South East All-age Autism Strategy

2021 – 2026

> **To ensure autistic people of all ages living in the South East can live “happier, healthier, longer lives”**
>
> **(NHS Long Term Plan, 2019)**

NHS England and NHS Improvement

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Contents

South East All-age Autism Strategy.

Foreword

I am delighted to present the new South East All-age Autism Strategy for 2021-2026, which aims to ensure the needs of autistic people living in our region are acknowledged and met.

This strategy has been developed by the South East Learning Disability and Autism team at NHS England and Improvement in partnership with autistic people, their families and carers, and professionals. It is informed by questionnaires, surveys and engagement events where we asked people what has to change in order to ensure services work better for autistic people.

Since the Autism Act became law in 2009, and the national strategy ‘Think Autism’ was published in 2014, significant strides have been made in improving services and gaining greater awareness and understanding of the needs of autistic people.

However, there are still many gaps in the local provision of support for autistic people and their families, and it has become clear that these gaps have been further exacerbated by the COVID-19 pandemic. In the South East we have witnessed increasing rates of referrals and a rising demand for autism services, resulting in extensive waiting times for individuals and families who are seeking support. This is unfortunately leading to poorer health outcomes and poorer life expectancy.

It is our hope that the South East All-age Autism Strategy will set out the expectations on local health services across the region, ensuring both specialist and mainstream mental and physical health services more effectively meet the needs of autistic people and their families.

As the NHS Long Term Plan clearly states, we must “do more to ensure that all people with a learning disability, autism, or both can live happier, healthier, longer lives.”

Anne Eden

Anne Eden – South East Regional Director, NHS England and NHS Improvement

Audience

This strategy was designed and developed for commissioners, system leads, and people responsible for the planning and delivery of health services. While the content is health focussed, multi-agency involvement and collaboration is vital to improve outcomes for autistic people and their families.

We recognise that the language used within this document may not be accessible to everyone. We have attempted to write in plain English, and where this has not been possible, we have provided a glossary of terminology. The executive summary has been written in an easy read format to allow the strategy to be shared and read more widely.

Identity-First Language

This strategy uses Identity-First language (i.e. ‘autistic people’ rather than ‘people with autism’) as this was the preference of most adults we spoke to. This also aligns with research based on the response of over 3,000 people, led by the National Autistic Society[1]. We do, however, acknowledge that some people prefer the term ‘person with autism’ or ‘person on the autistic spectrum’ and that others identify themselves as having Asperger Syndrome.

Many terms are used to describe autistic people, and there are a range of opinions regarding the way autism is, and should be, described. In this document, the terms ‘autism’, ‘autistic people’ and 'on the autistic spectrum', have been used to describe the individuals that the strategy seeks to support. The term “experts by experience” is also used to refer to autistic people and their families. Throughout this document when we refer to ‘autistic people’ this describes both children and adults.

Although there is disagreement as to which terminology to use, we ask the reader to look beyond the language used and focus on the message of the strategy.

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[1] *Kenny L, Hattersley C, Molins B, Buckley C, Povey C, Pellicano E. Which terms should be used to describe autism? Perspectives from the UK autism community. Autism. 2016;20(4):442-462*

One of the autistic people we consulted wrote the following statement, which we felt was incredibly important to include:

> *“We acknowledge that individuals will have their own preferences for how they refer to their diagnosis and thus, themselves. We therefore encourage clinicians, families, and the autistic community to engage further in open conversations around the language they prefer to use. This can help to establish comfortable terminology and stronger identity in relation to their own autism.”*
>
> **Conor Eldred-Earl** - Autistic Expert by Experience and Advisor

Content warning

In this strategy there are descriptions of people’s lives and experiences, which some people may find distressing. This includes discussion of eating disorders, self-harm and suicide. If anything you read upsets you please reach out to people around you, your GP or mental health practitioner, or access free support through:

Call **116 123** to talk to Samaritans, or email: jo@samaritans.org for a reply within 24 hours

Text "SHOUT" to **85258** to contact the Shout Crisis Text Line, or text "YM" if you're under 19

Mind – call **0300 123 3393** or text **86463** (9am to 6pm on weekdays)

Definition and key terms

It is acknowledged that some of the terms used in this document may mean different things to different people. To support the reader there is an extensive glossary which can be found at appendix 3. However, some of the more commonly used phrases can be found below.

Autism - Throughout this document, the term autism refers to a lifelong neuro-developmental condition which affects how people communicate and interact with the world. One in 100 people are autistic and there are estimated to be 700,000 autistic adults and children in the UK[2]. It is also acknowledged that due to disparities in diagnosis, and historically missed groups, this rate is likely to be substantially higher.

BAME – Black, Asian, and Minority Ethnic - Used to refer to members of non-white communities in the UK. We recognise that there are disagreements present in regard to how communities are defined and described. Following the publication of the report of the Commission on Race and Ethnic Disparities[3]. There was a recommendation included which called for the term BAME to be discontinued, the report states that we should stop using aggregated and unhelpful terms such as ‘BAME’, to better focus on understanding disparities and outcomes for specific ethnic groups.

Thinktank, British Future, research found that most ethnic minority Britons slightly prefer “ethnic minority” as an umbrella term, with two-thirds (68%) saying they either support or accept the term and only 13% opposed. In our writing we will use both BAME and Ethnic minority in parenthesise to describe these groups, with the acknowledgement that there will never be a term which can adequately capture the complex differences, similarities of experience, cultures and histories of the United Kingdoms’ ethnic minorities.

Vision - This refers to the desired future state for the region. A vision is typically defined in order to provide focus, set direction, and unite stakeholders regarding a collective ambition.

Strategy - The long-term plan of the specific action that will be taken in order to realise the vision.

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[2] https://www.autism.org.uk/advice-and-guidance/what-is-autism.

[3] Summary of recommendations - GOV.UK (www.gov.uk)

Introduction and context

Autism is a national priority, and the South East region is aware that variance currently exists in the support available to people across its geography. This document is intended set out a vision, key priorities and “direction of travel” (way in which support develops or progresses) for autism services in the South East of England. Whilst this is a health led piece of work, and therefore has a health focus, input has also been provided by autistic people and their families, social care, care providers, third and voluntary sector organisations.

Why is a regional strategy required?

Autistic people are at significantly greater risk of experiencing health inequalities than the neuro-typical population. They are more likely to experience major illnesses, including poor mental health and/or other co-morbid physical health conditions, face shorter healthy life expectancy and die earlier[4]. Autistic people are less likely to access screening, checks or treatment, and face significant barriers to accessing the services, information, and reasonable adjustments they need.

Nationally, there is significant variance in the care, quality, and support available for autistic people. This is despite a continued national focus following the Autism Act (2009)[5], Think Autism (2014)[6], and subsequent best practice guidance which have been published. The NHS Long Term Plan 2019 also commits to “do more to ensure that all people with a learning disability, autism, or both can live happier, healthier, longer lives.” [7]

A study across England in 2019 revealed that two in three autistic adults felt they were not getting the support they need[8] and that only 8% of autistic adults and 5% of families

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[4] *Croen, L. A. et al. (2015). The health status of adults on the autism spectrum. Autism Int. J. Res. Pract., Vol 19, 814–823.*

[5] Autism Act (2009), UK GOV

[6] THINK AUTISM - Fulfilling and Rewarding Lives, the strategy for adults with autism in England:
an update. (2014) DOH
Department of Health

[7] NHS Long Term Plan, (2019). NHS England

[8] *https://www.autism.org.uk/what-we-do/campaign/not-enough/about-the-autism-act*

thought that health and care services in their area had improved since the Autism Act[9]. Considering the national and local attention on autism since 2009, this raised significant concerns as to the speed of change and the delivery of quality services.

This is mirrored at a regional level and, presently, there is variance across the South East region with regards to the existing support available to autistic people. There are also discrepancies in the plans and ambitions of local systems to better meet the needs of autistic people in their area.

More recently COVID-19 has highlighted that improvement is desperately needed. Even though autism is a national priority, autistic people are being disproportionally impacted due to a lack of service provision, poor access to mainstream services, and a general lack of understanding of how to make reasonable adjustments to existing services. This occurs alongside the suspension of schools/education and day opportunities which has seen increasing strain on parents and families. It is clear these sizeable challenges are only growing.

Why a strategy is required – lived experience perspectives

In addition to the points outlined above, qualitative feedback was sought from people with lived experience. They were asked what it currently feels like to access care and support in the South East region, in order to understand where change is required and why this strategy is necessary.

> *“Our best outcomes come from people being able to recognise the strengths that come with neurodiversity*

> *“The community housing options offered to me after I was in hospital were too far from my home to be helpful ”*

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[9] https://www.autism.org.uk/what-we-do/campaign/not-enough/about-the-autism-act

> “ *There isn’t enough good support to help people stay healthy in the community or for when people are in crisis*

> “ *Communication between Health and Social Care is poor – it feels like they don’t talk*

> “ *Please do not focus on increasing the amount of support being delivered rather than the quality of support provided*

> “ *It felt like doctors and nurses in hospital did not know how to care for my autism*

> “ *People should be supported to live well with their autism & fulfil their potential*

> “ *We have seen talented autistic people with history of inpatient admissions who have not achieved what they are capable of in terms of employment and academically*

Strategy objectives

The objectives of the South East All-age Autism Strategy are:

- To reduce health inequalities and improve health access and outcomes for autistic people;
- To provide guidance to local systems in the South East regarding direction of travel in order to improve the offering for all autistic people, their families and supporters;

- To provide clarity regarding the tools that are available to help increase care quality and provision;
- To support the promotion of best practice in diagnosis, care, and support, ensuring responsive, consistent, and accessible physical and mental health pathways across the region.

Scope of the strategy

Please note that the strategy does not articulate or define what local services or provision should or could look like in the future. Definition of local offerings should be based on the needs of their local population and differing geographical and provider landscapes, and will be the responsibility of local systems and leaders to develop in their area. This includes reviewing existing services and co-producing future offerings, with local people at the centre of decision-making process.

How the strategy was shaped

The strategy has been led and developed by the NHS England and NHS Improvement Learning Disability and Autism team in the South East. Input has been provided by a range of key stakeholders, including autistic people and their families, system leaders from within the South East region (including Health, Social Care and providers), colleagues from the NHS England and NHS Improvement national autism team and mental health programmes, Health Education England, third sector and voluntary organisations such as Autistica, the National Autistic Society, and parent/ carer forums.

Input was provided via a combination of interviews, workshops, surveys and feedback sessions. This insight was used to inform and shape the strategy, as well as to test emerging findings, themes and recommendations throughout the development process.

The South East region is grateful to all contributors and extends thanks to everyone that has taken part in developing the strategy, especially those autistic people and their families who answered our surveys and attended workshops.

Next steps

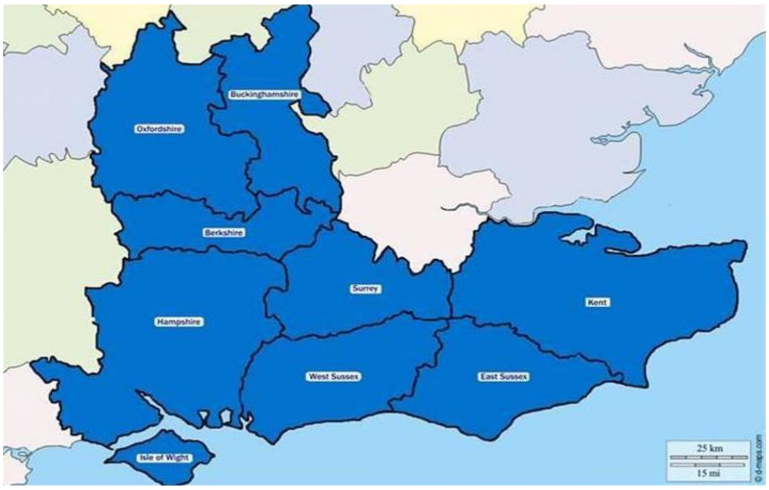
This strategy is intended as a central resource for systems to interpret and take forward, with changes made locally to refresh, update and revise delivery plans accordingly. Once the strategy has been shared, each system across the South East region will be asked to define their local autism ambition and delivery plan in response to this strategy, taking in to account current best practice and national guidance.

At the time of writing this strategy, a multi-agency autism strategy is being developed by the Department of Health and Social Care (DHSC), which sets the national direction of travel with regards to improving health and social care for autistic people and future funding. The region has chosen to define local priorities and needs in advance of this work (which is currently expected to be published in Spring 2021) in order to make progress more quickly on this key priority. The regional strategy is intended to complement the national strategy, and alignment of the two will be considered once the national document is published.

1. Scope and methodology

Scope

The strategy has been developed within the South East region with autism in mind and includes both children and adults. It will be delivered and monitored by the six Integrated Care Systems within the South East.



The scale of the group that this strategy seeks to impact is significant. It is estimated that as of 2020, there are a minimum of 71,389 autistic adults in the South East based on POPPI/PANSI[10] data. This population is expected to increase by approximately 10% between 2020 and 2035, ahead of the UK average population growth rate[11], reaching a total minimum of 78,973 adults by 2035. Given the current size and expected increase of this group, it is important that planning is undertaken to ensure the level of suitable provision required is made available. There are no official estimates as to the number of autistic children in the South East. However, population projections and prevalence estimates suggest that there is likely a minimum of 17,000 autistic children and young people, based on a prevalence range of 1%.More recent studies have suggested a prevalence rate amongst children in England of 1.76%[12], with male pupils showing a prevalence of 2.81% and female pupils, 0.65%. This is

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[10] *https://www.poppi.org.uk/ - summary table included in appendix.*

[11] *https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/nationalpopulationprojections/2018based*

[12] Roman-Urrestarazu A, van Kessel R, Allison C, Matthews FE, Brayne C, Baron-Cohen S. Association of Race/Ethnicity and Social Disadvantage With Autism Prevalence in 7 Million School Children in England. *JAMA Pediatr.* Published online March 29, 2021.

consistent with previous reporting although as discussed later prevalence difference between genders can point to historic barriers to assessment and diagnosis.

Methodology

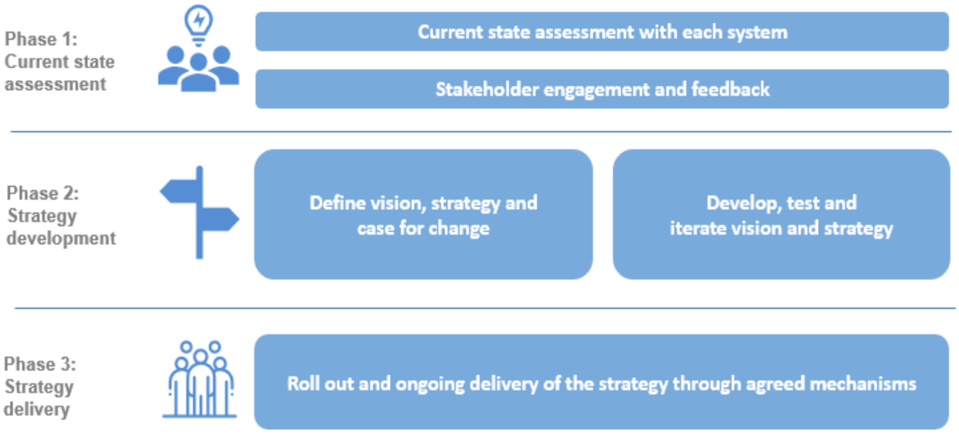
The strategy was developed over two key phases from July 2020 to March 2021. The methodology for the work is described below:

Phase 1: assess the current state – An ‘as-is’ review was undertaken of the level of provision, support, and strategic arrangements currently available for autistic people across each area within the South East region. The key objective for this phase was to understand the existing challenges and identify potential future opportunities for improvement to inform strategy development. This work was bolstered by a more detailed national autism community mapping exercise undertaken during January 2021.

Phase 2: develop the vision and strategy – A regional vision and aspiration was defined for the level of provision of care required to support autistic people, and a strategy to get there. The strategy was then developed and tested with autistic people, their families, and supporters as well as systems to make sure the findings and direction was appropriate and sufficiently ambitious.

The next phase, delivery, will commence once local systems have considered and confirmed how they will take the strategy forward and enable change for their population. The high-level approach undertaken to develop this work is shown below:

Table 1: Autism strategy development approach



2. Case for change

National picture

Nationally, a number of key challenges exist with regards to the care and support that autistic people receive. A full breakdown can be found within the appendix, however in summary these challenges include:

- An increasing number of autistic people in hospital, with a significant and rising number of young females. This maps to themes present across the UK, in that the total number of autistic people with no learning disability in hospital has remained flat or increased over the last five years[13].
- Increased prevalence of co-morbid eating disorders or disordered eating presentations amongst autistic children, young people and adults. Research suggesting that up to a third of women with eating disorders may be autistic, although these individuals often face misdiagnosis.[14] [15] Studies have also suggested that those who may have eating disorders or disordered eating may have more severe symptoms and show a poorer response to treatment as usual[16].
- Extended lengths of stay for autistic adults and children whilst in hospital, with an average adult length of stay in hospital of 35 months[17] and children 25 months.
- Significant wait times between autism referral and diagnosis for adults that range between 10 and 28 months and children between 10 and 30 months [18].
- A growing identified population of autistic people requiring support[19].
- Limited provision available to support people pre and/or post diagnosis.

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[13] *Assuring Transformation (AT) dataset – National inpatient statistics - September 2020.*

[14] Mandy, W., & Tchanturia, K. (2015). Do women with eating disorders who have social and flexibility difficulties really have autism? A case series. Molecular Autism, 6(1), 6.

[15] Westwood, H., & Tchanturia, K. (2017). Autism spectrum disorder in anorexia nervosa: An updated literature review. Current Psychiatry Reports, 19(7), 41.

[16] Tchanturia, K., Adamson, J., Leppanen, J., & Westwood, H. (2019). Characteristics of autism spectrum disorder in anorexia nervosa: A naturalistic study in an inpatient treatment programme. Autism, 23(1), 123–130.

[17] Assuring Transformation (AT) dataset – National inpatient statistics - September 2020.

[18] NHSE South East Care room regional data submission – October 2020

[19] https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/nationalpopulationprojections/2018based

- Significantly higher than average rates of suicidality and suicidal ideation present within the autistic population for children, young people and adults[20]. with an increased risk of suicide[21], suicidal ideation or suicide attempts[22] [23].
- Autism prevalence within adult inpatient mental health settings is estimated at between 2.4-9.9%[24] while autistic people account for one in one hundred people.
- Chronic health problems are significantly more common in autistic adults than in the neuro-typical population, and that these continue into old age [25] [26].
- Within inpatient hospitals there is higher use of seclusion and segregation for both autistic people and those with learning disabilities, within a study 71% of people whose care was reviewed had been segregated or secluded for three months or longer. A few people met had been in hospital more than 25 years[27].

The region is aware that data regarding autistic people who are not in hospital or accessing acute services is inconsistent. The region recognises difficulties accessing primary and secondary services present within the non-inpatient population and there needs to be an increasing the level of understanding of this group, their support needs, and how to reduce their health inequalities. This inequality of access will be an important area of focus for the South East region going forward, which aligns with national work to pilot an autism annual health check and strengthen GP held registers regarding autism.

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[20] Cassidy, S., Bradley, L., Shaw, R. et al. (2018). Risk markers for suicidality in autistic adults. Molecular Autism 9, 42

[21] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), 232–238.

[22] Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M., & Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: A clinical cohort study. The Lancet Psychiatry, 1(2), 142–147.

[23] Cassidy, S., & Rodgers, J. (2017). Understanding and prevention of suicide in autism. The Lancet Psychiatry, 4(6), e11.

[24] Tromans S, Chester V, Kiani R, Alexander R, Brugha T. The Prevalence of Autism Spectrum Disorders in Adult Psychiatric Inpatients: A Systematic Review. Clin Pract Epidemiol Ment Health. 2018; 14:177-187. Published 2018 Aug 29.

[25] Bishop-Fitzpatrick, L., & Kind, A. J. (2017). A scoping review of health disparities in autism spectrum disorder. Journal of Autism and Developmental Disorders, 47(11), 3380–3391.

[26] Bishop-Fitzpatrick, L., & Rubenstein, E. (2019). The physical and mental health of middle aged and older adults on the autism spectrum and the impact of intellectual disability. Research in Autism Spectrum Disorders, 63, 34–41.

[27] CQC. (2020) Out of sight – Who cares? - A review of restraint, seclusion and segregation for autistic people, and people with a learning disability and/or mental health condition.

We are committed to the principles of equality, recognising that there may be additional barriers to accessing support and help for some autistic people and their families. This is why we are committed to identifying and addressing these barriers experienced by specific groups such as older people, people from BAME communities (Ethnic minorities), women, and those who identify as LGBTQ+.

Regional picture (and alignment to national picture)

Regionally, challenges observed across the South East are consistent with the national picture outlined above.

Since March 2015, the number of autistic people from the South East in hospital has increased by over 20%[28], with increases also seen in hospital admission numbers, lengths of stay and diagnostic wait times. Variance exists both between systems and within local geographies with regards to access and support options available to people.

Examples of best practice and nationally exceptional services exist, but there is inequity of provision depending on where people live.

The South East All-age Autism Strategy will seek to address these challenges, and section 6 of the strategy will outline the approach to tackling them.

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[28] *Assuring Transformation (AT) dataset – South East region inpatient statistics - September 2020.*

3. Strategic vision for autism

Why a vision is required

A vision is required in order to provide focus, set direction, and unite all stakeholders regarding a collective ambition. The vision will be used as a ‘north star’ (immovable guide leading to a purposeful destination) to test the strategy, in order to ensure that everything the region does contributes to the realisation of this vision.

If the vision is the overall aim or end point, the strategy is what will be done to get there.

Design principles

A number of principles were followed whilst producing this strategy. These included:

Coproduction – Integral to all future work is the principle of co-production, which is summarised by the author as “a relationship where professionals, commissioners of services, and people using services share the power to plan and deliver support together, recognising that both partners have vital and equal contributions to make in order to improve quality of life for people and communities.” NEF describes this as the “active involvement of citizens in many aspects of designing, commissioning, and delivering services” [29]. This means ensuring that the views of people with lived experience are not only at the core of the strategy, but form the backbone of delivery, monitoring and reviewing services[30].

Transparency – Information and reflections were shared in good faith to give an honest picture of how systems are currently meeting local need. This means informed decisions can be made around where improvement is needed.

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[29] Slay, J. & Stephens, L. (2013). Co-production in mental health: A literature review. London: new economics foundation

[30] *Arnstein, Sherry R (1969). "A Ladder of Citizen Participation," Journal of the American Planning, Vol. 35, No. 4, pp. 216-224.*

Home not hospital – It was recognised that a key priority was that people should be living in the community rather than hospital where safe and possible, even when this may be more resource intensive and require significant changes or challenge.

Continuous improvement – A commitment to ongoing improvement, with the South East All-age Autism Strategy as the first step in this long journey toward health equality for the autistic population.

Regional vision for autistic people

The region has defined below its core objective, measures of success, and key enablers for delivery. The vision is intended to be aspirational whilst also being measurable, allowing progress to be assessed going forward.

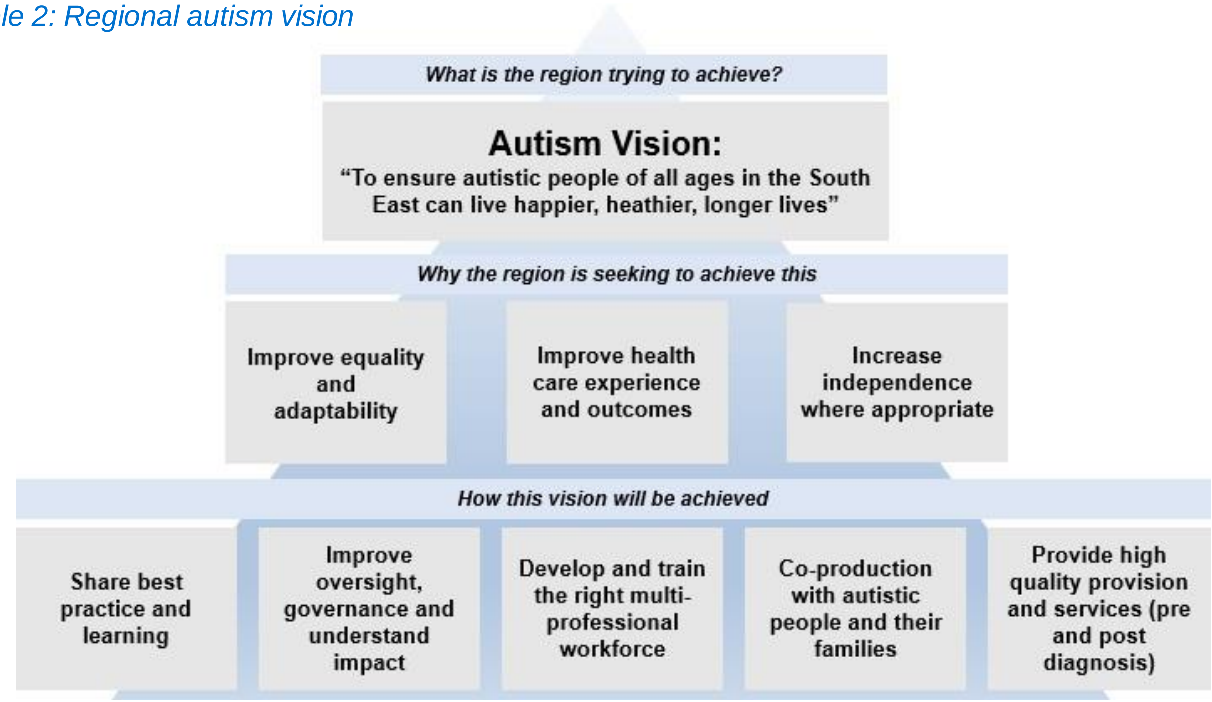
The following structure has been used to define the vision:

What? – What is the aspirational shared vision for autistic people in the South East?

Why? – Why is the region seeking to achieve this?

How? – How will the vision be achieved (and what are the core components?)

Table 2: Regional autism vision



Measurability / outcomes

There are several key performance indicators (KPIs) that demonstrate progress and upon which the success of this strategy will be measured going forward.

**To note, in some areas reliable data and benchmarks do not currently exist, so improvements will be measured once a baseline is established.*

KPIs for performance will be developed and driven through the All-age Autism Steering Group governance structure, in addition and in collaboration with current LDA Program governance arrangements. Example metrics to demonstrate progress might include:	Clinical measures; • Inpatient numbers • Number of autistic children in tier 4 out-of-area placements • Use of seclusion and restraint within inpatient hospitals • Length of stay • Diagnostic wait times • Gaps within service models, demonstrable through community mapping exercises • Satisfaction in both quality and accessibility of care received by Autistic people, their family and supporters *Non-clinical support measures* – these could include areas such as; • Access to education, employment, training, • Children and their family's access to Key-worker programme • Access and engagement with leisure and social activities • Formal and informal Quality of Life measures.

4. Key findings and themes

Current state assessment

In order to understand the current offering of care and support for autistic people in the South East, perspectives were gathered from people delivering and receiving care in the region.

A number of strategic and operational key lines of enquiry were explored following the initial feedback. Each of these was analysed through four lenses***;* capacity, capability, process, and ways of working*,*** with self-assessment ratings given by systems for each key line of enquiry. A summary of the key lines of enquiry and the self-assessment ratings given by each system are included in appendix 2.

Following this self-assessment process, a wide range of feedback was received from autistic people, their families, systems, and providers of health and social care services. We summarised this feedback in to ten key areas.

These ten key opportunity areas build on the challenges articulated by systems, and are intended to be forward focused, looking at the positive possibilities that can be harnessed for future improvement.

Testing the key opportunity areas

We tested the ten key opportunity areas using a 15-question survey. This listed each of the identified key opportunity areas and asked respondents if they agreed that this should be a priority for systems in the South East region. We received 423 responses from across the systems, with the highest number of responses coming from Hampshire, Sussex, Kent, and Berkshire.

For each of the key areas, a statement written in plain English was developed which matched the aims of the key area, this was done to increase accessibility and readership. We recognise that some of the respondents reported to find this patronising and apologies are made that this was felt by those respondents.

Demographic information

We also asked for demographic information to ensure we were hearing a variety of voices. Of the respondents who completed the survey, 20% identified as autistic adults, 56% identified as a family member/partner of an autistic person, 8% identified as a paid carer or advocate, 9% as a social worker or clinician and 7% identified as ‘other’. 48 individuals identified within multiple categories - this allowed for individuals who might have both a professional and personal relationship to autistic people and/ or autism. This could include autistic parents of autistic children, autistic clinicians and/ or social workers.

Within the gender breakdown of the survey responses we see a significant lean toward those identifying as female, with a total of 82% female, 14% male, 2% identifying as other, and 2% who preferred not to disclose.

10% of respondents identified as coming from a Black, Asian or minority ethnic background, 88% percent identified as not coming from a BAME (ethnic minority) background and 2% preferred not to disclose. This is reflective of the regional ethnic diversity data for the South East region of 90.6 % White British/ White other[31].

Identified themes

We also included the question ‘is there anything else you think local health and social care systems should focus on to improve services for autistic people? Or anything else you would like to add about you answers?’ to allow respondents to give more details to support their response.

Outside of the pre-written questions, multiple themes emerged detailing both good and poor practice. Many people spoke of long waits for services, finding it impossible to

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[31] Regional ethnic diversity - GOV.UK Ethnicity facts and figures (ethnicity-facts-figures.service.gov.uk)

navigate health systems, and being denied the services they needed when they needed them.

This should make the need for systemic change clear, with regards to how we plan and commission health services, how we deliver those services, and how we co-produce these changes with autistic people, their families and supporters.

Some of the people who responded felt this was merely a tick-box exercise. They felt they had been repeatedly canvassed for their views over the years and were unable to see change following them sharing their story, therefore they felt there was no point engaging in this survey.

We believe that this should be both a challenge to ourselves and our systems. This is an opportunity to demonstrate our capacity for self-reflection and make us more determined to make the changes autistic people need, taking our lead from, and working alongside, autistic people and their families.

Table 3: Key opportunity areas

Autism themes and opportunities

Increase sharing of good practice and learning

Share what works well through networks and a central store of good practice, successful pilots, and evidence base for systems to draw upon to benchmark or improve services

Improve data capture and analysis

Increase the quality and availability of data, supporting teams to make decisions based on robust information.

Focus on co-production

Embed principles such as participation and coproduction in all future work to amplify the voice of people with lived experience.

Increase offer for children and Young People

Develop further the support offer for Children, young people and those of transition age.

Refresh and redesign Service models

Redesign and transform what services look like based on the needs of local people.

Strengthen system governance and accountability

Strengthen accountability through robust and dedicated governance and frameworks at a system and regional level.

Improve community housing offers

Develop new housing models and to strengthen future planning and development at a regional and local level.

Increase volume and consistency of Autism training and awareness

Increase the training and support resources available to staff to help them better support Autistic people.

Workforce planning

Strengthen workforce planning and improve data around workforce capacity at a local and regional level.

Rebalance diagnostic and supporting provision

Strengthen and extend pre and post diagnostic support offers.

Priority 1

Increase sharing of good practice and learning

There is currently no systematic way for systems to draw on good practice or share learning within the region.

There is an opportunity to better share what works well through networks and a central store of good practice, successful pilots, a network of peers, and a central evidence base for systems to draw upon to benchmark or improve services.

96% of respondents reported that this should be a priority for the South East region

Priority 2

Focus on Co-production

Lived experience engagement is currently inconsistent meaning decisions are not always being made by the people they affect most.

There is an opportunity to embed the principle of coproduction in all future work making autistic people, their families and supporters central to all decisions.

Ensuring historically underserved groups' voices are targeted and elevated in this process.

> *I always feel that services are there for autistic people and non-autistic people are making those decisions. There are a lot of highly intelligent and capable autistic people who can contribute hugely to the decision-making processes so please include us rather than just make it about us*

Priority 3

Improve data capture and analysis

> *Collecting good, meaningful, data on the number of autistic people, with or without a LD, is paramount to planning services. For instance - there is no record of how many autistic adults are looking for housing and of what their needs are in our area*

Data quality and reporting around autism is variable and often limited across many areas.

There is an opportunity to increase the availability and quality of data, allowing local teams to make driven decisions based on robust information.

Priority 4

Refresh and redesign service models

Variation exists both between and within systems in the level of provision and services available to people.

There is an opportunity to redesign and transform what services look like based on the varying level of needs of local people, with a focus on the development of community services to support areas such as early intervention, admission avoidance, and a reduction in health inequalities.

> *Very frustrating listening to friends and family state that where they live, they get this support and that support. …. We seriously considered selling the house and just renting in more costly area just to get help for our son. Does that mean the NHS feel I am less important than the more well off people who live in these areas?*

Priority 5

Workforce planning

Difficulties exist in attracting and retaining skilled workforce in many localities.

There is an opportunity to strengthen workforce planning and improve data around workforce capacity at a local and regional level.

Use this planning process to make data driven decisions to improve the capacity and effectiveness of this workforce.

> *We need support workers who wont change all the time, you just get to know them and then they move*

96% of respondents felt this should be a priority

Priority 6

Increase volume and consistency of autism training and awareness

Autism awareness within provider organisations is mixed, with some good local offers but large gaps in training available.
There is an opportunity to increase the training and support resources available to staff to help them better support autistic people, with a focus on education, mainstream services (i.e., dentistry, GP, vision)
Ensuring experts by experience are involved in the planning, writing and delivery of training, and that autistic people are paid for their time and expertise at commensurate rates to their neurotypical colleagues.

> *Clear language used, and non-telephone options offered as standard, so many of us find telephones difficult. This is across all services not just autism specific ones, since autistics may well break arms, need knee replacements, etc just as the rest of the population, and so all services need to communicate in a clear manner, regardless of whether they know the patient is autistic*

Priority 7

Rebalance diagnostic and supporting provision

> *There is virtually no support offered whilst you sit on a 2-3 year waiting list, or in fact post-diagnosis, which I think is disgusting - we aren't seeking diagnosis for fun, for most autistic people diagnosed in adulthood it's because they are struggling massively…*

Resources at present are currently focussed primarily on diagnostic provision, with a limited pre- or post-diagnostic support offered in many areas.

There is an opportunity to improve the level of support available to people and their families and supporters before and after a diagnosis. This should occur alongside a continued focus on decreasing waiting times for diagnosis.

Priority 8

Strengthen system governance and accountability

System governance and accountability for delivery of improvements around autism often sits within wider organisational portfolios, meaning it can at times become a lower priority due to competing pressures.

There is an opportunity to strengthen accountability through robust and dedicated governance and agreed accountability frameworks at a system and regional level.

> *The points raised absolutely cover concerns and worries that we have for the long-term support of our son. It (autism) has desperately needed real attention in its own right, not bunched together with unrelated conditions* ”

Priority 9

Increase offer for Children and Young People

There is greater opportunity to support children and young people to live in the community and avoid harm and admission to hospital.

There is also the chance to develop further the support offer for children, young people and those of transition age, working closely with education.

All the support seems to be in school but if a young person has a late diagnosis so has had to mask for many years and then reaches burnout due to unmet needs and unable to attend school due to trauma there is very little support available

Early intervention services and support, family skill building, and supporting children and their families to navigate the care and education system

Priority 10

Improve local community housing offers

Community housing offers are currently of varying quality and availability, with support offers not always reflecting local need.

There is an opportunity to develop new accommodation models and strengthen future planning and development at a regional and local level.

> “*I spent 11 months waiting for funding to get to a place that was (supposedly) Autism specialist that was in a completely different county. It took 3 years (of being sectioned under mental health act) to get home*

**Quotes retrieved from responses to Question 15 of All-age Autism Strategy Survey which closed on 23/02/2020. Some of the quotes selected have been trimmed for length or edited to clearly state the subject. No quotes have been edited in a way to change their meaning or intention.*

- *If quotes have been edited this is made clear using parentheses ( )*
- *Where quotes have been trimmed this is made clear using ellipsis (…)*

5. Guidance and next steps

Regional actions and local guidance

Whilst this is a regional-level strategy which seeks to articulate what the South East region will do to support improvement, it is recognised that delivery will be largely at system ICS/CCG level. With this in mind, the strategy separates out what the NHS England and NHS Improvement South East Learning Disability and Autism team will do and what guidance it gives to systems to implement locally, with the information and next steps necessary in support of the vision for both. It is recognised that this will require multi-agency involvement and collaboration to deliver on the recommendations made and to improve health outcomes for autistic people and their families.

What the region will do

The South East region is committed to progressing a number of actions in order to achieve the autism vision. A summary of what the region will do has been split in to three categories, in line with the regional team operating model. These are laid out below:

Theme	Title	Description
Specialist support and advice	**Specialist advice**	Provide specialist clinical and operational guidance and support that systems can draw upon. Specialist regional roles will include: **Regional Learning Disability and Autism team roles:** • Strategic Housing lead. • Strategic Senior Case Manager – Adults and Autism • Regional Strategic Lead South East - Children and Young People **Regional Mental Health team roles:** • Equality Lead • Education lead • Employment Lead • Primary Care Lead • Learning Disability Lead • Mental Health Lead Additional operational expertise will also be provided to support developments in areas such as C(E)TR, Dynamic Support Register (creation and delivery) and discharge planning.
	Training and development	Training and development – support co-ordinated training offers to reduce the burden on systems to develop individual packages locally. This will include training on autism awareness and reasonable adjustments for staff both in inpatient units and in the community.
	Lived experience	Provide access to co-production models and methodology to support systems to effectively engage with their population. Providing support to access expert by experience groups who could support systems by providing input, support, and advice.

	Workforce planning	Facilitate workforce planning from across the region, targeting key staff groups and looking at what is required to support mainstream and specialist services. This will also include the facilitation of new roles and ways of working e.g. Peer support workers.
	Comms and engagement	Provision of central communication and campaign resource to pro-actively promote and deliver autism campaigns, share good practice, and support engagement with the autistic community.
Quality and improvement	**Strategy development**	Development of a regional autism strategy to set strategic direction.
	Share best practice and learning	Facilitate the sharing of national and regional best practice in a pro-active and structured manner, supporting systems to learn from work undertaken elsewhere.
	Share emerging practice	Support, test and share emerging practice and innovation being developed regionally, facilitating appropriate networks to support this.
	Funding	Prioritising the funding of autism-related transformation in future national/regional funding rounds.
Assurance and data	**Assurance and data**	Data and reporting tool to be provided and maintained through NHS England and NHS Improvement Care Room.
	Regional Benchmarking	Provide regional level data on autism to support local benchmarking, including a regional autism dashboard.
	Best practice data	Share and promote best practice methods for autism data collection, monitoring, and assurance.
	Governance improvement	Establish appropriate autism regional governance to support delivery of the strategy (e.g. autism steering group). This group will sit within the regional Learning Disability and Autism accountability structure, with reporting specifically to autism also taken to the regional Senior Leadership Team.

Guidance for systems

System guidance has been split in to two categories: strategic and operational considerations.

It is intended that the guidance included is supportive and should build upon actions already being taken forward in some areas. Whilst responsibility for delivery will sit locally, the region will work with local systems to support this through appropriate governance and information sharing.

Theme	Title	Description
Strategic considerations	**Strategy development**	All systems to develop local autism strategies that comply with evidence based best practice and national guidance where not already in place.
	Resource models	Systems to have in place appropriate team resource to support delivery of the autism agenda key long-term plan metrics.
	Operating model	Robust governance in place that places autism as a priority and has formal links and reporting within each respective Integrated Care System structure. Autism Partnership Boards to be in place and well embedded within the system.
	Leadership support	Ensure that there is clear leadership and accountability for autism, with designated named leadership for autism in all local systems.
	Training and development	Support staff to participate in autism related training and development. This will include Oliver McGowan mandatory training and any other core or advanced training once available. Ensure locally procured training is co-produced and co-delivered by autistic people.

	People from BAME (Ethnic minority) backgrounds and hard to reach groups	Increased focus upon health inequalities present within BAME (Ethnic minority), LGBTQ+, Gypsy, Roma and traveller communities, refugee, and other hard to reach or historically underserved / mis-served communities. Increased focus on the monitoring of protected characteristics and better understanding of the needs of these groups in terms of autism related care and support. There is an expectation for systems to demonstrate through a policy statement how they intend to reach out to, and monitor engagement with, underserved and hard to reach groups.
Operational considerations	**Quality guidelines and standards**	Ensure all commissioned services are benchmarked against NICE Quality Standards on autism diagnosis, treatment and care and all clinical best practice guidance for specific co-morbidities. Ensure all new provisions are developed to meet and exceed these standards.
	Community mapping	Undertake mapping of current level of community services and provision in line with national planning/reporting exercise (November 2020 – January 2021). Ensure this mapping continues to occur regularly to help continually identify gaps in service and respond to changing community need. Continuing to use this information for future service planning and delivery in collaboration with local autism partnership boards and parent/carer forums.
	Service development	Service redesign and development work to be undertaken in line with findings/recommendations following the national community mapping exercise (April 2021 onwards). Ensure that services develop in line with best practice – including assessment and diagnosis – and that a priority is placed upon pro-active and compassionate care, support and understanding.
	Admission avoidance and crisis	Strengthen ways of working and integration across hospital and community services to ensure effective admission avoidance. Improve access to mental health and learning disability services for people of all ages and provide greater support for the most vulnerable through strengthened crisis care pathways utilising all-age Dynamic Support Registers and Care (Education) and Treatment Review processes, with robust supporting governance in place. There is a continued and enduring focus on building capable environments and communities to ensure crisis care can be provided in the community safely.

	Data capture and analysis	Strengthen autism reporting and data capture, with reporting in place at a system and ICS level. Systems should be in place to ensure data is utilised to guide future decisions, there should be local sharing of this data to support benchmarking against best practice.
	Reasonable adjustments	Ongoing reasonable adjustment programmes in all provider organisations, including the inclusion of autism in reasonable adjustment 'flags' on Summary Care Records. Ensuring the understanding and monitoring of reasonable adjustments across mainstream and specialist services. Considering locally how these will be monitored and adapted as required, alongside experts by experience.
	Tactical considerations	To include areas such as: • Undertake reviews for all admissions and embed a mechanism to learn from these, involving experts by experience within this process; • Full roll out and embedding of the green light toolkit across all acute mental health settings; • Extension of LeDeR reviews for autistic people with no learning disability, in line with revised LeDeR policy; • Adoption of keyworkers for all children and young people at risk of admission or currently admitted to inpatient environments, as a priority, in line with LTP recommendations.
	Communication and information sharing	Improve the level of information available to autistic people and their families through better guidance and signposting, and greater support for self-help, self- management, and parent/carer groups locally.

6. Conclusion and next steps

Conclusion

In summary, a number of challenges and key themes have been identified through this work that require improvement. Development of the vision, key enablers and measures of success are an important step in fostering change, but it is the action that comes next which will make a difference to the lives of autistic people, their families and supporters.

Next steps

The South East region has created a framework for action, but there are number of delivery requirements on systems to achieve the vision and as such, a significant joint effort is required.

Delivery of the South East All-age Autism Strategy will commence in April 2021 and will be monitored by the Autism All-age Steering Group. This group will be formed of key stakeholders across health, education, social care, community, and voluntary sectors alongside autistic people and family representatives.

The group will be quickly developing a strategy implementation plan so that by June 2021 all key actions, including a response to gaps identified by the national community services mapping exercise, can be taken forward.

7. Appendix

Appendix contents

1. Evidence base – National and Regional
2. Current state assessments – (Region/ System)
3. Glossary

Appendix item 1: Evidence base – National and regional

Population

The South East region covers a total adult population of approximately 9,274,900 people. Based on POPPI/PANSI[32] data it is estimated that in 2020, 71,389 are predicted to be autistic. This population is expected to increase by approximately 10% between 2020 and 2035, ahead of the UK average population growth rate[33], reaching a total of 78,973 people in 2035. Given the size and expected increase of this group, it is important that planning is undertaken to ensure the level of suitable provision required is made available.

Age (adults)	Predicted group size – 2020	Predicted group size – 2035
18-64	54,366	55,403
65+	17,023	23,570
Total	**71,389**	**78,973**

There are no official estimates as to the number of autistic children in the South East. However, population projections and prevalence estimates suggest that there is likely 17,000 autistic children, based on a prevalence range of 1%.

Inpatient numbers – the national picture

Since the start of the Transforming Care programme in 2015, overall numbers of people with a learning disability in an hospital inpatient setting have gradually decreased. However, little progress has been made with reducing the amount of

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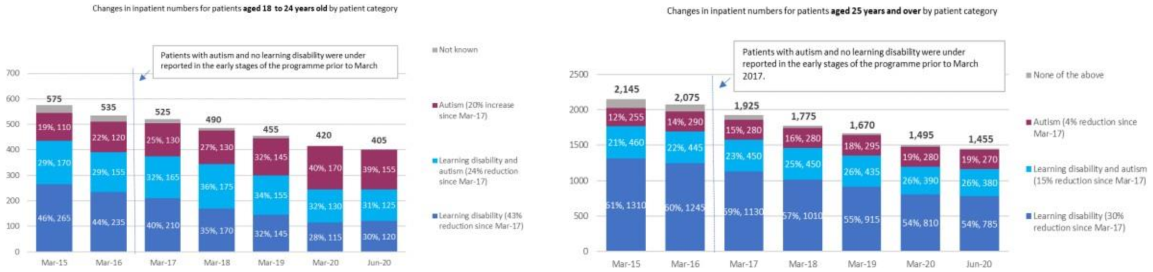
[32] https://www.poppi.org.uk/

[33] https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/nationalpopulationprojections/2018based

autistic people (both autism only, and those with a learning disability) in hospital, with these numbers largely remaining flat.

As such, the ratio of autistic people in a hospital inpatient setting versus those with a learning disability has increased substantially, particularly in younger people. Notwithstanding the under reporting of autism prior to March 2017, in September 2020 autistic people with no learning disability accounted nationally for 81% of inpatients under the age of 18 within the LDA program cohort, rising to 96% of inpatients when including autistic children with a learning disability. This represents a shift from only 43% in 2015. Over the same period, this increased from 19% to 39% of 18-24-year olds, and from 12% to 19% for adults over 25 within the Transforming Care Cohort.[34] This growth has been significant, and many systems have not kept up with this changing reality.

Table 1: National - Changes in LDA inpatient numbers 2015-2020l



Changes in inpatient numbers for patients **aged 18 to 24 years old** by patient category

Patients with autism and no learning disability were under reported in the early stages of the programme prior to March

Changes in inpatient numbers for patients **aged 25 years and over** by patient category

Patients with autism and no learning disability were under reported in the early stages of the programme prior to March 2017.

Age and gender

As a percentage of inpatients, there are significantly more Children under-18 in the autism only cohort (27%) versus the learning disability and autism group (5%). Admissions of autistic people (single and dual learning disability diagnosis) have also seen a slight increase since March 2015, whereas this has again reduced for other diagnosis, showing the challenge and lack of progress made in supporting autistic people to have their needs met effectively in the community during crisis.

Within this under-18 Autism only group, females over index at 68%. This changes with age, shifting to a significant male dominance in adults (86%), which supports research

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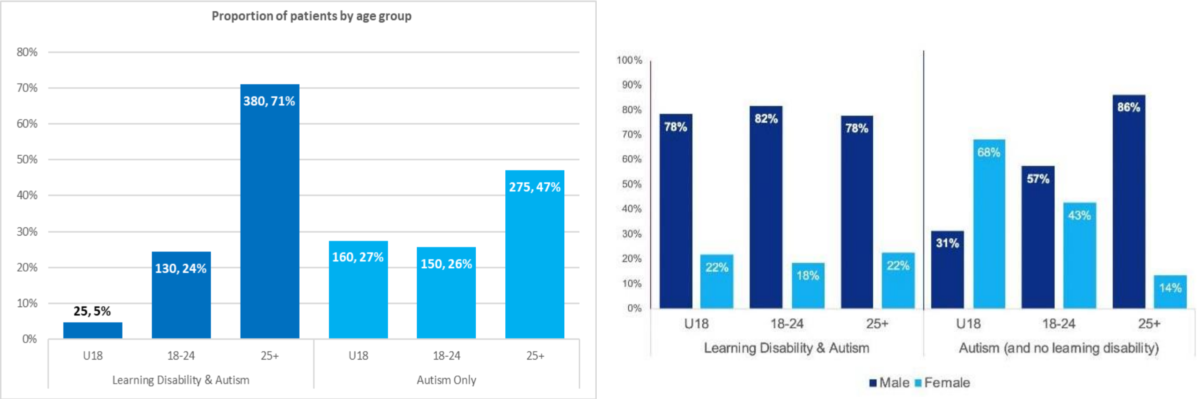
[34] Source: Assuring Transformation, June 2020

concluding that autism is commonly underdiagnosed in adult females[35]. This could impact future work with a spike in women needing autism services in future years. It is also indicative of where our response needs to be, with young autistic people, particularly women and girls, as a key area of focus.

Table 2: National - Proportion of inpatient by age and gender



Autistic people still have substantially longer lengths of stay in hospital, with a high volume of adults having lengths of stay over five years (40%), though this is less pronounced than within learning disability. Length of stay for autistic young people is lower, with over 70% under one year. Across all age categories, reducing both admission rate and length of stay must be a priority.

Amongst autistic adults aged 25+, those with no learning disability are more likely to be in a secure setting (60%) than those with a learning disability and autism (35%). This is lower for children, with 16% of under 18’s with autism (or autism and a learning disability) currently in a secure setting.

Diagnostic waiting times

National Autism waiting times statistics are currently at an experimental stage, with work ongoing to improve data quality, coverage, and known limitations. As such, national level information has not been included in this strategy but regardless of this, it is widely held that people with autism are waiting for significant amounts of time

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[35] https://www.autism.org.uk/advice-and-guidance/what-is-autism/autistic-women-and-girls

between referral and diagnosis across the country. More information on waiting times within the South East region are included below.

Inpatient numbers – the regional picture

Data for the South East region is outlined below to provide context to the key challenges from a quantitative perspective and how this compares to the national picture.

Inpatient numbers

Within the South East region, there are as many autistic people in hospital as those with a learning disability, as is the case nationally. Crucially, since 2015 the overall amount of people with a learning disability in hospital has decreased (172 in March 2016 to 125 at the end of August 2020), whereas numbers of people with autism (single diagnosis) have significantly increased (70 in March 2016 to 122 at the end of August 2020).

Autistic people now account for 85% of under 18's and 37% of adults [36] within the LDA program cohort, in an inpatient setting in the South East showing the size of the challenge, particularly for young people. Within under 18's, an overwhelming majority (74%) of under-18 patients with autism (and no learning disability) were female. The proportion of females decreases by age, to 57% in 18-24s and down to 22% in over 25s. Females make up a much lower proportion of under 25's with a learning disability and autism, with 20% of under-18x and 7% of 18-24s being female.

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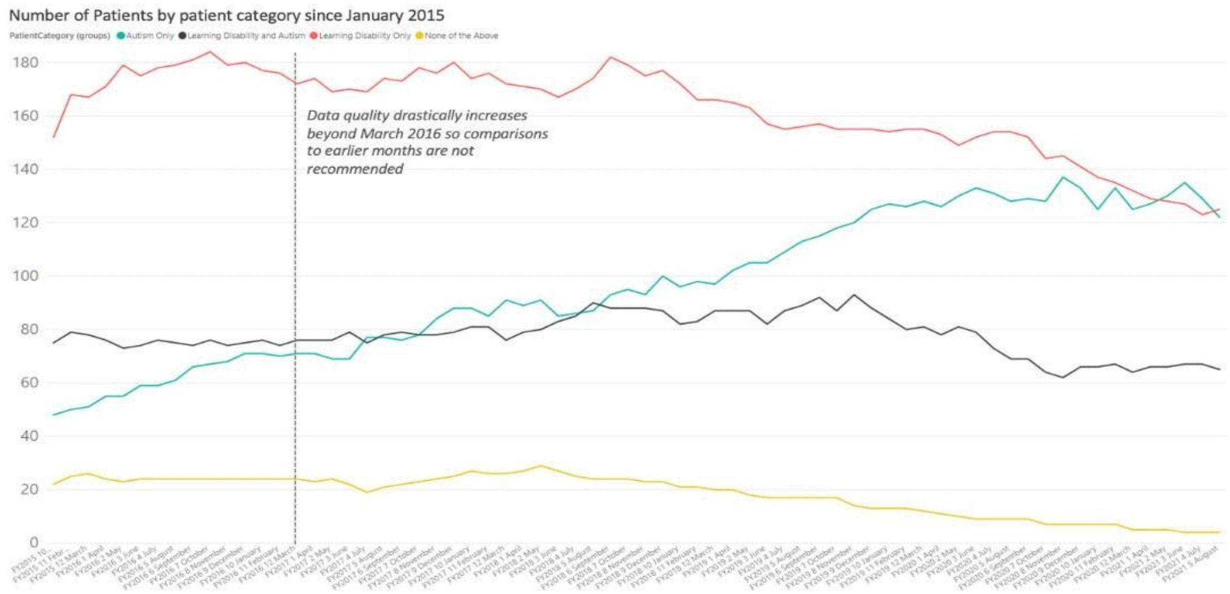
[36] *NHSE Care Room data September 2020*

Table 3: SE: Inpatients by diagnosis since 2015



Length of stay

The majority (78.1%) of current autism patients the South East region have been in hospital for fewer than five years, with an average length of stay of 41 months for adults and 10 months for children.

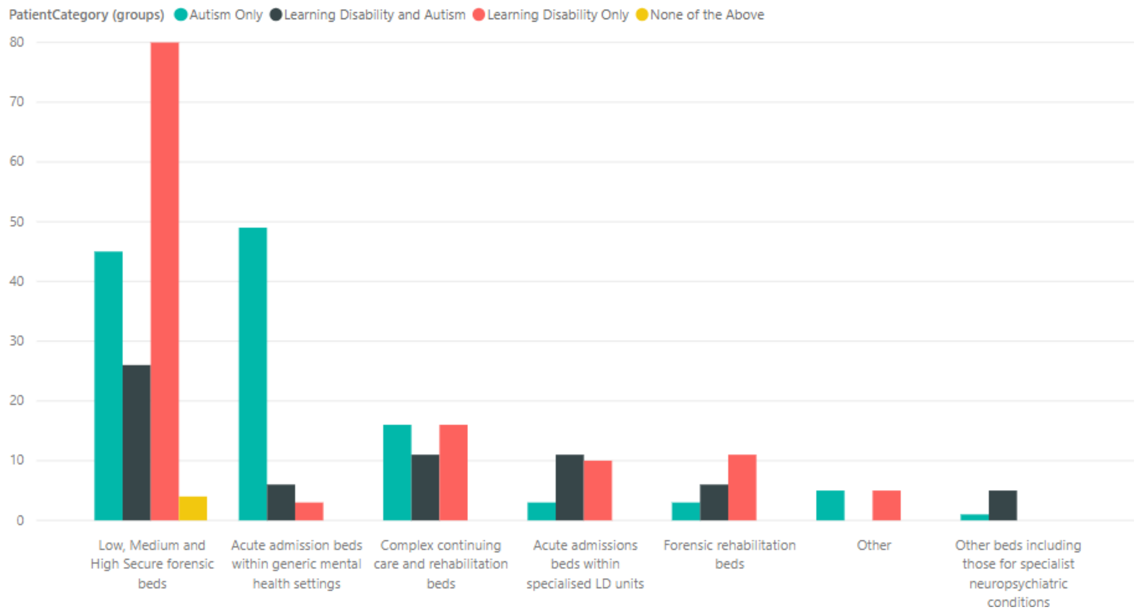
Lengths of stay are greatest in Kent, Surrey, and Sussex which is a concern. This is in line with the overall picture for these regions where they typically have a greater volume of more complex patients. The strategy will seek to identify how length of stay can be reduced in order for people to have access to the most appropriate treatment in the right setting.

Setting

Autistic people in the South East (especially those without a learning disability) are far more likely to be treated in an acute admission bed in a generic mental health setting than patients with a learning disability only, who are more often in secure units and complex/specialised beds in non-secure units.

This correlates with data from a national GP Patient Survey[37] in which 40.5% of respondents who said they have autism also said they had a mental health condition. This over indexes versus people with a learning disability only by five points (35%), showing the importance of making reasonable adjustments to mainstream mental health for autistic people. Around 65% of autistic people in the South East region are currently being treated in their local area rather than in an out of area placement, which is in line with other diagnosis.

Table 4: SE: current setting of all inpatients – by diagnosis



Diagnostic waiting times - Regional

Whilst national data on autism waiting times is not yet robust enough to include in this report, mapping of current wait times from referral to diagnosis within the region was undertaken as part of the strategy development.

This data was provided by local systems and in many areas included a broad range. and does come with a caveat on its reliability. The strategy seeks to call out data quality as a key theme to enable benchmarking.

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[37] *GP Patient Survey, July 2020 Publication – NSHE source*

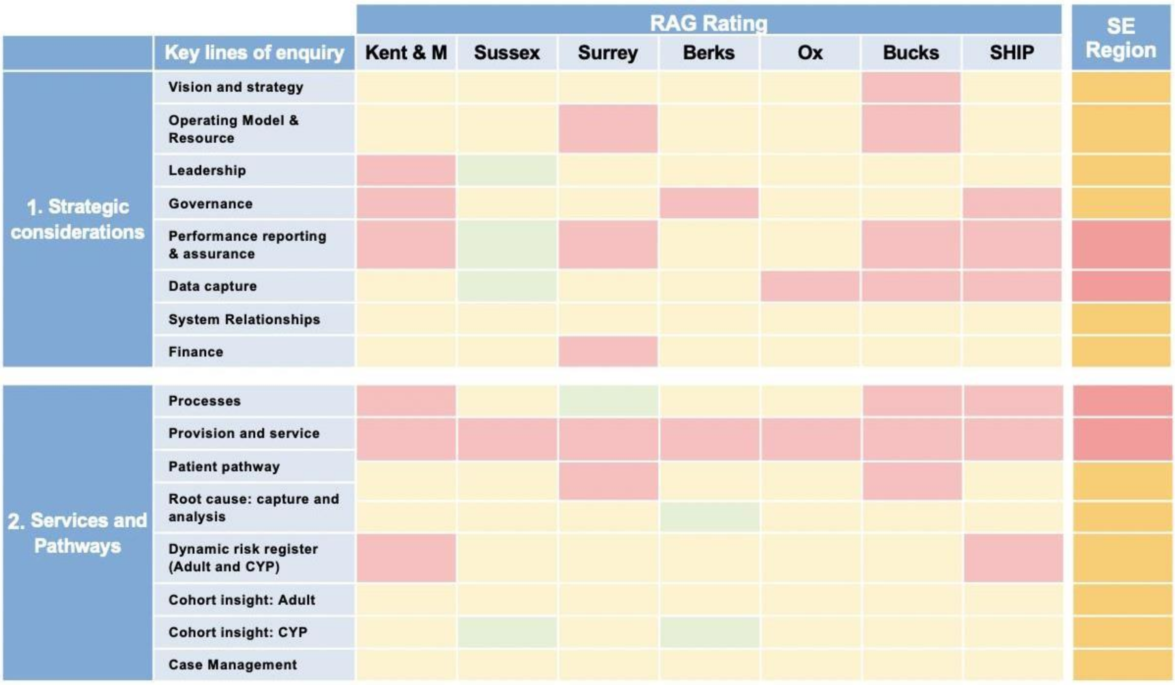
Notwithstanding these data issues, this information shows us that both adults and children are waiting longer than desired for diagnosis (children under 18 are waiting between 12 and 20 months, adults between 8 and 28 months), which will look to be addressed as part of the future model.

Appendix item 2: Current state assessment framework – regional and local

A current state assessment approach was used to help identify key challenges across the South East region, with an outline self-assessment rating given to each key line of enquiry.

These ratings were intended to highlight areas of strength and key challenges within systems, with common themes from across the South East informing development of the regional strategy. A summary is included below at a regional level, and system level summaries can be found in the strategy supporting documents.

Table 5: Current state assessment summary – Regional level



		RAG Rating							SE Region
	Key lines of enquiry	Kent & M	Sussex	Surrey	Berks	Ox	Bucks	SHIP	
1. Strategic considerations	Vision and strategy	🟨	🟨	🟨	🟨	🟨	🟥	🟨	🟨
	Operating Model & Resource	🟨	🟨	🟥	🟨	🟨	🟥	🟨	🟨
	Leadership	🟥	🟩	🟨	🟨	🟨	🟨	🟨	🟨
	Governance	🟥	🟨	🟨	🟥	🟨	🟨	🟥	🟨
	Performance reporting & assurance	🟥	🟩	🟥	🟨	🟨	🟥	🟥	🟥
	Data capture	🟨	🟩	🟨	🟨	🟥	🟥	🟥	🟥
	System Relationships	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨
	Finance	🟨	🟨	🟥	🟨	🟨	🟨	🟨	🟨
2. Services and Pathways	Processes	🟥	🟨	🟩	🟨	🟨	🟥	🟥	🟥
	Provision and service	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥
	Patient pathway	🟨	🟨	🟥	🟨	🟨	🟥	🟨	🟨
	Root cause: capture and analysis	🟨	🟨	🟨	🟩	🟨	🟨	🟨	🟨
	Dynamic risk register (Adult and CYP)	🟥	🟨	🟨	🟨	🟨	🟨	🟥	🟨
	Cohort insight: Adult	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨
	Cohort insight: CYP	🟨	🟩	🟨	🟩	🟨	🟨	🟨	🟨
	Case Management	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨

Appendix item 3: Glossary of terms

Term	Expanded if required	Definition
Autism		Refers to a lifelong neurodevelopmental condition which affects how people communicate and interact with the world.
BAME	Black, Asian and Minority Ethnic	Used to refer to members of non-white communities in the UK. We recognise that there are disagreements in regard to how these communities are defined and described. Thinktank British Future research found that most ethnic minority Britons slightly prefer “ethnic minority” as an umbrella term, with two-thirds (68%) saying they either support or accept the term and only 13% opposed. In our writing we will use both BAME and Ethnic minority in parenthesise to describe these groups.
C(E)TR	Care (Education) Treatment Review	CTRs are for people whose behaviour is seen as challenging and/or for people with a mental health condition. They aim to prevent people from having to go into hospital when they don’t need to. CTRs also help to improve the quality-of-care people receive in hospital by asking key questions and making recommendations that lead to improvements in safety, care and treatment.
CCG	Clinical Commissioning Group	Clinical Commissioning Groups are responsible for implementing the commissioning roles as set out in the Health and Social Care Act 2012.
Commissioner		Person responsible for procuring health services. It is a complex process, involving the assessment and understanding of a population’s health needs.
Diagnosis		Investigation or analysis of the cause or nature of a condition, situation, or problem
DSR	Dynamic Support Register	Registers to identify people with a learning disability, autism or both who display, or are at risk of developing, behaviour that challenges or mental health conditions who were most likely to be at risk of admission.

EHCP	Education, Health and Care Plan	An EHC plan is a legal document that describes a child or young person's special educational, health and social care needs.
Ethnic Minority		Used to refer to members of non-white communities in the UK. We recognise that there are disagreements in regard to how these communities are defined and described. Thinktank British Future research found that most ethnic minority Britons slightly prefer "ethnic minority" as an umbrella term, with two-thirds (68%) saying they either support or accept the term and only 13% opposed. In our writing we will use both BAME and Ethnic minority in parenthesise to describe these groups.
Green Light Toolkit		A guide to auditing and improving your mental health service so that it is effective in supporting autistic people and people with learning disabilities.
ICS	Integrated Care System	New partnerships between the organisations that meet health and care needs across an area, to coordinate services and to plan in a way that improves population health and reduces inequalities between different groups.
LGBTQ+	Lesbian, Gay, Bisexual, Transgender, Queer and Others	LGBTQ+ stands for lesbian, gay, bisexual, transgender, questioning (queer) and "plus," which represents other sexual identities including pansexual, asexual and omnisexual.
NAS	National Autistic Society	The National Autistic Society is a British charity for autistic people. The organisation describes its purpose to improve the lives of autistic people in the UK.
NHS	National Health Service	The National Health Service (NHS) is the publicly funded national healthcare system in the United Kingdom.
NHSE SE Regional team		One of seven integrated regional teams who play a leadership role in the geographies they support. They make decisions about how best to support and assure performance in their region, as well as supporting system transformation.
NHSE/I	NHS England and Improvement	NHS England and NHS Improvement are working together as a new single organisation to better support the NHS to deliver improved care for patients.

NICE	National Institute of Health and Care Excellence	Provide the NHS, and those who rely on it for their care, with an increasing range of advice on effective, good value healthcare.
Neuro-typical	NT	Individuals of the pre-dominant neurotype, used to refer to the non-neurodivergent community
PHB	Personal Health Budget	Personal health budgets are a way of offering individuals with disabilities and long-term conditions greater choice and control in how the NHS supports them in improving their health and managing their care.
SEN	Special Educational Need	Special Educational Needs (SEN) is a legal term. It describes the needs of a child who has a difficulty or disability which makes learning harder for them than for other children their age.
STAMP	Supporting Treatment and Appropriate Medication in Paediatrics	Looks at how clinicians can support children and young people with a learning disability, autism or both better.
STOMP	Stopping over medication of people with a learning disability, autism or both	A national project involving many different organisations which are helping to stop the overuse of these medicines.
STP	Sustainability Transformation Partnership	Bring together NHS, local authority and other health and care organisations to collaboratively determine the future of their health and care system.
Systems		Describing local Health and Social Care systems, usually split by ICS and CCG boundaries.