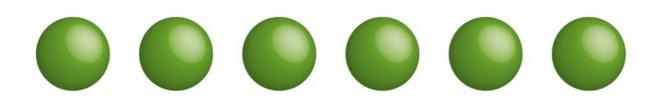




## Appendix 1

# Autism Strategy Framework for Sutton







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## I Introduction

#### Why are we doing this now?

- The Department of Health (DH) has asked all councils to carry out a selfassessment of the progress they are making towards the priorities set out in the national autism strategy, *Fulfilling and Rewarding Lives*.<sup>1</sup>
- Through our local self-assessment work, we realise that while we have many good approaches and services in place that are benefiting people with autism in the borough, there is more we could do.
- This framework is the first step towards developing a more comprehensive approach to autism in Sutton. It links with a separate piece of work on the transition from children's to adult services.

#### Whose strategy is it?

The development of this framework has been led by LB Sutton Adult Social Care, with input from people with autism, third sector organisations and other professionals. Over 40 stakeholders were brought together to discuss what is working well, and what needs to change at an event facilitated by NDTi and Ambitious about Autism. The framework draws on what stakeholders told us. Although the Council has led the work so far, making sure that Sutton is a welcoming and supportive community in which people with autism can lead good lives is a task which involves many partners and organisations. It is our aspiration that the document will help other agencies to recognise the contribution they can make to improving the lives of people with autism in Sutton.

#### Who does it cover?

Autism is a spectrum condition. This means that, while all people with autism share certain difficulties in communicating with others and making sense of the world, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives, but others may also have learning disabilities and need a lifetime of specialist support.

<sup>&</sup>lt;sup>1</sup> https://www.gov.uk/government/news/fulfilling-and-rewarding-lives-the-strategy-for-adults-with-autism-in-england

This framework is intended to cover all adults and young people with autism in Sutton. It uses the term 'people with autism' to mean anyone who is on the autistic spectrum.

#### What do we know about people with autism in Sutton?

Many people with autism may never have been in touch with services since they left school. Some will be living full, independent lives without any support from external agencies. It is therefore difficult to know exactly how many people with autism live in Sutton. It is estimated that about one in every hundred people are on the autistic spectrum. Around a half may also have a learning disability. The table below gives estimates of the local population of people with autism, based on this figure. The numbers are set to rise slowly between 2012 and 2016, but the increase is likely to be fairly small.

## People aged 18-64 predicted to be on the autism spectrum, by age and gender, projected to 2016 in London Borough of Sutton

Autism Spectrum Condition – All People	2012	2013	2014	2015	2016
People aged 18-24 predicted to be on the					
autism spectrum	148	146	146	144	144
People aged 25-34 predicted to be on the autism spectrum	272	281	286	291	293
People aged 35-44 predicted to be on the autism spectrum	297	299	303	309	313
People aged 45-54 predicted to be on the autism spectrum	282	289	293	297	299
People aged 55-64 predicted to be on the autism spectrum	196	196	198	204	208
Total population aged 18- 64 predicted to be on the autism spectrum	1,197	1,211	1,227	1,246	1,258

#### **The Vision**

The Government's vision is:

'All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents'.

- In Sutton we share this vision. We want people with autism to be able to expect:
  - An autism aware and friendly Sutton, where all services understand autism, and treat people with autism well
  - A lifelong approach, with no gaps between children's and adult services
  - Good information about what is available
  - Their voices to be heard.



## **II Priority Areas**

This section looks in turn at all the areas that the DH has identified as important in the selfassessment. For each area, we have set out the current situation, based on what stakeholders told us, and the knowledge held by the council. We then set out what should ideally be in place. This section draws on the good practice expertise of Ambitious about Autism. Finally, each section sets out a number of priority actions, which aim to bring Sutton closer to the good practice model. These also draw on discussions with stakeholders.

#### Planning

#### Where are we now?

Local stakeholders told us about some good examples of individual planning for people with autism, although planning was not always joined up across agencies, and reviews were not carried out consistently.

Planning of services across Sutton was a more difficult area. The information on which planning should be based was patchy. We are not certain how many people with autism live in the borough (although the estimate on page 4 is a good starting point), what their circumstances are, and what help they might need to live full lives and to make a contribution. Mainstream strategies, such as housing, do not specifically address autism. People with autism and their carers do not have a strong voice in discussions about services in Sutton.

#### What does good look like - where would we like to be?

- For individual people with autism, good person-centred planning should be in place.
- Information on the numbers of people with autism in the area should be available, as well as on likely future numbers, based on information from schools.
- There should be a multiagency group in place to act as a focus for planning and action on autism, with links into other groups such as the Health and Wellbeing Board.

The voices of people with autism should be at the heart of the planning process.

#### What are we going to do next?

The council and CCG will:

- Agree a new planning structure for autism to act as a focus for the work set out in this document. This will need to:
  - Be sponsored and supported at a senior strategic level
  - $\circ~$  Feed into the Health and Wellbeing Board
  - Keep an overview of the work streams described below, which may be delivered by small, short-term groups.
- Improve local data and information we have about autism, by including this in the Joint Strategic Needs Assessment.
- Make sure that autism is included in the wider council and CCG's work to develop joint integrated commissioning.

#### Training

#### Where are we now?

We have made training available in a number of different ways. All staff at the Council receives equality and diversity training, and autism is included within this. Also, specific training on autism is available for everyone who works in social care, as well as other interested staff. Finally, we have just introduced a multi-agency, e-learning programme on autism. This can be accessed by all our partner agencies across Sutton, and it aims to raise awareness of autism in organisations such as the NHS, CCG, Police, Housing, Education, Employment and many others.

Our stakeholders said that there is more to be done. Some professionals, such as GPs, teachers and the police could play a key role in supporting people with autism, and there should be targeted training available for them. People with autism themselves could make an important contribution to delivering training, as their stories are a powerful way of increasing understanding of the impact of autism.

#### What does good look like - where would we like to be?

A Sutton wide multiagency local training strategy on autism should be in place. This should include:

- Induction sessions that make the connections with equality, diversity and the needs of vulnerable groups
- Autism awareness for front line staff in all agencies that might come into contact with people with autism
- Specialist training for staff such as social workers and GPs.
- All training should include the voices and stories of people with autism, who should play a central role in delivering training.
- Funding for autism training should be identified.
- Guides on levels of training for each department and agency should be produced, and the number of staff who has received training should be kept under review.
- Training for parents/carers should be available, possibly from voluntary organisations.

#### What are we going to do next?

We will set up a short-term task group to agree a multiagency strategy on training and development on autism. This will build on what we already have in place to:

- Develop a tiered approach that includes general awareness, as well as more specialist training
- Review the e-learning programme, including how best to promote it and bring it in line with best practice, particularly through bringing in the experience and voice of people with autism
- Identify people with autism who will work with us to strengthen our training.

#### **Diagnosis pathway**

#### Where are we now?

The Clinical Commissioning Group (CCG) has introduced a new referral and diagnostic pathway for Sutton. This includes accessing specialist diagnostic services from the South London and Maudsley Trust. If a GP thinks someone may have autism, they can make a referral. We do not yet have a clear picture of how well known and well used this service is among GPs in Sutton.

Our stakeholders thought that the diagnosis pathway generally worked well for children in Sutton. For adults, though, the picture was less positive. Stakeholders were not clear how

to access specialist diagnosis, and once people were in the system; waiting lists for diagnosis could be long.

#### What does good look like - where would we like to be?

- Information on autism, and the pathways into services should be available to adults with autism, as well as to their relatives and carers.
- Information on autism, and the pathways into services should be available to professionals who are most likely to come into contact with people with autism.
- There could be a single entry point for all adults on the autistic spectrum and clear visual information for people with autism and their families/carers on how to get a diagnosis, and on the range of services that is available.
- Once a person has had a diagnosis of autism, tailored information about their service options and follow up support should be available, including a trigger for a Community Care Assessment.
- Local services should be in line with NICE guidelines for the diagnostic process and support for adults with autism<sup>2</sup>.

#### What are we going to do next?

The CCG and council will:

- Agree a communications strategy for the new pathway, so that all relevant professionals, particularly social care staff and GPs, know that it is in place, and understand what it means for them.
- Involve stakeholders in reviewing how well the new pathway is working once it has been in place for six months. This will include looking at whether a local diagnostic service is needed.
- Review referral pathway and include a trigger for offering a community care assessment following diagnosis.

<sup>&</sup>lt;sup>2</sup> <u>http://publications.nice.org.uk/autism-recognition-referral-diagnosis-and-management-of-adults-on-the-autism-spectrum-cg142</u>

#### **Care and support**

#### Where are we now?

Sutton is very committed to helping people live independently in the community. About 30 organisations operate in Sutton offering different types of support, from taking people out for social activities, to providing help with personal care such as washing and dressing. People have as much choice and control as possible, and many people who are eligible for council help have a personal budget.

People with autism who meet the council's eligibility criteria will benefit from our focus on independent living, choice and control. But we do not yet have any services in place that are designed specifically for people with autism, and there is a limited range of very flexible, personalised services on which people can spend their personal budgets.

Stakeholders agreed that people with autism who also have a learning disability are generally well supported in Sutton. But they highlighted the lack of continuity between children's services and adult services and also told us about a number of gaps in services, including advocacy, social groups, and services that have a high level of expertise and knowledge about autism.

#### What does good look like - where would we like to be?

- The person with autism should always be at the centre of all decisions about their care.
- A range of services and opportunities should be in place for people across the autism spectrum.
- This should include tailored, personalised services for people with autism who have a personal budget.
- Support should be available to help people with autism make best use of mainstream services in the community, such as leisure and transport services.
- There should be specific activity groups in place for adults with high functioning autism who do not wish to socialise in other areas, as well as other support, such as befriending, to tackle social isolation.

Information and support should be available to families and carers.

#### What are we going to do next?

We will:

- Carry out a mapping exercise to build a complete picture of what is available for people with autism in Sutton.
- Look at how best to make this information widely available to the people who need it – for example by developing a dedicated website.
- Work with people with autism and other stakeholders to help them set up activities and social groups, where this is what they want.
- Make sure that services commissioned by CCG and the Council (for example from private, voluntary and independent organisations) are autism-aware and friendly.

#### Housing

#### Where are we now?

Sutton has done a great deal of work to make sure that a good range of flexible, adaptable housing is in place locally for anyone who needs it. The Council has made rapid progress in moving away from residential care, towards helping people to live independently in the community. Unusually, several units are made available each year specifically for people with a learning disability, including people with autism.

Floating support services are also available for people who may sometimes need support in their own homes.

Stakeholders told us that some good quality housing services are available in Sutton. But local services can be expensive, and there is little support to prepare people who want to live independently. As a result, many adults with autism continue to live with their families, even though they would prefer independent living.

#### What does good look like - where would we like to be?

- People who plan and provide housing should consider the needs of people with autism across the spectrum and make sure that the barriers for people with autism are identified and tackled.
- People with autism should be included in engagement exercises about housing strategy.
- Housing should be available that offers different levels of flexible support, and help people to take up employment.
- Councils should reduce the number of out of borough residential placements, and instead should make sure that supported housing based options are in place.

#### What are we going to do next?

We will:

- Work with colleagues in housing to make sure that the needs of people with autism who do not have a diagnosis of learning disability are also taken account of in our local housing strategy.
- Make sure that out housing planning is based on good information on future need by including housing in our transition work with young people.

#### Employment

#### Where are we now?

Supported employment opportunities are available from Mencap Pathway for people with autism who also have a learning disability. The Council also has an inclusive approach to employing people with a range of disabilities in visible roles. As well as employing people in the Council, the Community Equipment Service, which is now based in Croydon, also includes a number of staff with disabilities.

Stakeholders fed back that people were not aware of what employment support was available in Sutton. They also felt that there was not enough help for people to identify their potential strengths. Employers, too, had little information on employing people with autism.

#### What does good look like?

The council and wider NHS should increase employment opportunities, both paid and voluntary, for people with autism, by developing an Employment Pathway and actively promoting the benefits of employing people with autism to employers.

#### What are we going to do next?

We will:

- Review existing supported employment in Sutton to make sure it is suitable for people with autism.
- Build employment into our pilot work on transitions as a strong theme.
- Work with partners such as Job Centre Plus and Connexions to improve the support available.
- As big public sector employers, the Council and NHS should act as model an autism-aware and friendly approach.

#### **Criminal Justice**

#### Where are we now?

The council and the local police work closely together on community safety issues. Anyone who comes into contact with the police, and who may be vulnerable, has the support of the Appropriate Adult Service to make sure that they are being treated well. Organisations in Sutton are working together to identify whether autism is a factor for any local repeat offenders. They are also looking at preventing people from becoming involved with the police by providing support at an earlier stage. Training and awareness raising about autism are available to the police and other partners.

Stakeholders told us about some good examples where people with autism had been treated well by police, and about strong links between court and health services. However, there seemed to be little specialist expertise available in the criminal justice system in Sutton. The support that was available, such as the intermediary scheme for vulnerable people, was not widely known about.

#### What does good look like - where would we like to be?

There needs to be a joined up approach across all the partner agencies, with good information and training for front line staff

#### What are we going to do next?

We will:

Work with the local police to review current custody arrangements, court diversion schemes and training



## III What happens next?

This document is just the first step. Although LB Sutton has led the process of drawing it together, it needs to be supported by all the partner agencies – through the Health and Wellbeing Board. It also needs to be discussed further with our stakeholders, including people with autism. Our draft action plan, which draws together all the actions set out above, includes some actions that can be delivered relatively quickly and easily, others will need much further development, via small time-limited task groups.



## **IV Action Plan**

This section brings together the recommendations and commitments included in the framework. They will need to be prioritised and refined by the new planning structure, once this is in place.

- Agree a new planning structure for autism to act as a focus for the work set out in this document. This should be driven using a dynamic project and implementation plan and will need to:
  - o Be sponsored and supported at strategic level
  - Feed into the Health and Wellbeing Board
  - Keep an overview of the work streams described below, which may be delivered by small, short-term groups.
- Improve the local data and information we have about autism, by including this in the Joint Strategic Needs Assessment.
- Make sure that autism is included in the wider council and CCG's work to develop joint integrated commissioning.
- Make sure that services commissioned by CCG and the Council (for example from private, voluntary and independent organisations) are autism aware and friendly.
- Set up a short-term task group to agree a multiagency strategy on training and development on autism. This will build on what we already have in place to:
  - Develop a tiered approach that includes general awareness, as well as more specialist training
  - Review the e-learning programme, including how best to promote it and bring it in line with best practice, particularly through bringing in the experience and voice of people with autism
  - o Identify people with autism who will work with us to strengthen our training.
- Agree a communications strategy for the new diagnostic pathway, so that all relevant professionals, particularly social care staff and GPs, know that it is in place, and understand what it means for them.

- Involve stakeholders in reviewing how well the new pathway is working once it has been in place for six months. This will include looking at whether a local diagnostic service is needed.
- Carry out a mapping exercise to build a complete picture of what is available for people with autism in Sutton.
- Look at how best to make this information widely available to the people who need it – for example by developing a dedicated website.
- Work with people with autism and other stakeholders to help them set up activities and social groups, where this is what they want.
- Work with colleagues in housing to make sure that the needs of people with autism who do not have a diagnosis of learning disability are also taken account of in our local housing strategy.
- Make sure that out housing planning is based on good information on future need by including housing in our transition work with young people.
- Review existing supported employment in Sutton to make sure it is suitable for people with autism.
- Build employment into our pilot work on transitions as a strong theme.
- Work with partners such as Job Centre Plus and Connexions to improve the support available.
- As big public sector employers, the Council and NHS should act as model an autism-friendly approach.
- Work with the local police to review current custody arrangements, court diversion schemes and training
- Work with local probation services to improve links and services for people with ASD.