dramatically deteriorated which means we now have a lot of work just to get him back to*

where he was at the beginning of the process. His sleep has also deteriorated so we are coping with everything with no sleep and waiting again for a referral for a sleep clinic."

Survey respondent

Parents who identified their children as needing an ASC assessment slightly later (4 to 6 years old) told us that long delays of a year or more in the diagnostic process often meant their children received no support during the transition between primary and secondary school, leading to a drop-off in their academic progress and increasing difficulties in their social and home lives. Parents expressed frustration with the referral process. Many parents feel that their GP or SENCO either made the wrong referral or was reluctant to refer the child at all, preferring to adopt a "wait and see" approach, despite the parent's conviction that their child was struggling and in need of support. This often led to further weeks or months of delay in an already very slow process. Parents also cited lack of accurate information as a factor in delayed referrals. Parents told us they would often learn things near the end of the diagnostic pathway that would have been vital for them to know at the start, but that they weren't given this information at first contact.

"It's been 7 years since my boy was diagnosed but school refused to accept it. Had TAC meeting … to push for EHCP – the school and social services 'put it to a vote' and it was only afterwards I found out that it [the EHCP] was a right and that it shouldn't have been a vote."

Focus group participant

4.5. Inconsistency of service experiences

Once accessed, many service users were positive about their experience of specialist services.

"Some schools very good – Thomas Tallis had a huge SEND department which was excellent."

When individuals and families access services quickly and consistently, most report their experiences to be very positive.

"I found OTs [occupational therapists] very helpful."

"Went for Signet course which was very helpful."

Focus group participants

However, parents told us their experience varied across services in the borough. Many attributed this to a combination of factors including high staff turnover, lack of capacity or funds for services, and a low understanding of ASC among individual staff members. Lack of understanding is extremely important to service users. Many told us the difference a single member of staff had on their experience.

Parents spoke of a lack of follow up in some services; for example, being promised an assessment which never materialised. Others described situations of inappropriate discharge from specialist services, forcing parents to bring their case to the tribunal to continue accessing the services.

"I have been at tribunals where the parents have been legally aided, so they can get funding for reports... been in a situation where SALT says to discharge [the child], but the independent report has list of recommendations... [SALT] asked by judge what they disagree with and can't answer it."
"The independents are not constrained by budget and resource constraints... can pursue [their case] through the courts, but it takes a long time and can cost a fortune."

FLAG support service

Many parents told us that despite receiving an EHCP, schools did not implement it. We were told that some parents and (some) schools did not understand EHCPs and how they work. Some parents, and educators, think recommendations in the EHCP are optional, rather than statutory adjustments for a child that a school must implement.

"It was not always possible to get an EHCP for my child. When they got one, it was not always helpful because teachers at school didn't follow it ... local authority would not give my child a place at a special education school ... school ignored recommendations for implementing support in EHCP."

Mother at local support group

Other parents told us their experience of the assessment process was positive and were promised "the moon and stars" in support and interventions. However, not all services made good on their promises, leaving parents frustrated and dispirited.

Many service users and families described their frustration with a lack of accountability for school SENCOs. Although part of the local SEND services, SENCOs are monitored by school management systems and each school has oversight for school-based services. Parents told us they felt this weakened governance and the ability of SEND services to properly assess the quality of SENCO support. Many parents told us the lack of independent complaint system (i.e. outside of school management) made them reluctant to raise concerns about SENCO support; they did not trust or believe issues would be properly investigated and resolved.

"…you have to constantly fight to get any help for your child… SENCOs vary and they have no one apart from the headteacher monitoring them so if they don't see a problem with your child then you will not get very far even if you have 10 professionals out of school saying there are so many complex problems that [the child] needs help with." –

Survey respondent

"Lack of accountability and no oversight of schools."
"They're supposed to be under the SENCO, but no one monitors the SENCO."

Focus group participants

Overall, parents told us inconsistency in how the services functioned across the borough led to a "postcode lottery", meaning that, depending on where they lived, some did and some did not receive the services they needed.

"ASD Outreach is in some schools not others – postcode lottery – meaning some kids get Lego therapy [and access to other services] without a diagnosis."

Mother of ASC child, focus group participant

4.6. Lack of communication between services

Due to complex needs, many autistic people access multiple services involving health and social care. Parents told us communication and information sharing among specialist services, GPs, social services and schools was poor. Many told us stories of referrals getting lost or delayed between services and that appointments are often cancelled or rearranged, with little warning.

When appointments do go ahead as planned, relevant notes and information are not always available, and service users and their families must repeat themselves, multiple times, to different professionals and services. One mother recounted how CAMHS refused to accept a referral for her son because they were mistakenly informed, by another service, that he was receiving therapy at school, when this was not the case.

> *"CAMHS didn't want to do the therapy because the school was supposed to be doing it, but they didn't."*

Similarly, she described how her son was also discharged from the speech and language therapist (SALT) for the same reason.

> *"SALT discharged and took him off the EHCP because he's receiving services from school, even though he isn't."*

Lack of communication between school SENCOs and specialist services was a common theme. Parents and service providers agreed on the importance of having the right support for children and young people in school, and specialist ASC services are made available through schools in the borough. However, families report that a lack of effective communication and information sharing between schools and outside providers creates disjointed services where some children and families fall between the gaps and fail to receive support from either.

Families shared many examples of poor communication leading to concerns not being satisfactorily addressed. A parent at the focus group recounted her frustration and anger at her child's school over its repeated delays in reporting his diagnosis to the ASD Outreach Service,[7] and at their poor handling of her complaint to the SENCO. On contacting the outreach service herself, she found the school had not passed the complaint on.

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[7] Greenwich services directory http://familiesinformation.royalgreenwich.gov.uk/kb5/greenwich/fsd/service.page?id=M6SjWQu2ybw

"Post-diagnosis I was told [by the primary school] that ASD Outreach would be coming in and that I would have to wait... I was then told by ASD Outreach that they hadn't been contacted at all and that the school hadn't done it."

Focus group participant

Inconsistency and (late notice) rescheduling of appointments is a source of significant stress for service users and their families. Consistency is of prime importance in the lives of autistic people and last-minute switches and cancellation of appointments causes a great deal of disruption and anxiety.

4.7. Lack of acceptance/understanding of ASC across all services

A frequent lack of understanding and acceptance about ASC in schools, surgeries, specialist services and social services is a source of stress and frustration for autistic people and their families. Many parents and service users told us that old and outdated stereotypes about autism are still used by educators, social workers, GPs, psychiatric professionals and even SEND coordinators. Participants in the focus group and surveys told us how professionals would "go over their head" when making decisions about a person's care or support, not giving adequate opportunity to discuss options and decisions with the service user or their family. As a result, inappropriate or insufficient services are given, and the relationship between service users and service providers is damaged.

"So much money wasted in meetings with me, but they had never spoken to my child!"

Focus group participant

Parents of girls with "high functioning" autism told us of their experience of misdiagnosis by service professionals and (in some cases) refusing access to SEND services. We know this is a national as well as a local issue with atypical presentation for girls.[8] Parents of autistic girls told us the huge impact a lack of diagnosis and access to services had on their daughters and the family. A decline in mental, physical and emotional health has negative effects on education and personal life, leaving a legacy that cannot always be undone.

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[8] https://senmagazine.co.uk/articles/articles/senarticles/is-autism-different-for-girls

For CYP, school staff (from SENCOs to headteachers) are central in accessing support. Most children and families access SEND services through school SENCOs. Many parents told us that schools were often inflexible and not all teachers were prepared to make reasonable adjustments for autistic children, even for children with an EHCP.

“It starts with the school, [parents] shouldn't have to fight for everything. They [teachers] should have the appropriate knowledge/training. There need to be trained ASC specialist teachers in schools. SENCOs should be regulated and have specific qualifications.”

Focus group parent

Parents who educate their child at home have little access to support. Parents told us that schools “didn’t want to know” if a child left the school to be home educated and any support they were receiving was abruptly cut off.

“Home-schooled children and their parents … struggle to access services or support because their children are not in full time education [they are] denied access because their children are not in school.”

Parent at local autistic support group

Parents told us that accessing respite and short breaks services is a struggle. Parents are told they don’t meet the threshold for assistance, despite finding day-to-day life a significant struggle. Focus group participants told us that because they gave the appearance of being able to cope, most services assumed that they could and refused to help until a crisis was reached.

“I have to live in a fortress … CAMHS knew what was going on … there was no network support and I’m single parent with 4 kids. I asked multiple times for a social worker but never got one because [I] didn't meet the threshold.”

“Don't get keyworker because [they said I was] 'coping'”

Focus group participants

Parents told us that ASC training and awareness for professionals and parents/carers is essential for understanding the needs of ASC CYP to make a positive impact on a young person's life, and support families and carers. Many parents were disappointed at how little training was available for themselves and professionals or that it was not always given priority by professionals.

"Training is essential. Was told by social services she [social worker] had to do it … [then] said they didn't have time to do the training."

"Teachers aren't trained and don't know enough about ASD."

"Training is there and is essential, but can be hard to find."

Focus group participants

5.8. Lack of transition and adult ASC services

There is a critical lack of adult services in the borough, and young people have little transition to adult health and social services and feel ill prepared for adult life. Transition between child and adult services is a known issue among service providers, but it remains a critical issue for autistic young people as many have complex needs requiring support from multiple services.

Parents of young adults told us they were worried about their child's future. These young people struggle to live independently, and the local authority seemed, to them, to be unable or unwilling to help them.

"I have had no support for my daughter who was diagnosed aged 27."

"Once the children become adults, they do not get much support."

Survey respondents

ASC adults and their families told us they waited up to or over 2 years to get a diagnosis, only to be told there were no services available for them. Many reported feeling alone, isolated and vulnerable. They felt the services simply washed their hands of them since there was nothing on offer.

"My child is now an adult – diagnosed at 25! The GP … offered medication (Ritalin), but because he refused, they signed him off – no other options?"

"Services drop off completely at 18."

"My brother 35, never leaves the house, puts on weight, has to phone the doctor to get his medications? How has he been allowed to cocoon himself in his house?"

"My husband is on the waiting list, the wait time is 48 months."

Focus group participants

Lack of services and support for ASC adults is a critical issue for the NHS, as noted in the NHS Long Term Plan.[9] ASC adults who live independently are often vulnerable; 70% or more live with one or more co-occurring mental or physical health condition, and lack of support can result in rapidly escalating complex health and social problems. These problems could be avoided if appropriate support and interventions are available.

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[9] https://www.longtermplan.nhs.uk/online-version/chapter-3-further-progress-on-care-quality-and-outcomes/a-strong-start-in-life-for-children-and-young-people/learning-disability-and-autism

5. Recommendations

Recommendation 1:

Increase pre- and post-diagnostic support and guidance for autistic CYP and adults.

Considering the extensive waiting period between referral and assessment, CYP and their families need greater access to advice and support during this time.

- Assessment and diagnostic service providers must ensure that information about how the diagnostic pathway works is clear and easily accessible to autistic people and their families.
- Assessment and diagnostic service providers must ensure that they have timely communications with service users throughout the referral and assessment pathway and reduce the need for “last-minute” changes, cancellations and changes in service continuity.
- Assessment and diagnostic service providers must work with third sector organisations and support groups (such as NAS Greenwich) to ensure they have accurate information about how diagnostic pathway and related support services work and can therefore give accurate advice and guidance to their members.

Recommendation 2:

Coordinate and share information and signposting resources across the borough.

Greenwich has already developed a website for the local offer, with the help and input of CYP and their families. However, awareness of its existence remains low among service users and providers in many parts of the borough.

- RGB must renew efforts into promoting awareness of the local offer throughout the borough, particularly with service providers and support organisations such as NAS Greenwich, Oxleas, and ASD Outreach.

Many voluntary sector organisations provide information, signposting and support, but statutory service providers are not aware of, or are unclear about what services voluntary sector organisations do and do not provide for ASC service users and their families.

- Statutory service providers must collate and communicate accurate and up-to-date information about voluntary sector services and organisations available in the borough to accurately signpost autistic people to the help and support they need.
- Statutory service providers must work with Healthwatch Greenwich to ensure they have accurate information about what services are available and can therefore appropriately give accurate information and signpost residents.

Recommendation 3:

Increase ASC awareness across all health, social and education services.

Awareness and up to date understanding ASC among professionals and support workers is a key contributor to service users' experience. Professionals who serve as first points of contact, such as SENCOs, GPs, health visitors and nurses, must have good understanding of ASC and referral pathways in SEND services. Staff and professionals working with ASC CYP should be aware of their duties and obligations as specified in the SEND code of practice. Professionals must actively listen to the experiences of ASC people and their families when engaging with them, and ensure they are properly involved and consulted in decisions regarding their care.

- Greenwich borough and SEND services must promote greater understanding and awareness of ASC, especially among frontline staff and teachers.
- Working with voluntary sector organisation such as Healthwatch Greenwich and NAS Greenwich, consideration should be given to including ASC awareness as a mandatory training for front-line staff in health, social and education services.

Recommendation 4:

Create and support services for ASC adults.

Beyond the assessment and diagnostic service provided by Oxleas, there are no specialist services for autistic adults in Greenwich. Voluntary organisations, such as NAS Greenwich, offer informal support groups but the offer is limited by a lack of resources.

- Working with the voluntary sector, Greenwich borough and Greenwich CCG must prioritise the commissioning and development of specialist support services, such as counselling, for ASC adults and their families.

Recommendation 5:

Improve information sharing between services.

SEND services should work together with primary and secondary healthcare and social services to form a more cohesive system of information sharing, enabling services users to move between services smoothly without information being lost or needlessly repeated.

- SEND services must improve information sharing policies and work with Greenwich borough and Greenwich CCG to ensure that information is being effectively shared between GPs, specialists, and schools where necessary.

Recommendation 6:

Improve support for ECHP plans and support for home-schooled children.

- Greenwich borough must demonstrate that schools are fully aware of their statutory duties towards families, are fully implementing ECHP plans, and are providing parents with accurate information.
- Greenwich borough must ensure that structures are in place to support ASC home-schooled children and are operating effectively.
- SEND services must demonstrate that school SENCOs are appropriately trained for their role and have a good understanding of ASC and its presentation; in particular, the different ways it can present in girls.

  Greenwich borough must demonstrate oversight of SENCOs outside of individual schools, so that parents feel able to come forward with concerns with confidence that they will be resolved fairly and impartially.

All recommendations to be followed-up: April 2020

6. Provider response

Commissioners, service providers and key stakeholders are given the opportunity to review our reports prior to publication, to check for factual accuracy and to provide a response if required.

Comments received from RBG Public Health.

- On page 19 the report states: '*Many service users and families described their frustration with a lack of accountability for school SENCOs. Although part of the local SEND services, SENCOs are monitored by school management systems and each school has oversight for school-based services. Parents told us they felt this weakened governance and the ability of SEND services to properly assess the quality of SENCO support. Many parents told us the lack of independent complaint system (i.e. outside of school management) made them reluctant to raise concerns about SENCO support; they did not trust or believe issues would be properly investigated and resolved.*' This concludes with Recommendation 6 stating that the Borough has '*oversight of SENCOs outside of individual schools*'. It is not within our authority to govern SENCOs. We would suggest recommending that the SENCO networks be used to further develop the skills of SENCOs and provide professional challenge and support.

- Some data can be refreshed. The presentation ***(Autism Workshop: Voluntary Sector RBG Children's Services11th December 2019)*** provides up-to-date stats about ASD, schools and support services. Contact Roz Weeks Roz.Weeks@royalgreenwich.gov.uk for a copy of the presentation.

7. Methodology

Our aim is to gather people's experiences with various services and service providers using interviews, focus groups and small surveys, rather than conducting large scale quantitative research. We have found this method to be the most effective and efficient method of capturing insight and engaging with communities and service users.

Key questions

Our investigation used themes and questions based on initial feedback received from ASC service users:

- How satisfied are children and young people, as well as their parents/carers, with the process of ASD diagnosis in Greenwich?
- Do children and young people and their families feel able to access support – emotionally, educationally and practically – both before and after diagnosis?
- If not, what, in their opinion, are the greatest barriers to access?

7.1. Online survey

We designed and published an online survey. We promoted this across social media platforms including Twitter and Facebook, and email to local support groups and organisations for autistic people and their families. The survey ran for 2 months from October 2018 to December 2018 and for another 2 months from April 2019 to June 2019 and received **65 responses.**

Most of those completing our online questionnaire were women with just under half aged 25 – 44 and a further half aged 45 – 64. Over two thirds of respondents to our online questionnaire were white with two fifths identifying themselves as from a BAME group or preferring not to say. Nearly a third had a disability and four fifths identified as a carer.

7.2. Focus Groups

Four focus groups were carried out.

Two focus groups were aimed at parents and carers of autistic people. There were two 90 minute sessions over the course of half a day, attended by 10 people, all parents or carers of autistic children or young people. Nine participants were female and one male. Eight participants were white British and two were from BAME communities.

A third focus group took place with school SENCOs and other school support staff. A total of six individuals attended.

A fourth focus group took place at James Wolfe Primary School (a SEN specialist school); five individuals attended. All were parents of autistic children attending the school.

7.3. One to one interviews

Three one to one interviews took place via phone and email with adult service users and parents of autistic children to build a more detailed picture of how services impact the lives of autistic individuals both as children and adults.

7.4. Strengths and weaknesses

Our qualitative approach has allowed us to gain a very detailed picture of how CYP, their relatives and carers are affective by their experience and interaction with specialist services. We have formed a clear picture of their journey through services and where things worked well and where there are opportunities for improvement.

However, our qualitative approach means that we have focused on a small number of service users and cannot represent a wider perspective. We are aware that the views and experiences represented in our report does not reflect the experiences of all service user in the borough. However, the challenges and difficulties raised by those we spoke to are an important reflection of user experience and the effectiveness of specialist services. Moreover, it is likely that other service users have encountered the same or similar problems. If many of the people we spoke to experience a similar problem, it points to a strong likelihood of a significant problem within the service.

7.5. Similar studies

With ASC rapidly coming to the forefront of the NHS priority list, it is perhaps unsurprising that other Healthwatch organisations have undertaken similar investigations of their local ASC and SEND services. Two examples are the joint report by Healthwatch Lancashire and Healthwatch Blackpool on the experiences of their learning disability communities with local health and social services; and Healthwatch Norfolk's report on CYP and families' experiences of the diagnostic pathway for ASC and accessing local SEND services.

Similar findings to those of Healthwatch Greenwich were also described in the ASC reports of Healthwatch Norfolk and Healthwatch Blackpool and Lancashire. Both noted how a lack of understanding and awareness of ASC among professionals and care workers had a direct and detrimental effect on the quality of care and support for local ASC children and adults.

Healthwatch Norfolk described how local families of ASC CYP also experienced long wait times for assessment and diagnosis, frequent poor communication between the different services, and an overall perceived lack of support for ASC people and their families/carers from the local authority, health and education services.

These similarities between our findings and those of other local Healthwatch organisations point to a wider systemic issue with ASC services at a national level. Across the board, a lack of investment in ASC services, results in understaffing and underfunding.

8. Appendices

8.1. Appendix 1 – Data Collection Tools

ASC Survey Questions

For parents/guardians

Which school did/does your child attend?

When did you first notice your child might have autism or other special educational needs?

Who was the first person you spoke to (or spoke to you)?

Did they provide you with help, advice or support you needed at the time?

Did your child have an assessment or go through a diagnostic process?

How long did you have to wait for the assessment/diagnosis?

If you had a long wait for an assessment or diagnosis, did you receive any support or access any services whilst you were waiting? What was it like?

What else (if anything) could have been provided for you during this process?

If diagnosed, how old was your child at diagnosis?

How did you feel about the process?

Did you feel supported?

Did you receive the information you needed?

What happened after the diagnosis? For example, was there a follow up from health professionals? Were you signposted to other services?

Did you get a copy of the diagnosis/assessment?

Overall, how do you feel about the diagnostic/assessment process?

Do you have any other comments about the diagnostic/assessment process?

Did you receive a leaflet or information about the Royal Borough of Greenwich Autistic Spectrum Condition (ASC) Outreach Service?

Have you had any input from speech and language therapy (SALT) services?

Overall, how do you feel about the SALT service?

Were you offered any training about autism and ways to support your child?

Overall, how did you feel about the training?

What services are you/your child currently accessing (or have accessed previously)?

Overall, how would you rate the services you received or are currently accessing?

Do you attend or have you attended any autism support groups/clubs?

Please share your experiences of attending these groups.
Did your child receive an Education and Health Care Plan (EHCP)?
Is there anything you would like to tell us about the EHCP process?
Overall, how would you rate your satisfaction with the services for Children and Young People with autism in Greenwich?
Overall, is there anything that could have improved your experience?
Is there anything else you would like to tell us?
Gender
Age band
Ethnicity
Religion
Sexual orientation
Are you a carer?
Do you consider yourself to have any disability? If yes, how would you describe it?
If you are happy to speak to us about the information you have provided in this survey, please complete your details below. We will not share your information with anyone else.
Would you like to hear more information about the work of Healthwatch Greenwich (for example, via our ebulletin)?

For adults
Which school do/did you attend?
When did you first become aware you might have autism or other special educational needs?
Who was the first person you spoke to (or spoke to you)?
Did they provide you with help, advice or support you needed at the time?
Did you have an assessment or go through a diagnostic process?
How long did you have to wait for the assessment/diagnosis?
If you had a long wait for an assessment or diagnosis, did you receive any support or access any services whilst you were waiting? What was it like?
What else (if anything) could have been provided for you during this process?
If diagnosed, how old were you at diagnosis?
How old are you now?
How did you feel about the process?

Did you feel supported?

Did you receive the information you needed?

What happened after the diagnosis? For example, was there a follow up from health professionals? Were you signposted to other services?

Did you get a copy of the diagnosis/assessment?

Overall, how do you feel about the diagnostic/assessment process?

Do you have any other comments about the diagnostic/assessment process?

What services are you currently accessing (or have accessed previously)?

Overall, how would you rate the services you received or are currently accessing?

Do you attend or have you attended any autism support groups/clubs?

Please share your experiences of attending these groups.

Did you receive an Education and Health Care Plan (EHCP)?

Is there anything you would like to tell us about the EHCP process?

Overall, how would you rate your satisfaction with the services for Children and Young People with autism in Greenwich?

Overall, is there anything that could have improved your experience?

Is there anything else you would like to tell us?

Gender

Age band:

Ethnicity

Religion

Sexual orientation

Are you a carer?

Do you consider yourself to have any disability? If yes, how would you describe it?

If you are happy to speak to us about the information you have provided in this survey, please complete your details below. We will not share your information with anyone else.

Would you like to hear more information about the work of Healthwatch Greenwich (for example, via our ebulletin)?

Focus Group Guide

Questions for Parents/Carers

When did you first notice something/ think your child might be on the spectrum?

So what did you do? Who did you speak to first?

How long did/has the process taken from first contact to confirmation that your child is/isn't on the spectrum?

What happened next? What information/ support were you given? (if any?)

Did your child receive an EHCP (Education and Health Care Plan)? How did it affect your experience with accessing services/support (if at all?)

What part of the process was hardest? Which part was easiest?

Have you had a main point/person of contact?

Who do you talk to if you need help/advice?

What organisations have you had contact with?

Who do you think is responsible for ASD/ SEN services in Greenwich?

What would you change about your experience/ How could the services be improved for future parents/carers and children?

8.2. Glossary of terms

ASC (ASD): *Autistic spectrum condition (also known as autistic spectrum disorder), a lifelong developmental condition affecting a person's communication skills.*

Asperger's syndrome: *An outdated term that once described a high functioning form of autism. No longer used in clinical diagnosis, as all presentations of autism now come under the umbrella of ASC.*

CAHMS: *Child and Adolescent Mental Health Services, responsible for providing mental health services for children under 18 in all localities.*

CCG: *Clinical Commissioning Group, responsible for commissioning health services in particular localities.*

CQC: *Care Quality Commission, responsible for quality monitoring of all NHS service providers.*

CYP: *Children and young people. In terms of SEND services, this refers to any person between the ages of 0-25.*

DMO: *Designated medical officer. Responsible for overseeing health services which form a part of SEND.*

EHCP: *Education and health care plan. A legal document tailored to individuals with complex health, education and social care needs, detailing support and adjustments that services are legally required to provide for them.*

FLAG: *Families Living with Autism in Greenwich, a local support group for autistic children, young people and their families, which also provides assistance with EHCP assessments and cases going to tribunal.*

LA: *Local authority, referring to the council and other local governing bodies.*

NAS: *National Autistic Society, a British charity for autistic people. The purpose of the organisation is to improve the lives of autistic people in the UK.*

OFSTED: *Office for Standards in Education, Children's Services and Skills. Responsible for inspecting a range of educational institutions, including state schools and some independent schools.*

PDA: *Pathological demand avoidance, a condition which is part of the autism spectrum and is characterised by an overwhelming need to avoid or resist demands.*

SALT: *Speech and language therapy, a service that specialises in supporting children and adults with speech delays or difficulties.*

SEN: *Special educational needs, refers to a child or young person with difficulties requiring extra support in their educational institution.*

SENCO: *Special educational needs coordinator, a teacher who is responsible for special educational needs in school. Every school in the UK is obliged to employ a SENCO as they ensure all students with learning disabilities are equipped to obtain the right help and support they need at school.*

SEND: *Special educational needs or disability*

SENDIASS: *Special Educational Needs and Disabilities Information Advice and Support Service. A free, confidential and impartial service for parents and carers, children and young people (up to 25 years.)*

SPD: *Sensory processing disorder, a condition in which the brain has trouble receiving, interpreting and responding to information that comes in through the senses.*

9. Acknowledgements

9.1. Disclaimer

Our report is an account and summary of information shared with us by service users. It is not intended to be representative of the experience of all service users.

9.2. Acknowledgements

Healthwatch Greenwich would like to thank service users, service providers and our volunteers who have assisted us. We would like to give particular thanks to NAS Greenwich, James Wolfe Primary School, and RBG Public Health for their support and contribution to our report.

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If you require this report in an alternative format, please contact us at the address above.

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