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## DEVELOPMENT OF NEW ALL-AGE AUTISM STRATEGY

**Purpose of report:** To update on progress in developing a 5-year All-Age Autism Strategy across Adult Social Care, Children, Lifelong Learning and Culture, and Health in Surrey.

### Introduction

*“...We autistics (people) have a unique way of looking at the world... We have much to offer but are often undervalued and underutilised.”*

*“If all options were available to me ... if I could have better understood how my strengths/interests might translate into different career opportunities ... if I'd been given accurate information about FE (Further Education) options, etc, I would have made more well-informed choices.”*

1. Surrey's current adults' autism strategy is joint with learning disability and runs from 2016-2020. This has supported progress in addressing the needs of the autistic community in Surrey, but governance and responsibility specifically for autism have not always been clear, and gaps in services have persisted. Autistic people and carers in the Autism Partnership Board have asked that we develop a separate all-age autism strategy.
2. The Autism Act 2009 and the strategy it mandates relate to adults, but the Department of Health and Social Care have announced that the next version of the national autism strategy in 2021 will also cover children. This is a welcome change; closer joint working between Children's and Adult's services will help reduce expensive and sometimes inappropriate placements, and unnecessary crisis responses. In Surrey, Children's and Adults' services are working to develop our strategy together, so that it will address all ages and support services to join up. The plan is for the strategy to include an overarching set of strategic intentions, with age-appropriate delivery plans and processes sitting underneath.
3. Services for autistic people are commissioned in a variety of ways. Most Adult Social Care services are spot purchased, with those in Education, SEND and Health more likely to be contracted. The strategy will need to address a wide range of support, including:

- a) Working with partners across the system to make existing universal services more accessible
- b) Community preventative support and information
- c) Market Management - effective use of existing resource to ensure availability, accessibility, range and impact of services available for spot purchase by health and social care or using direct payments
- d) Contracted clinical services, for example those delivering diagnosis, ongoing mental health support and crisis responses
- e) Education – effective use and monitoring of forecasting data and actual levels of demand to ensure sufficient appropriate school/education provision

<b>Data and Demographics</b>
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4. Surrey's autistic population consists of approximately 12,000 people (See Appendix 1), made up of:

- a) 2,500 children aged 0-16
- b) 1,000 young people aged 17-25
- c) 8,500 people aged 26 and over

- 4.1 Autism is the single most common primary need identified in Education Health and Care Plans (EHCPs). 1,471 EHCPs were issued in 2019 and 32.77% of these were for autism.
- 4.2 11.5% of autistic students are currently placed in Surrey maintained specialist schools which specialise in need areas other than autism.
- 4.3 Historically, autism has been thought to be much more common in males, but nationally and internationally, the proportions are changing as autism becomes better recognised in girls and women. In Surrey, the proportion of girls in the EHCP cohort with autism as a primary need has risen from 14% to 18% over the last 4 years. Referrals to Surrey's adult autism diagnostic service are now approximately equally split in terms of gender. This probably reflects under recognition of females in early diagnosis. The proportions open to Adult Social Care are 30% women: 70% men.
- 4.4 20% of the adult autistic population receive a service from Adult Social Care. People identified as autistic make up 36% of the caseload of the ASC Learning Disability and Autism Team, and 54% of the caseload of the ASC Transition Team identified with a service need of learning disability.
- 4.5 Referrals to Surrey's Neurodevelopmental Team for an autism diagnosis in adults are increasing year on year. In 2018/19 the team assessed 851 people, and in 2019/20, this had increased to 944. While most of the referrals are for people under 30, the service covers all ages, and has diagnosed people in their 70s and 80s. Waiting times for a diagnosis have also increased, despite streamlining of processes. The average wait time in 2019/20 was 370 days.
- 4.6 NICE – The National Institute for Health and Care Excellence – has produced guidance that GP practices should maintain a register of autistic patients on their

books, but these registers are not yet in place. Once collected, this information would give us much more accurate data for Surrey's autism prevalence than we are able to produce currently. We had started piloting this before the Covid pandemic and will pick it up under this strategy once GP practices are in a position to prioritise this again.

- 4.7 We have heard anecdotally from our prison teams that autistic people are significantly overrepresented in prisons and the criminal justice system, but this data is not collected across the prison population. Some studies have borne this out, suggesting up to 13% of the prison population may be autistic.
5. We know that we need better data to inform planning. Improving the data we collect will form an underpinning piece of work for the strategy.

## Governance

6. A strategy that covers Children's and Adults' services in Health, Education, Social Care and the wider service system requires new governance processes and relationships.
7. Adults services have set up a sub-group of the Autism Partnership Board to involve more autistic adults in the work of the Board overseeing the strategy. Children's services are setting up a Children's Autism Partnership Board to sit alongside the adults' Board. Appendix 2 shows the proposed governance structure across children's and adults services.

## Consultation, Coproduction and Drafting of the Strategy

8. The development of the strategy has been based on coproduction; a "*Nothing about us without us*" approach, involving autistic young people and adults and family carers at every stage. This will need to continue, and engagement and ownership from all parties will be essential to the successful implementation of this strategy.
9. We have carried out an online survey, which received 1,165 detailed responses (109 autistic people, 756 family members, carers or partners of autistic people, 237 professionals, 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, and are working to pull all the input together to inform the draft strategy.
10. We have pulled the key themes and priorities into a series of proposed workstreams, and are currently identifying named leads to develop the workplans for delivery. Our intention is to have each workstream co-led by a person with lived experience – either an autistic person or a family carer. The workstreams will report into the Children's and

Adults' Autism Partnership Boards, and through them into the governance structure described in Appendix 2.

## Themes – Background, Issues Raised and Proposed Workstreams

11. Surrey Adult Autism Partnership Board's most recent Self-Assessment for Department of Health and Social Care identified many areas of progress, but we scored Red in three areas:
  - 11.1 Diagnosis waiting times – This is a known issue across children's and adults' services, and reflects the position in many areas nationally.
  - 11.2 Crisis Support – This is a critical gap that has also been reflected strongly in the consultation
  - 11.3 Housing Policy – This reflects a need for better join-up with Districts and Boroughs around autism
  
12. The Mental Health Task Group Report that was presented to Select Committee in October 2020 noted several areas that dovetail with the remit of this autism strategy. In particular, the report found:
  - 12.1 That services need to work more closely together to identify and meet the mental health support needs of autistic people, and address the risk of people falling between services.
  - 12.2 That a lack of understanding of autism and how it interacts with mental health has led to mental health needs being misdiagnosed, and problems with support. The report recommends training across the system to support services adjusting the way they work to be accessible to autistic people.
  
13. The areas identified by the Self-Assessment and the Mental Health Task Group were reflected in the consultation responses for this strategy. The priority themes identified to feed into Surrey's All Age Autism Strategy are summarised in the following proposed workstreams:
  - a. Awareness and understanding of autism in services and the wider community**
    - i. Community
    - ii. Workforce
    - iii. Autistic people – support for self-understanding
    - iv. Family carers – support for family understanding
  
  - b. Information and Navigation to live an active life**
    - i. Information about where to find support
    - ii. Information about autism for the public and wider community
    - iii. Information targeted for autistic people and families
    - iv. Support to navigate the system
  
  - c. Education and Preparation for Adulthood**

- i. Educational provision which enables children and young people to be educated within their local community
- ii. Address early intervention and education across all age ranges, including lifelong learning
- iii. A curriculum which prepares autistic children and young people for adulthood
- iv. Improved accessibility, quality and experience of statutory processes

**d. Health and Social Care Support**

- i. Service design / redesign to address gaps, including those relating to Transforming Care
- ii. Mental Health support – improving the autism accessibility of community, crisis and forensic support services, and ensuring that a diagnosis of autism does not act as a barrier to accessing mental health support
- iii. Physical Health and Primary Care
- iv. Assessment of needs
- v. Diagnosis
- vi. Social Care
- vii. Developing our in-house expertise (health and social care)
- viii. Support for family carers
- ix. Strengths-based approach, and proactive planning around skills development for independence
- x. Market Management – addressing the range and accessibility of existing Learning Disability and Mental Health provider offer, and clarifying where we need different services from the market for autistic people
- xi. Influencing and supporting the voluntary sector and “universal plus” options, where support or technology is put in place to facilitate access to universal services or employment

**e. Housing and Independent Living**

- i. Link to preparation for adulthood work
- ii. Adult Social Care – link to independent living framework
- iii. Accessibility of District and Borough housing processes
- iv. Lobbying – National standards for disability access in housing

**f. Employment**

- i. SCC, the NHS in Surrey, and the organisations we commission should lead by example in employing autistic people
- ii. Supported employment, strengthening the DWP universal offer, building on the voluntary sector offer, working with employers
- iii. Developing the strengths-based work of existing supported living, outreach and day activity providers, supporting autistic people to find jobs and voluntary roles.
- iv. Preparation for adulthood – Learning skills for independence including travel training & expectation of employment / taking on positive roles.

This includes work placements and employment readiness for people with significant support needs

14. The development of the strategy and the delivery of each of these workstreams will require a lead officer, a person with lived experience and a range of other stakeholders from across the service system. The strategy development and implementation will also need project management and Communications support. Our expected workstream staffing implications and proposed membership are outlined in Appendix 4.

## Conclusions

15. Children and young autistic people in Surrey should be able to grow up feeling rooted in their community and use their strengths to build successful and fulfilled lives. We know that there are significant barriers to achieving this within Surrey's service system. We need sufficient schools and colleges accessible to children and young people across the autism spectrum, so that they can be educated closer to home. Services do not link up well enough, and there is a commonly reported experience of people "falling through the gaps". Many autistic people experience the transition to adult support as disjointed. Many of the universal support services we all rely on in the community need a better understanding of autism so that they can make reasonable adjustments. People struggle to navigate the service system, and to find the information they need to access support that is available. Opportunities for employment are limited, and support is often not available where it is needed. Mental health support in the community is not always accessible to autistic people, and support is not always available when people are in crisis. The workstreams we have identified are all interdependent, and together will aim to address these issues.
16. Many of the solutions lie with improved accessibility of universal support and current targeted service offers. Improved access to existing support and building community awareness will aim to avoid crises. This will reduce the pressure on more intensive, specialist services, while providing autistic people with better life outcomes.
17. We had many powerful quotes from autistic people during the consultation, and have included a selection of them in this document:
  - 17.1 On Social Care *"My enabling independence lady helped me with a schedule and taught me some things I was too embarrassed to ask for help with"*  
*"None of the support workers really understand autism, they think they do, but they really don't"*
  - 17.2 On the Police *"I think my autism led them to misread me"*
  - 17.3 On Diagnosis *"an earlier diagnosis would have helped but I am extremely grateful for now having an accurate diagnosis as my life now makes more sense and I can use tools that work more effectively for me"*

- 17.4 On Housing *“On housing its “you get what you get” ...and there is never enough information... When I was bidding I got limited help and it was so confusing”*
- 17.5 On Community Settings *“leisure activities are not accessible due to overwhelming lights and sounds”*
- 17.6 On Mental Health Support (We need) *“Some understanding that an autistic person can have mental health problems too. Don’t refuse to help with a MH problem just because someone is autistic. You can have both problems!!”*  
*“As soon as I got my diagnosis at age 44 I was dismissed from CMHT (Community Mental Health Teams), I still have massive MH (Mental Health) issues. No one helps me, I regularly take overdoses or hurt myself, no one helps, no one wants to help”*  
*“The mental health teams are amazing and quite literally saved my life more than once”*
- 17.7 On Mental Health Hospitals *“the environment is completely inconducive to Autistics”*  
*“I was very scared” “My admissions have only added to my distress”*  
*“knowledge of ASD (Autism Spectrum Disorder) in females is pretty much non-existent, in both community and inpatient settings”*

18. This strategy aims to address the issues identified in the consultation over a 5-year period. We will set up working groups to identify and implement improved service design and approaches to address each of the key issues.

## Recommendations

1. To endorse the strategic themes and continued development and implementation of the Surrey All-Age Autism Strategy 2021-2026 across Adult Social Care, Children Families Lifelong Learning and Culture and Health.
2. To acknowledge the resource implications (staff and timelines) for the development and implementation of the strategy.

## Next steps

- Drafting strategy – to include input from Select Committee: January 2021
- Draft Strategy published on Surrey Says for final input and comments: February 2021
- Final draft and signoff from Committees in Common: April 2021
- Implementation: April 2021 - 2026

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**Sources / background papers:**

[Autism Act 2009](#)

[National Autism Strategy](#) and [Statutory Guidance](#)

[Surrey Adults Learning Disability and Autism Strategy 2016 - 2020](#)

[IPC – Ordinary and Unique Lives](#)

Emerging South East Region Autism Strategy being developed by NHS England and NHS Improvement

**Appendices:**

1. Data
2. Governance Structure
3. Autism Partnership Board Current Information
4. All Age Autism Strategy Development and Implementation – Staffing Implications