

Engagement to improve services for autistic people in south east London

Engagement Assurance Committee

July 2026

Introduction

Autism is a lifelong neurodevelopmental condition that affects how people communicate and interact with the world. Autism is not a medical condition but some people need support to help them with certain things. This support is provided by a range of services across education, social care, health and the voluntary and community sector. In south east London it has been recognised that there is variation in support for autistic people, particularly adults who are autistic but do not have intellectual impairments or disabilities.

The Integrated Care Service (ICS) wanted to understand how the south east London autistic community experience the services they access and to learn where there are opportunities for improvement.

We set up a project page on our on-line engagement platform at [Help us to improve services for autistic people in south east London | Let's Talk Health and Care South East London](#) . A survey and a series of focus groups with autistic people and carers were designed to collect information and views about current services and understand about gaps. The following slides provide a summary of the findings from the survey, the focus groups and the recruitment of people with lived experience as members of the project steering group.

How were people involved?

We created alternative ways for people to share their experience and tell us what they thought:

- An **on-line survey** asking for the views and experiences of autistic people and carers of autistic people was published on the '[*Let's Talk Health and Care in South East London*](#)' page of the ICS engagement platform.
- We invited autistic people, and their carers, to attend **focus groups** to have a conversation looking at gaps in services for autistic people and how we might address these gaps to ensure autistic residents of southeast London get their needs met
- We also recruited two people with lived experience from the autistic community to sit on a **planning group** involving ICS staff and NHS providers looking at future service provision.



Summary of key findings (1)

Gaps in services for autistic individuals

Of those taking part in the on-line survey, 89% had accessed support services.

The most common service accessed by autistic individuals was ‘mental health services’ (78%).

However, when asked about gaps in services, the majority of respondents (75%) identified the gap they’d experienced most was “*services that support my mental health needs*”. This suggests that, although mental health services were being used, they were perhaps not considered by autistic people to be the most appropriate level of mental health support or, that it did not meet their requirements as a neurodivergent user.

Other key gaps autistic respondents said that they had experienced included:

- **Services that help me understand my autism (65%)**
- **Services that support my communication needs (56%).**

Summary of key findings (2)

Gaps in services for autistic individuals

Further gaps in services were highlighted.

- The need for better transition from children's services to adult services was identified by many autistic people and their carers

"Information about services and support, such as how to apply for social housing, how direct payments work, what can be accessed and what can't."

"There needs to be a better transition from child to adult services. Currently the services jump from one to another, to a person with autism this is very difficult."

- Another gap was in relation to information to enable people to find the right services and support:
- On average, approximately 40% of autistic respondents also highlighted a need for services aimed at developing skills for daily life; employment support and more support for families/carers.

Summary of key findings (3)

Gaps in services for carers of autistic individuals

- 66% of respondents who were parents or carers of autistic person had accessed services and support for autistic people in south east London. **62% had accessed education support services and 55% had accessed mental health services.**
- When asked about gaps in services, **75% of parents or carers of an autistic person said that the gap they'd experienced most was in services that support the person's mental health needs.**
- On average, **approximately 72% of parents or carers of autistic person also highlighted a need for services that help the person they support to develop the skills they need in their daily lives.**

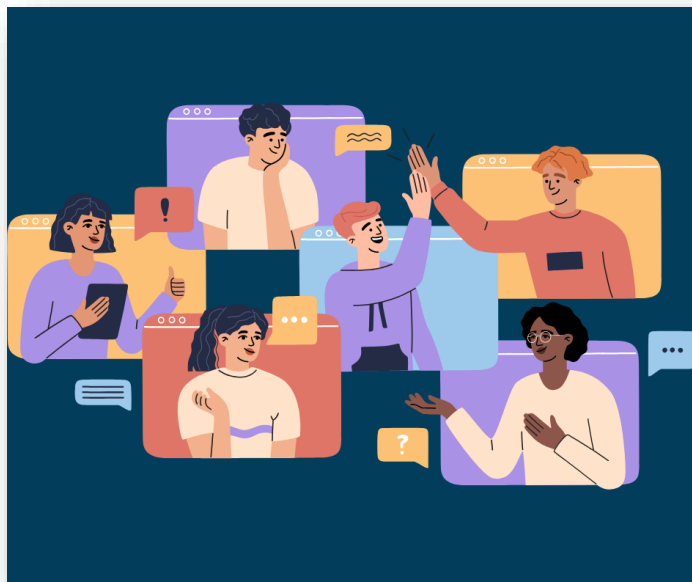


"I need somewhere for my son to go where he can learn to cook, use a washing machine, make a bed."

Summary of key findings (4)

Focus group

In addition to the survey, we held two focus groups – online and in-person - to have an open discussion with residents about what services for the autistic community should look like. Four key themes emerged from these discussions:



	Improving training and awareness for frontline health professionals
	Involving autistic people in improving services
	Improving communication and information sharing
	Better integration of services and agencies (including the voluntary sector) at a local level

Summary of key findings (5)

Key insights

- Both the survey and focus groups revealed the need for improved autism services in southeast London, particularly in relation to mental health.
- Other areas of improvement including:
 - long waiting times
 - lack of autism awareness among healthcare professionals
 - lack of effective inter-agency communication and planning
 - call for accessible, tailored services that involve autistic people in their design and delivery
- Gaps in service provision were identified across various areas, including physical health, mental health, communication support, and social/recreational activities.

The survey findings provide actionable insights for developing a comprehensive community autism team that addresses these gaps and improves the lives of autistic individuals and their families in southeast London.



Recommendations and actions (1)



1. Service Gaps:

The research highlighted a need for more neuro-affirmative, accessible and tailored **mental health support, access to specialised services** and a more **integrated 'offer'** that includes support for physical health, employment and social needs.

- **Action:** Invest in autism-specific training for mental health professionals, focusing on therapeutic approaches tailored to autistic needs.
- **Action:** Expand the availability of specialised services for autistic adults, including diagnostic services, physical health and communication support.
- **Action:** Develop a comprehensive community autism team that addresses these gaps by providing integrated support across all domains.

2. Need for autism-informed service design:

Autistic individuals value **accessible services** with flexible opening times, **tailored support** and **meaningful involvement of autistic people**.

- **Action:** Design services with accessibility in mind, including online appointment booking, clear communication materials, and sensory-friendly environments.
- **Action:** Implement person-centred approaches that prioritise individual needs and preferences, including reasonable adjustments and alternative communication methods.
- **Action:** Establish co-production initiatives that ensure autistic individuals have a voice in the design, delivery, and evaluation of services.

Recommendations and actions (2)

3. Addressing misconceptions and discrimination:

The survey and focus groups highlighted the danger of **gender and ethnic bias** (whereby older women and certain ethnic groups are particularly vulnerable to misdiagnosis) and the **lack of understanding and awareness of autism** in society.

- **Action:** Provide training on recognising autism in women and older adults, challenging stereotypes and addressing gender bias in diagnosis.
- **Action:** Promote a culture of respect and understanding within services, ensuring staff are trained to communicate effectively with autistic adults.

4. Prioritising key services:

Those taking part in the survey and focus groups supported the creation of a **community autism team** and were eager to promote the value of **peer support and social connection**.

- **Action:** Establish a multidisciplinary team with expertise in autism to provide holistic support and coordinate care across different services incorporating support for autistic parents/caregivers, life coaching, crisis intervention, and cultural competency training.
- **Action:** Facilitate peer support networks and social groups where autistic individuals can connect, share experiences, and reduce feelings of isolation.



Recruiting people with lived experience to the steering group

- We carried out an open and transparent recruitment process whereby people with lived experience of autism and their carers / family members were invited to express interest in becoming advisory members of a Task & Finish Group by filling in a short form. The group oversaw the design of the Community Autism Service.
- 2 positions were available.
- Task & Finish Group members with lived experience would be reimbursed for their time and contribution in line with ICB policy.
- The LD & Autism Programme received 8 expressions of interest from individuals with lived experience
- The two positions were filled following informal conversations / interviews with LD & Autism Programme team members.
- Applicants included parents, grand-parents and one caring for their parents.
- The majority identified as autistic.
- Almost half worked in roles supporting autistic people (in schools or in advice roles, for example).
- Several had previously contributed to planning groups such as those supporting local autism strategies.

The new community autism service

The engagement identified “the need for more neuro-affirmative, accessible and tailored health support” and “access to specialised services”.

Integrated care and support is more widely available for autistic individuals with a learning disability. There are very few support services within the NHS for adults who are autistic only and have complex or enduring needs related to their experience of autism.

Mental health services and support offers were often considered to be inappropriate or not designed with autism in mind.

The Community Autism Service is therefore designed to provide multidisciplinary, person-centred support and advocacy services to autistic adults who are not eligible for a learning disability service or community mental health services or other relevant care setting.

The Community Autism Service will provide a broad range of healthcare support, both physical and psychological, for adults registered with a GP within Southeast London

The Community Autism Service will deliver services for autistic adults identified as requiring specialist services directly associated with their autism. The service will be particularly mindful of supporting autistic adults who are from marginalised, seldom heard and, underrepresented communities including those known to be those experiencing health inequalities.

The new community autism service (1/4)

Community Autism Service (CAS) Core Functions

Assessment and Intervention: Comprehensive multidisciplinary need assessments across physical, mental, and psychosocial health for autistic adults.

Case Management: Person-centred care planning.

Health Facilitation: Supporting autistic adults to access health services in circumstances where they are unable to advocate for themselves or need care coordination.

Support in the community: Supporting individuals in their community, including the home. The Service is not restricted to conventional clinics or health settings.

Behavioural support: Functional analysis, formulation, and support plans to manage behaviours of concern.

Support to systems: CAS will offer support to the system around the referred individual to improve integrated working and multi-agency support.

Training and Education: Promoting awareness of neurodiversity in the wider community and developing effective capacity building for carers, families, and mainstream services.

The new community autism service (2/4)

Service aims

- Empower and enable autistic adults referred to the service to lead fulfilling and independent lives.
- Ensure that the voices and views of autistic adults, their carers and communities are heard and play a key role in coproducing/codesigning the service.
- Enable partnership working and coordination across multiple agencies and sectors to develop a consistent, collaborative, and integrated approach to supporting autistic adults in south east London affected by challenging circumstances relating to their autism.
- Enable access to preventive initiatives, including enabling individuals and their carers who have a critical role in developing and maintaining solutions to difficulties.
- Provide training to partners in the wider pathway of support to engage effectively with autistic adults, and to ensure their wider needs are met.
- Improve health outcomes and reduce health inequalities for eligible autistic adults,.
- Provide timely access to specialist assessment, intervention, and support.
- Support people to live as independently as possible in the community.

The new community autism service (3/4)

CAS – the Two ‘Pillars of Support’

Intervention

The service will develop packages of care and support for autistic adults presenting with multiple or persistent health and well-being needs/vulnerabilities. These needs/vulnerabilities will significantly impair their ability to live independently and safely. These include persistent or erratic non-attendance at appointments, failure to respond to verbal or written communication from services, etc. and may include individuals who present in police custody, youth offending services, social care, and/or mental health services.

Prevention

Autistic adults who have multiple risk factors (e.g. family breakdown, history of mental illness in the family, poverty and social exclusion, experience of crime, domestic violence or abuse, difficulties in environments such as education or care, or adverse childhood experiences) are at high risk of social exclusion and poor mental and physical ill-health.

The service aims to work with agencies associated with these issues or autistic individuals experiencing these issues to initiate support as early as possible to reduce the risk of problems becoming entrenched.

The new community autism service (4/4)

CAS will operate two teams, one covering SLaM Trust area and one covering Oxleas Trust area.

Staffing

Professionals including (but not limited to) the following roles:

- Psychologist
- Speech & Language Therapist
- Occupational Therapist
- Nurse Practitioner
- Support worker(s)/ Autism liaison worker
- Behaviour Analyst

Questions and answers

If you would like more information, please email us at:



ida.pмотeam@selondonics.nhs.uk

Or

ian.sutton@selondonics.nhs.uk