

# Strategy for Adults with Autism in Kent

## Summary

### Why do we need a strategy?

It is a requirement for all Local Authorities to have a strategy for adults with autism as set out in the National Autism Strategy, 'Fulfilling and Rewarding Lives' (2010) and to have a local plan in place. In addition to the statutory and moral responsibility to improve support and care for all people with autism there is also an economic argument for improving the support and care for all people with autism. A study led by the London School of Economics and Political Science estimates that autism costs the UK at least £32 billion per year in treatment, lost earnings, and care and support for children and adults with autism. This is far higher than for other conditions, for example: £12 billion for cancer, £8 billion for heart disease and £5 billion for stroke. They estimated the cost of an autism spectrum disorder throughout a person's lifespan as £0.92 million for those without intellectual disability.

### Scope of the Strategy

The strategy primarily addresses the needs of adults with autism who do not have a co-occurring learning disability (including people diagnosed with Asperger's Syndrome) who live within the boundaries or are the responsibility of Kent County Council. Although mainly focusing on those over 18 years old, issues related to young people in transition are also included.

### Organisation of the Strategy

The strategy is organised in sections reflecting the national strategy. Each section follows the same format:

- The views of people with autism
- The current situation (as of February 2016)
- Future commitments and priorities,
- Best practice,
- Key messages
- Key strategic objectives.

The views of people with autism are incorporated throughout the document. These include 'I' statements which were identified when engaging with people with autism in developing the national guidance 'Think Autism'.

## The Challenge – Prevalence and Needs

It is thought that the overall prevalence of adults with autism nationally is 1.1% of the population<sup>1</sup>. With the Kent adult population (16 to 90+ years old) at the time of writing estimated at 1,221,000 then this would include approximately 13,431 people with autism. Current estimates suggest over half these will have a co-occurring learning disability and approximately 6,700 will have autism in the absence of a learning disability.

Autism diagnosis rates are higher in males compared to females. The figure most often quoted is around 4:1. However an accurate estimate of the exact ratio is not available and estimates differ depending on whether people also have a learning disability. In addition autism spectrum disorders are under-diagnosed in females, and therefore the male to female ratio may be closer than is currently quoted.

Autism rarely occurs in isolation and is with other conditions such as ADHD, epilepsy, dyslexia and mental health issues. According to the National Autistic Society:

- 70% of people with autism have one co-existing condition and 50 % have two
- 70% have a learning difficulty, 50% have a learning disability
- 65% of people with Asperger's Syndrome have a psychiatric condition
- 84% of those with a Pervasive Developmental Disorder diagnosis have anxiety
- 30% have ADHD
- 10% have Obsessive Compulsive Disorder
- 25% have epilepsy.

People with autism are sometimes seen to display challenging behaviour, which can be difficult for those who support them and which can significantly impact on their quality of life and that of their family and/or carers.

Challenges facing many people with autism:

- Being socially excluded due to the difficulty with social communication and maintaining relationships
- Difficulty in securing and /or maintaining employment
- Inconsistency in the response of services with people's needs 'falling between' services as autism does not always fit into traditional service silos such as mental health, physical disabilities and learning disabilities
- Risk of homelessness

- Risk of all forms of exploitation
- Being involved in the criminal justice system which does not understand their needs
- Increased physical health problems due to difficulties in engaging with health services or sensory sensitivities interfering with personal care.

### **The Collective Vision**

We fully endorse the priority areas and vision for people with autism set out in the National Strategy for Adults with Autism in England and Wales.

“All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them”

At the core of this strategy is the desire to create an autism friendly society in its widest sense.

### **Core Principles Underpinning the Autism Strategy**

- All adults with autism are treated equally and fairly and not discriminated against on the grounds of their condition, sexual orientation, gender identity, race, colour or religion
- Adults with autism are able to live their lives free from the risk of discrimination, hate crime and abuse
- People with autism have equal access to mainstream health and social care with reasonable adjustments made to achieve this
- The awareness of the condition and how to create autism friendly environments and provide autism friendly support is promoted and provided to all – encouraging communities to be “autism friendly”
- People with autism and their carers have the opportunity to express their views and opinions during the development of relevant services, guidance and policies and there is ongoing engagement
- A preventative approach underpins service development
- Services are flexible, based on individual needs and maximise choice and control for the person with autism and their families, carers

## **Core Strategic Objectives**

### **Leadership, Planning and Commissioning**

- 1 To work more collaboratively with our partners and across children's and adult services
- 2 To develop systems to routinely collect data on people with autism – numbers and needs
- 3 To extend the membership of the Autism Collaborative, and to develop the group into an Autism Action Alliance and implement the Action Plan

### **Engagement with People with Autism and their Carers**

- 4 To ensure people with autism and their families and carers are involved and have their opinions heard
- 5 To improve the understanding of Commissioners of the experience of people with autism (including the effectiveness of services and the outcomes achieved for individuals). This will include feedback from people with autism and their families and carers

### **Diagnosis, Assessment and Support**

- 6 To address the current waiting list for diagnostic assessments
- 7 To implement the Neurodevelopmental Pathway to include:
  - Multidisciplinary diagnosis and assessment including those with complex needs
  - Post diagnostic support services
  - Provision of specialist interventions
  - Positive behaviour management service
  - Specialist information, advice and training service for mainstream professionals

### **Facing Life Changes (Transition)**

- 8 Develop and implement the Neurodevelopmental Pathway ensuring the needs of young people in transition are addressed
- 9 Ensure that there is sufficient good quality further education provision to meet the needs of young people across the autistic spectrum as close to the family home as possible
- 10 Ensure a smooth transition from children's to adult services

### **Training and Further Education**

- 11 To establish a clear transfer process for transition from school to college
- 12 Establish tracking of people subject to EHCPs above statutory school age to remain alert of those NEET and whose destinations are not known
- 13 Commission outcomes for 0-25 Speech and Language Therapy
- 14 Educational establishments provide autism friendly support and environments and promote positive outcomes
- 15 Fewer young people drop out of college without qualifications

### **Employment**

- 16 To provide a range of support to people with autism to increase the numbers of people with autism who are in employment – paid or voluntary

### **Housing, Care and Support**

- 18 Undertake a housing needs assessment of people with autism
- 19 Develop a diverse housing market that provides various levels of skilled support
- 20 Work with the market to develop a range of housing related support services
- 21 Ensure social care, health and educational support services provide skilled, effective, autism friendly support, using an enabling and empowering approach
- 22 Develop specialist services that can provide assessment and treatment, ideally within individuals' current home or, where necessary, in small local specialist units implementing positive behaviour support and the SPELL framework

### **Workforce Development**

- 23 Ensure a range of levels training of training in autism is identified as a priority within local workforce development plans across relevant agencies and providers
- 24 Work with other organisations and agencies, including those in educational settings, the criminal justice system, employment support services, and the voluntary sector, to promote the provision and take-up of autism awareness training among their staff training among their staff

## **The Criminal Justice System**

- 25 To improve the experience of people with autism within the Criminal Justice System
- 26 To set up a task and finish group to identify gaps and issues for people with autism in the Criminal Justice System

## **Carers**

- 27 To identify the numbers and needs of carers with autism in Kent and the families and carers of those with autism and provide appropriate services and support in line with requirements of the Care Act
- 28 Training is available and accessible for families and those who provide support for people with autism in an unpaid capacity

## **Autism Friendly' Communities and Conclusions**

In Kent we are committed to building community capacity in line with the Government's Think Local Act Personal (TLAP) initiative:

Building social support networks

Encouraging membership of groups

Nurturing an inclusive community

Enabling everyone to make a contribution (participation and co-production)

Addressing these areas produces better outcomes for individuals and communities, in terms of better physical health, mental health and wellbeing as well as benefits beyond health and social care. There are other benefits include positive effects on crime and community safety, educational attainment, public sector efficiency, income, viability of local services and better neighbourhoods.

One of the key ways to make some of these things happen is by supporting people with autism to have a role in their local community – through work (paid or voluntary), through taking part in local and through using the same community facilities as others. This requires such facilities and events to be autism friendly.

The vision for this strategy is that if we achieve the core strategic objectives, Kent will be closer to having communities that understand, accept and support people with autism as set out in Think Autism (2014).