Surrey Integrated All Age Autism Strategy
DRAFT

Contents

Introduction

This strategy has been brought together by autistic children, young people, adults and family carers together with professionals from across Surrey's service system, to make our joint ambitions clear. We want to achieve an autism friendly approach across the County in education, health, social care, work and communities. We want services to have a more joined-up, proactive and autism-accessible offer so that autistic people have equality of access. The Strategy will promote a cultural shift so that community and service settings are understanding and welcoming for autistic children and adults.

We have agreed to use the term autistic people to refer to children, young people and adults.

Our Vision

Our vision is for Surrey to be a place that offers opportunities for people to live healthy and fulfilling lives, where people's contributions to their local communities are welcomed, supported and valued, and no-one is left behind. These opportunities should extend to all autistic people in Surrey. All organisations involved in developing and implementing this strategy are committed to ensuring that the vision and aims will be delivered in full for autistic people.

The development of the strategy has been centred around involvement of autistic people and family carers. The implementation of the strategy will continue this, with a commitment to ongoing involvement and engagement with Surrey's community of autistic people and family carers.

What is Autism?

There are several names used to describe the autism spectrum, including Autistic Spectrum Disorder, Autism Spectrum Condition, and others which have been used to describe a part of the spectrum, such as Asperger Syndrome or Classic Autism. In this strategy we use the term 'autism' to refer to the whole autism spectrum and the strategy recognises that autism is one of a wider range of neurodiverse conditions.

"Autism is a lifelong developmental disability which affects how people communicate and interact with the world. One in 100 people are on the autism spectrum and there are around 700,000 autistic adults and children in the UK. Autism is a spectrum condition and affects people in different ways. Like all people, autistic people have their own strengths and weaknesses." (https://www.autism.org.uk/advice-and-guidance/what-is-autism)

The way that autistic people experience their environment can lead to areas of strength or difficulty, that vary between individuals and may not be immediately obvious. For example, autistic people can have:
- Strong attention to detail
- Above average technical or creative skills
- Character strengths, such as honesty and loyalty

- Differences in sensory processing, including over- and under-sensitivity
- Difficulty predicting what is going to happen next
- Difficulty knowing or understanding what other people think or feel

Autism varies widely and is often referred to as a spectrum. However, this spectrum is not linear - it is not possible to line autistic people up in order of being more or less autistic. Different features of autism vary from individual to individual, as well as over the lifespan. How an autistic person appears in a particular environment may not be representative of how they appear in other environments.

We know that not everyone autistic has had or would like a diagnostic assessment. Our aim is that changes promoted by this strategy will benefit autistic and other neurodivergent people whether or not they have a diagnosis.

Co-occurring conditions

The National Institute for Health and Care Excellence (NICE) estimates that around 70% of autistic people have an additional condition, which is "often unrecognised". The main conditions that co-occur more frequently in autistic people compared with the general population include:

- Mental health conditions. Research suggests that 70% of autistic people have a mental health condition, and that 40% have two or more. Autistic people are up to four times more likely to have anxiety, and twice as likely to have depression. Research has shown that autistic people are more vulnerable to negative life experiences, which may also impact mental health. Compared to the general population, autistic people report having a lower quality of life.9
- Neurodevelopmental conditions. These are caused by differences in early brain development, and affect the way that a person processes information, thinks, or learns. Autism is one such condition, and it is common for autistic people to have other neurodevelopmental conditions. These include general learning disabilities (affecting between 15% and 30% of autistic people), specific learning difficulties (such as dyslexia and attention-deficit hyper-activity disorder), and other conditions such as epilepsy. Delays in language development are common in autism, and up to 30% of autistic people are non-speaking (completely, temporarily, or in certain contexts).

The Local Picture

Surrey's population in 2021 is projected to be 1.23 million so, our best approximation of its autistic population is 12,300 people, made up of:

- o 2,900 children aged 0-17
- o 900 young people aged 18-24
- o 8,200 people aged 25 and over

AUTISTIC PEOPLE IN SURREY - ESTIMATE BY AGE GROUP

Age 25 and over, 68%
Age 0-17, 24%
Age 18-24, 8%
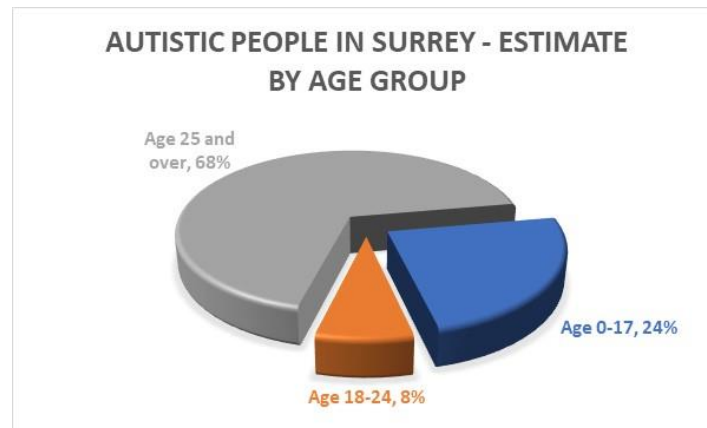
Children and Young People with Autism in Surrey -

The total number of Education, Health and Care Plans (EHCPs) for young people up to the age of 25 in 2020 was 10,762 of which 3,653 or 34% with primary need of autism as follows:

- Male – 2,958 or 81% of all plans with primary need of autism
- Female – 695 or 19% of the total number of plans with primary need of autism

EHCPS IN 2020 BY GENDER

Male 81%
Female, 19%
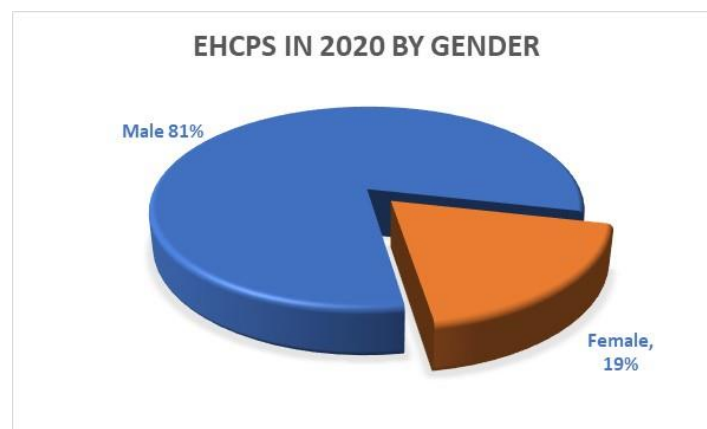
Adult Population / People 18 and Over in Surrey

National data shows the number of people aged 18 and over with autistic spectrum disorders in Surrey in 2021 is about 9,100. A summary of recent research shows that autism is about three times more common in men than women.

20% of Surrey's predicted adult autistic population (1,834 people) are in receipt of a service from Adult Social Care (ASC), and a third of these are women.
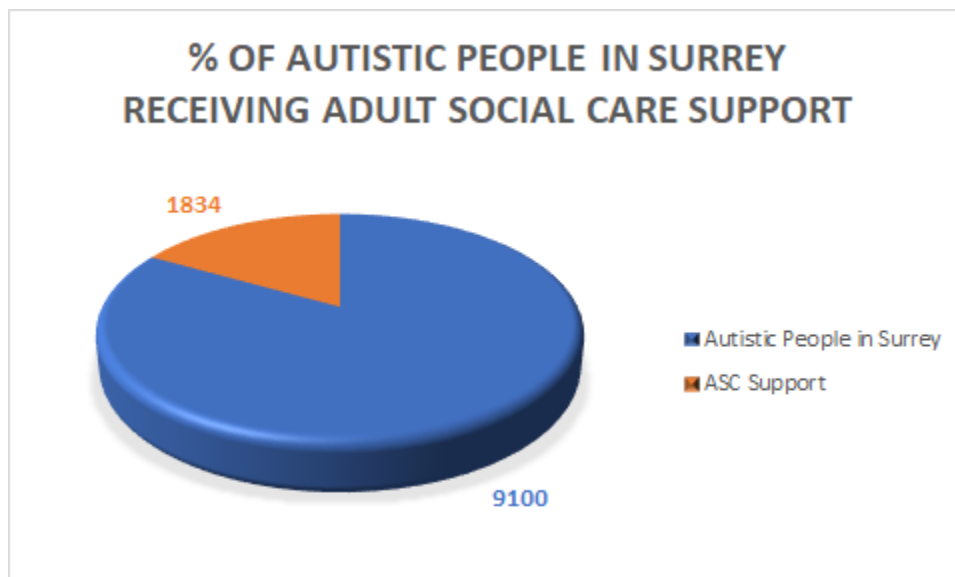
Why do we need a Strategy?

Autistic people and family carers have told us that there are significant barriers to achieving our vision across the service system and the wider community. Addressing these barriers will require better understanding of autism, and culture change across Surrey's services and community.

These are not quick things to deliver, but we know that with focussed leadership across the system over time, autistic children, young people and adults in Surrey can be supported to achieve better outcomes. The work of the strategy will need to be embedded in organisations and the wider community so that it is sustained and can be built on. We are committed to bringing the right people together to break down barriers to community access and use our resources effectively to deliver the support that people need. Our strategy is here to focus the action of all the partners across Surrey who will work together to make the changes we need to see.

Outcomes of Our Consultation

We carried out a public consultation in 2020. Professionals, autistic people, and carers developed a set of questions to ask people about their experiences and how things could be improved in Surrey. We received 1,165 detailed responses.

- 109 autistic people,
- 756 family members, carers or partners of autistic people,
- 237 professionals; and
- 63 'others'.
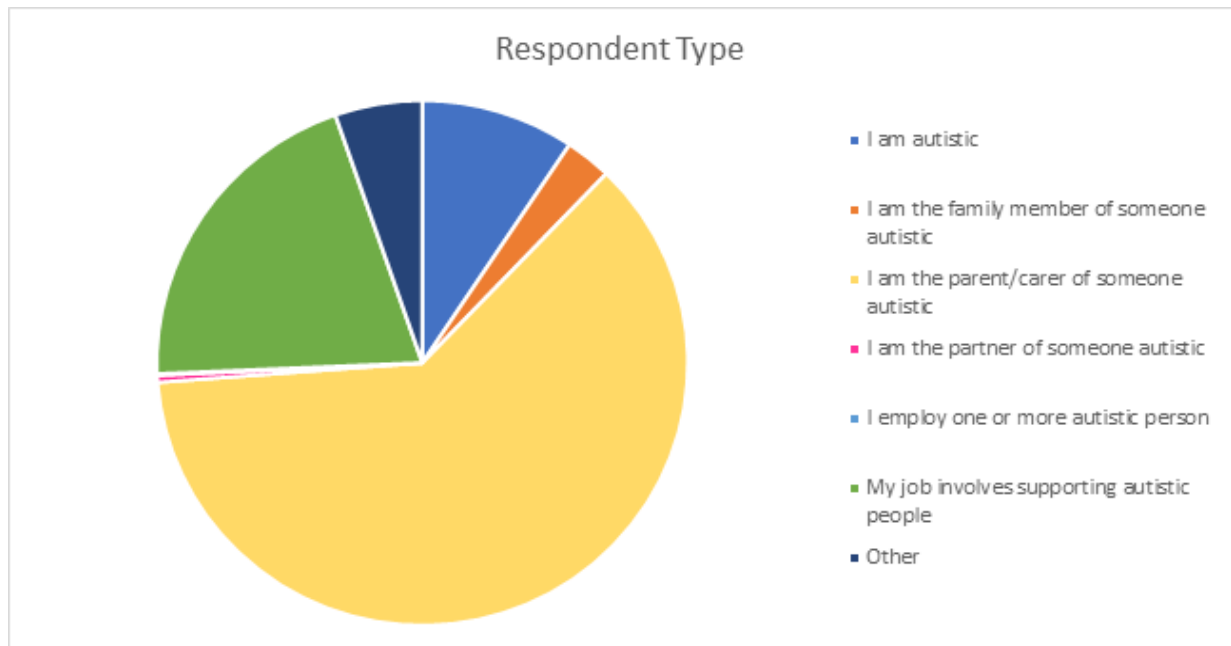
We have worked with London South Bank University to analyse the responses and draw together the key themes. We have checked the themes with autistic young people and adults, families, carers and professionals through a series of online workshops.

Priorities identified by autistic people:
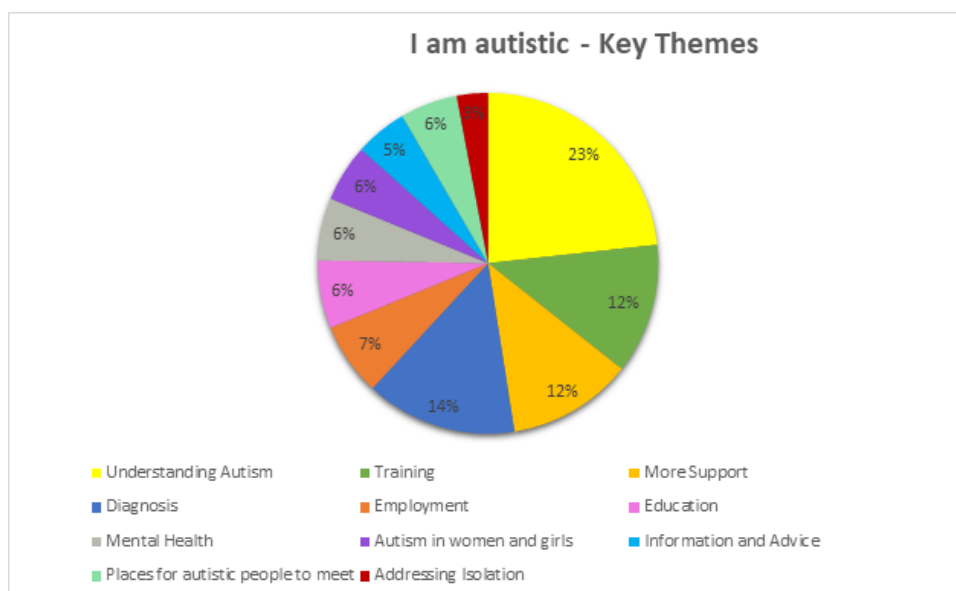
Priorities identified by family members and parent/carers of someone autistic:

Family member, parent/carer of someone autistic - Key Themes

Legend:
- Understanding Autism
- Diagnosis
- Training
- Availability of services
- Education
- Information and Advice
- Transitions
- Joined up services
- EHCPs
- Funding
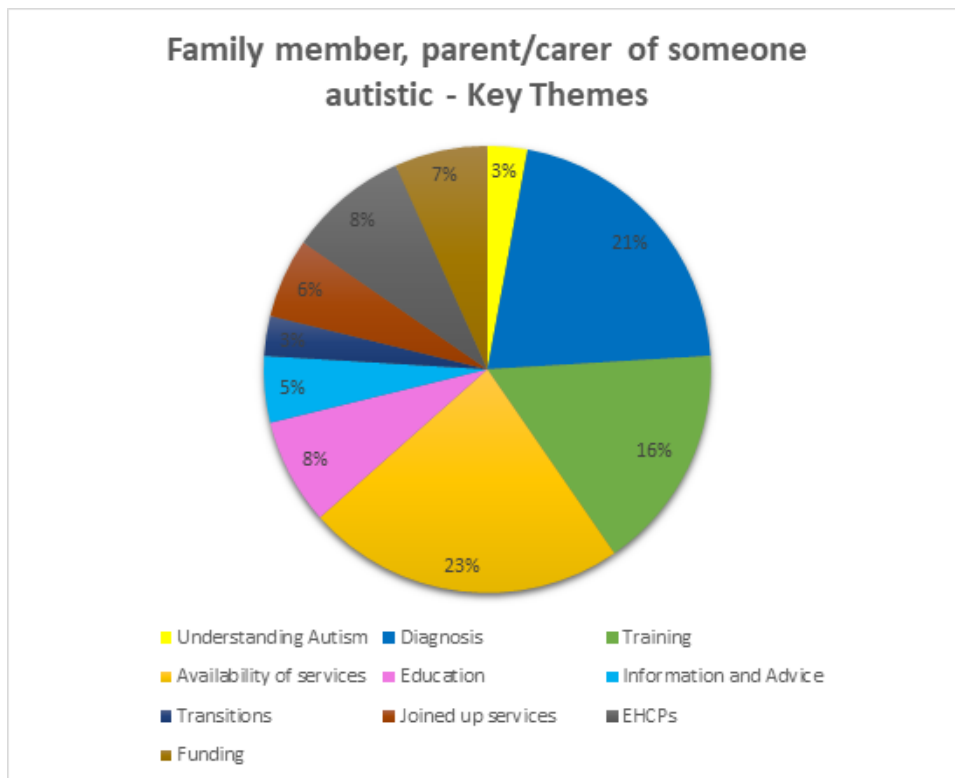
Priorities identified by people whose job involves supporting autistic people:

My job involves supporting autistic people - Key Themes

Legend:
- Funding
- Joined up services
- EHCPs
- Information and Advice
- Transitions
- Availability of Services
- Education
- Diagnosis
- Understanding Autism
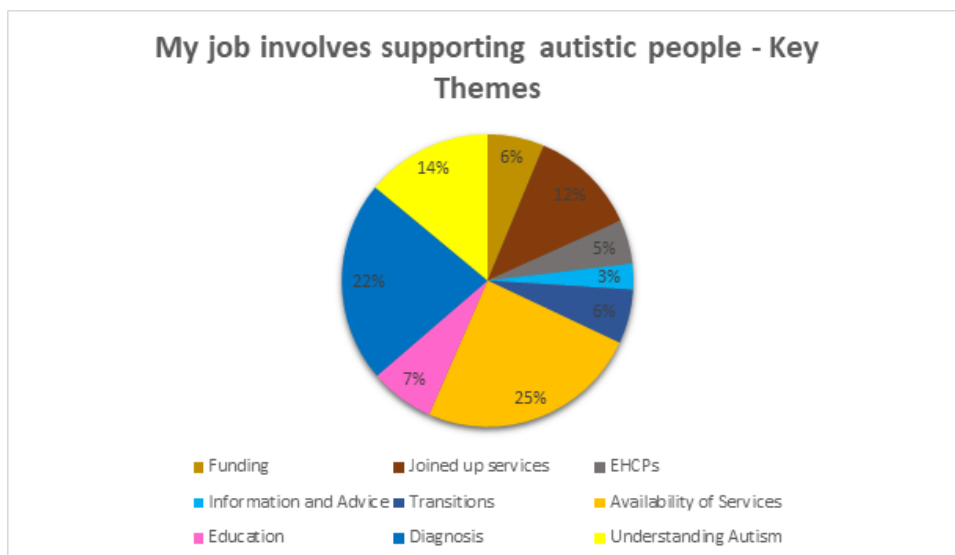
Our Principles

- **My Voice** - Work on developing and implementing the strategy will involve autistic people and family carers. – Nothing About Us Without Us. We make fair and strong decisions together.
- **Partnership Working** – Many different agencies and organisations will be involved in delivering this strategy. We will work together towards the common goals outlined here.
- **Strengths-Based Approach** – We intend to build on strengths of individuals, organisations and communities
- **Closer to Home** – We will aim for autistic people to be included and supported in their local communities as far as possible. When people require specialist support that cannot be delivered in every locality, we will aim for support to be in-County wherever possible.
- **Efficient use of Resources** – We know that services have limited resources, and this strategy is ambitious in aiming for widespread change. Making the system more joined-up, inclusive and accessible will prevent crises for autistic people and their families, and improve efficiency across the service system. To ensure the change can be as wide as possible we will use the resources available in the most effective way.

Our Plan

Over the next 5 years, bringing people together to develop and implement work plans focusing on the following priority areas:
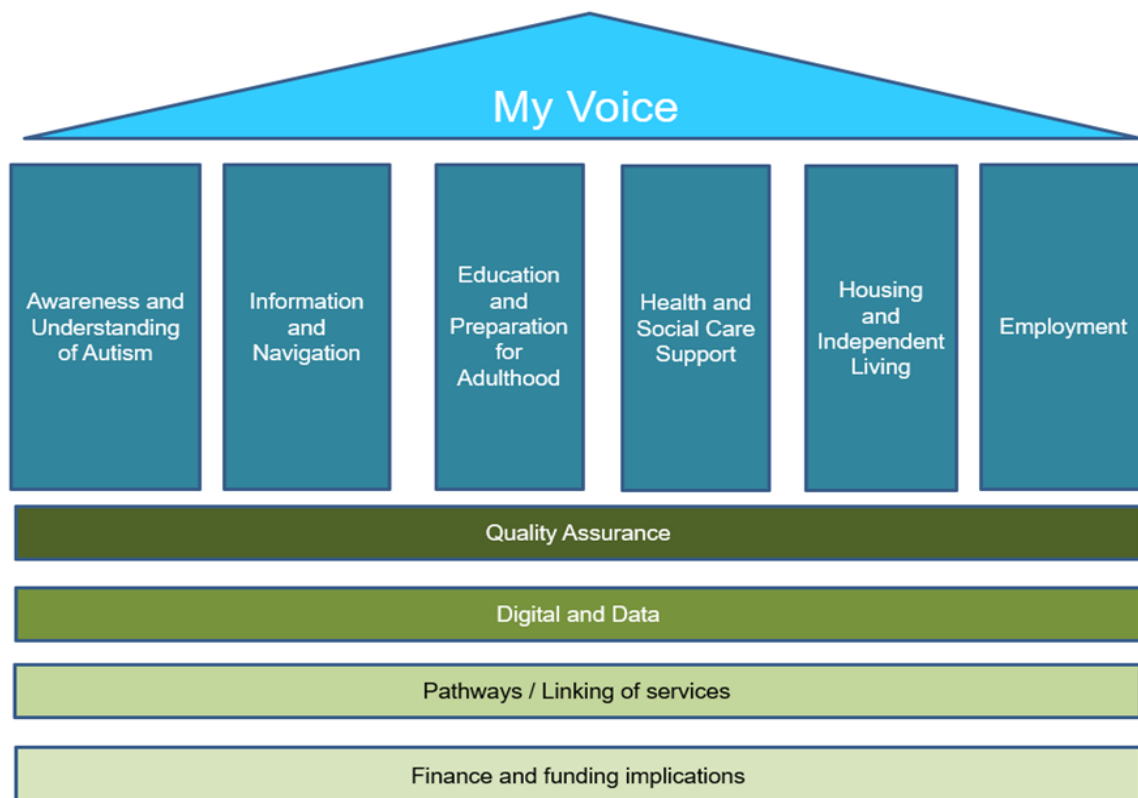
The work carried out to implement the plan will report back through the Children's and Adults' Autism Partnership Boards and the decision-making bodies for Surrey County Council and the NHS in Surrey.

Making our plan happen

We have divided up our plan into the priority areas shown above. Each section will be backed up by an action plan developed and monitored by people from services working with autistic people and family carers.

My Voice

What do we want to achieve?	What could work better?	What do we need to do?
Autistic people and their family carers are involved in developing and implementing the strategy, and in designing and making changes to services	Autistic people and their family carers could be more involved in developing and implementing improvements to services and community support	Establish a Children's Autism Partnership Board to support involvement of autistic children and young people. Develop a Reference Group of autistic young people / family carers to support development and implementation of the strategy Maintain and build on current involvement in the Adults' Autism Partnership Board. Develop a Reference Group of autistic people to support development and implementation of the strategy. Ensure involvement of experts by experience in the strategy workstreams

Awareness and understanding of autism in services and the wider community

What do we want to achieve?	What could work better?	What do we need to do?
Community		
Autistic people are understood, welcomed and can access community services, for example leisure facilities, shops, youth clubs and community events	Wider awareness and understanding of autism community	Develop options and approaches for an autism training offer for community services, and priorities for rollout of training across the 5-year lifespan of the strategy
Services		

What do we want to achieve?	What could work better?	What do we need to do?
Services are inclusive, accessible and helpful for autistic people and family carers	Better awareness and understanding of autism across services, front line staff and managers Service design accounts for the needs of autistic people and their family carers	Develop options and approaches for an autism training offer for community services, and priorities for rollout of training across the 5-year lifespan of the strategy Develop processes to audit autism accessibility of services to ensure continuous improvement
Family carers		
Family carers understand the strengths and needs of their autistic family member(s) and how to support them	Autism training for family carers which is relevant and proportionate to need	Develop options and approaches for an autism training offer for family carers
Autistic people		
Autistic people are supported to understand what their autism means for them, their strengths and skills and so that they can live fulfilling lives	An autism training offer which is relevant and proportionate to individual need	Develop options and approaches for an autism training offer for autistic people

Information and Navigation to live an active life

What do we want to achieve?	What could work better?	What do we need to do?
Information about where to find advice, signposting and support across education, health, care and the community can be found in one place and is accessible to all. Autistic people and family carers are able to find information and support which helps them to live an active life	Easy access to information and advice for service users and providers A single place which allows for a seamless flow of information Support to navigate the system • Peer support • Autism champions • Advocacy	Review and revise current information and advice content held on various websites across agencies. Work to agree a single place which brings together all information, advice and signposting currently held in a number of different places. Ensure content is available to those who do not access digital media. Develop options for peer support and autism champions

Education and Preparation for Adulthood

What do we want to achieve?	What could work better?	What do we need to do?
Inclusive educational provision which enables children and young people to be taught within their local community, whether or not they have an EHCP	All Surrey education settings, mainstream and special, understand autism and can meet the holistic needs of their community of children School-to-school support Learning from placement breakdowns, complaints and making changes	Develop options and approaches for a multi-layered training programme for education settings, including school to school support. To include a focus on the need for reasonable adjustments to environments and practice for pupils with sensory difficulties. Commit to a multi-agency continuous improvement cycle – involving children and parents in lessons learnt. Explain what children, parents and carers should expect from their schools.
Autistic people have their needs identified and met at the earliest time	Early intervention	For children in education settings front-line services operate in a team around the school model, providing early and additional support when needed. Review service provision within and across agencies to ensure that autistic people have their needs identified and met at the earliest time, through a graduated response.
On leaving education young people are prepared to live as full and independent an adult life as possible	An increased focus on the 4 key preparation for adulthood areas fully informed by the pupil's aspirations and the family carer's views, irrespective of the type of school the pupil attends Improved transition planning	We need to ensure preparation for adulthood is included in all pathway planning. We need to have the right curricula, which includes a clear focus on the development of the skills needed to live as independent and fulfilling life as possible.

What do we want to achieve?	What could work better?	What do we need to do?
	Increased access to work experience Parents fully understand the range of possibilities available after education	Improve joined up working across agencies and services to ensure that transition planning is timely and seamless. We need to improve understanding and community involvement. Information about the range of options available after education.
Children and young people who need an education, health and care need assessment receive one.	Everyone understands the support available for a child or young person without a statutory assessment and when a statutory assessment is needed. Improved understanding that a diagnosis of Autism does not necessarily mean an EHCP is required and that children can progress without EHCP Improved experience of statutory processes including timeliness and co-production with family and carers EHCPs are of better quality with pupil voice centred in the plan	Further embed the graduated approach in schools and settings ensuring that staff have support, training and advice to meet the needs of children and young people with Autism. Provide information about support and training for parents of children with autism on the Local Offer both pre and post a diagnosis. Further embed co-production of the EHCP with families and ensure feedback from them improves our working practices and processes. Ensure the voice of the child/young person and the family is at the centre.

Health and Social Care support

What do we want to achieve?	What could work better?	What do we need to do?
Assessment Diagnosis and Support		
To engage everyone involved to improve health and wellbeing for autistic children and adults.	All health and care professionals have a better awareness of autism in particular in women	Develop strength-based options for pre- and post-diagnostic support for people's resilience in the

What do we want to achieve?	What could work better?	What do we need to do?
To have a robust neurodevelopmental assessment pathway for children and adults. Diagnosis will happen at the time appropriate for the individual. Families and autistic people will know how to access support, have an assessment of their needs, and be able to live a fulfilling life.	and girls, leading to appropriate support and referral for assessment of need People need to know where and how to access support in their local area Shorter waiting times for diagnostic assessment Coordinated support for people pre- and post-diagnosis Developing support options to ensure greater inclusion	community, such as circles of support, and links to the voluntary sector Develop options for increasing diagnostic capacity to enable timely assessments Plan for management of neurodevelopmental conditions Understand and address the gaps in the commissioning of services
Mental Health and Wellbeing		
Autistic people have good mental health and wellbeing, and access to Mental Health services as required as part of a graduated response	Improve ability of Mental Health services staff to recognise and respond appropriately to autistic people's needs and understand how to treat their Mental health and wellbeing better. Training and work on culture change to avoid diagnostic overshadowing and ensure reasonable adjustments are made so that a	Deliver a dynamic programme of training to upskill the workforce (see Awareness and understanding of autism in services and the wider community work stream). Develop stronger links with voluntary and private sector partners to meet people's needs in a holistic, person centred way. To enable autistic people to actively influence decisions about the way the

What do we want to achieve?	What could work better?	What do we need to do?
	diagnosis of autism does not act as a barrier to accessing mental health support.	support they need is delivered.
	Early identification and co-ordinated response to support autistic people who have low-level mental health needs within the community to prevent crisis and hospital admissions	Develop community resilience by ensuring reasonable adjustments in universal services/community settings Review mental health pathways and skills within services from an autism lens in order to support autistic people in the community. Promote good mental health and wellbeing in all settings Better at defining what the graduated response will look like
	Mental health hospitals recognise and respond better to autistic people	Review autism accessibility of Mental Health hospital provision.
	Avoiding unnecessary mental health hospital admissions, and timely and safe facilitation of discharge	We need to ensure that Mental Health services are fully engaged with Surrey's Transforming Care approach.
	Suicide prevention work in Surrey needs to recognise and respond better to autism	To ensure that suicide prevention work in Surrey takes account of autism.

What do we want to achieve?	What could work better?	What do we need to do?
Community Support		
Autistic people and family carers can live a fulfilling life in the community. Facilities available to the community make reasonable adjustments to be autism accessible. This means that there are services and supports available to autistic people who are not eligible for statutory services.	Accessibility, inclusion and awareness in wider services and the community	Work to promote "Autism Friendly Communities" Identify and prioritise community facilities, universal services and voluntary sector offer for focussed work on autism friendliness in the community. Promote joint work to make adjustments to make the community more accessible.
	Public sector bodies in Surrey building in requirements for contractors to support community access for autistic people. This may be through Social Value in contracts, Section 106 or other arrangements.	Make links with contracts departments in these organisations to develop these possibilities.
Health Inequalities		
Mainstream health services make reasonable adjustments Ensure autistic people get access to the health support they need, in line with the national NHS Long-Term Plan and NICE guidance.	Improve understanding of autism in primary and acute health settings to enable reasonable adjustments to deliver better health care	Workforce education and skills development (see Awareness and understanding of autism in services and the wider community work stream). Work with GP practices around implementing autism registers Scope options for flagging autism on

What do we want to achieve?	What could work better?	What do we need to do?
		medical records, where people want this. Proactive reasonable adjustments to support access to screening. Deliver proactive health checks and screening to enable the early identification of health needs.
Mental Health and Wellbeing		
Autistic people have good mental health and wellbeing, and access to Mental Health services as required as part of a graduated response	Improve ability of Mental Health services staff to recognise and respond appropriately to autistic needs and the impact on mental health and wellbeing better Training and work on culture change to avoid diagnostic overshadowing and ensure reasonable adjustments are made so that a diagnosis of autism does not act as a barrier to accessing mental health support.	Deliver a dynamic programme of training to upskill the workforce (see Awareness and understanding of autism in services and the wider community work stream).
	Early identification and co-ordinated response to support autistic people who have low-level mental health needs within the community to	Develop community resilience by ensuring reasonable adjustments in universal services/community settings

What do we want to achieve?	What could work better?	What do we need to do?
	prevent crisis and hospital admissions	Review mental health pathways and skills within services from an autism lens in order to support autistic people in the community. Promote good mental health and wellbeing on a wider basis Better at defining what the graduated response will look like Review mental health pathways and skills within services from an autism lens in order to support autistic people in the community.
	Mental health hospitals recognise and respond better to autistic people	Review autism accessibility of Mental Health hospital provision.
	Avoiding unnecessary mental health hospital admissions, and timely and safe facilitation of discharge	We need to ensure that Mental Health services are fully engaged with Surrey's Transforming Care approach.
	Suicide prevention work in Surrey needs to recognise and respond better to autism	To ensure that suicide prevention work in Surrey takes account of autism.
Health and Social Care Teams		

What do we want to achieve?	What could work better?	What do we need to do?
When an autistic person or family carer is assessed by a health or social care team or the Contact Centre, the assessor will understand autism, and the impact it may have. The Health and Social Care Teams most likely to be supporting autistic people and family carers will be sources of autism expertise for the County. The teams will use a strengths-based approach, planning proactively around skills development for independence.	Better understanding of autism in health and social care teams and SCC Contact Centre. Assessment is timely and takes into consideration the individual needs of the autistic person.	Develop and deliver improved autism training to health and social care teams and the Contact Centre. This will include understanding of how autism impacts on strengths-based work. Build links between teams with good understanding of autism
Market Management		
There is a suitable range of autism accessible support in Surrey that people can purchase with a personal budget or personal health budget. This includes support when people struggle with their mental health, and support for older autistic people. It includes low-level support for people to live in the community, and avoid escalating levels of needs. It will also include more specialist support when things go wrong, to avoid unnecessary hospital admissions and facilitate timely discharge.	A wider range of autism-accessible support delivered by providers including private, voluntary and independent sector. Requirements for autism accessibility, training and understanding written into specifications and contracts, and monitored. Providers work proactively to support people to	Ensure autism needs and strengths-based approaches are included in commissioning of: • Outreach support • Day and evening activities • Education • Health services and therapies • Short Breaks and other family carer support • Community Mental Health Support • Home Based Care

What do we want to achieve?	What could work better?	What do we need to do?
	develop skills for independence, and take on positive roles in society.	• Employment support • Supported living • Residential and Nursing Care Scope the services currently offered for autistic people and their family carers in Surrey, and identify gaps and inconsistencies in the offer. Work with the provider market to address the gaps.
Forensic support, including police, prisons and criminal justice –		
Surrey Police recognise the needs of autistic people, and make reasonable adjustments. The criminal justice system, including the courts and court liaison, and prisons recognise the needs of autistic people and make reasonable adjustments. When autistic people are at risk of undertaking criminal activity, they can get support from services that understand their autism (e.g Youth Offenders Service, Forensic Services).	Understanding of autism and reasonable adjustments throughout Surrey Police.	Build on the current Pegasus scheme to ensure autism accessibility, and extend current good practice. Build on current Police autism training offer.
	Understanding of autism and reasonable adjustments in Youth Offending Services, Courts, Court Liaison, Probation and the criminal justice system.	Develop options for autism training and awareness-raising in these services.
	Coordination across community and criminal justice system	Develop a clear integrated forensic pathway to support autistic people at risk of offending, homeless and substance misuse

What do we want to achieve?	What could work better?	What do we need to do?
		and in the criminal justice system.
	Understand from youth offending teams what support is required for autistic people	Work with all partner agencies to identify anyone that has been excluded from society, education and social care. Supporting schools and education provisions with reasonable adjustments Workforce development for criminal justice – training for police etc..

Housing and Independent living

What do we want to achieve?	What could work better?	What do we need to do?
Preparation for Independence		
Young people are better prepared for work and independent living when they leave education	Link between preparation for adulthood work and adult support	Support autistic young people to raise expectations and learn the skills they will need for independence. To include independence skills in EHCPs where appropriate, including for academically able young people.
ASC Independent Living		
Housing and support is available and accessible for autistic people eligible for Adult Social Care Support	The Independent Living Framework to specify autism accessibility. Accommodation and Support commissioned for people with mental	Independent Living framework delivers Schemes where staff have skills in supporting autistic people

What do we want to achieve?	What could work better?	What do we need to do?
	health needs and older people to include provision with suitable environments and staff skills for autistic people.	• Schemes where the built environment is accessible for autistic people • A variety of accommodation options including options for sharing with an appropriate peer group, and for people who do not wish to share Commissioning of accommodation and support for people with mental health needs and older people addresses autism needs.
District and Borough Housing		
For District and Borough Housing staff to understand autism, and make reasonable adjustments so that housing processes are autism accessible. For borough housing stock to be autism accessible.	Accessibility of District and Borough housing processes, and housing stock for autistic people	- Autism training for District and Borough housing staff - Review housing processes (e.g. housing lists, bidding for properties, adaptations etc.) in terms of autism accessibility
Building Standards		
Autism accessibility is considered in all new buildings	Standards for disability access are set nationally.	Lobbying for national disability access standards in housing to include the needs of autistic people.

Employment

What do we want to achieve?	What could work better?	What do we need to do?
Preparation for Adulthood		
Autistic children and young people leave education with the skills and understanding they need to get employment.	Access to employment for young people leaving education.	Increased work experience opportunities, better links to employers. Include people with significant support needs in this work. Learning skills for independence including travel training and expectation of employment / taking on positive roles.
Work opportunities		

What do we want to achieve?	What could work better?	What do we need to do?
More job opportunities for autistic people in Surrey	Access to supported employment, supported internships, apprenticeships and other employment schemes	Build links between organisations to improve understanding of autism, and accessibility of schemes. Identify funding streams to support this work. Supporting autistic people to retain work.
	Employment-related voluntary sector offer for autistic people	Build links between organisations supporting autistic people in employment.
	Accessibility of the DWP universal offer- Employers making reasonable adjustments	Build links with DWP in Surrey, and employers
Leading by example		
Councils and the NHS in Surrey, and the organisations we commission leading by example in employing autistic people	Better understanding of autism in organisations Reasonable adjustments to recruitments processes and job roles Building autism accessibility into "Social Value" requirements when tendering and letting contracts Organisations supporting autistic people placing more emphasis on employment.	Ensure the importance of understanding autism is built into organisations' equalities training HR departments to report on the autism reasonable adjustments they have made. Monitor the number of autistic employees self-identifying in equalities data Contracts departments reporting on autism-related social value requirements they have put in place Develop the strengths-based work of existing supported living, outreach and day activity providers, supporting autistic people to find jobs and voluntary roles.

Glossary

All Age Autism Strategic Framework Glossary

ASC – Adult Social Care

ASD – Autism Spectrum Disorder

Co-morbid - existing simultaneously with and usually independently of another medical condition

Co-occurring conditions – Other conditions that people may have alongside autism. People may need support with other conditions that is delivered with reasonable adjustments for their autism

Diagnostic overshadowing - the attribution of a person's difficulties to autism, when they actually reflect a comorbid condition, such as a co-occurring mental health condition.

DWP – Department of Work and Pensions

EHCPs – Education, Health and Care Plans

GP – General Practitioner

HR – Human Resources

LSBU – London South Bank University

NHS – National Health Service

NICE - National Institute for Health and Care Excellence

POPPI – Projecting Older people Population Information

PANSI – Projecting Adult Needs and Service Information

SCC – Surrey County Council

School Model - A local network consisting of **schools** and other education and family support services that meet on a regular basis to have a shared conversation about children and young people that they may be worried about and that early help and intervention may stop concerns escalating.

Social Value - the quantification of the relative importance that people place on the changes they experience in their lives.

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