

Cambridgeshire Autism Strategy and Action Plan 2015/16 to 2018/19.

1. Introduction

1.1. Autism is a lifelong developmental disability, sometimes referred to as Autistic Spectrum Disorder (ASD) or Autistic Spectrum Condition (ASC). It affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism may also experience over-or under-sensitivity to sounds, touch, tastes, smells, light or colours. Asperger Syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language. In this document we refer to this diverse group as 'people with autism'.

1.2. Cambridgeshire's strategy for improving the lives of people with autism has traditionally formed part of the Learning Disability commissioning strategy. However as autism affects a range of people with different needs it has been decided to create a single strategy that addresses the circumstances of people with autism as a distinct group.

1.3. This strategy includes an action plan that builds on a previous action plan designed to implement 'Leading Fulfilling and Rewarding Lives' (2010), the government's plan to put the requirements of the Autism Act into effect. It also addresses new requirements arising from the publication of 'Think Autism' (2014) and new 'Adult Autism Strategy: Statutory Guidance' issued in March 2015. This action plan is detailed in section 4 below and shows how these plans and guidance will be implemented in Cambridgeshire.

2. Where are we now

2.1. It is estimated that about 1% of the population nationally are on the autistic spectrum, the majority being male, although there may be under-reporting of females with autism. In Cambridgeshire this amounted to about 6,300 people in 2012 and is

estimated to increase to over 6,500 people in 2016. (Cambridgeshire Insight at: <http://www.cambridgeshireinsight.org.uk/population-and-demographics/population-forecasts>) This included 4160 people of working age in 2012 and 4552 in 2016. People with autism often have no obvious disability and some individuals may not wish to have their condition recognised. Diagnostic services are not readily available to all ages and these factors may result in relatively few people being diagnosed compared with the numbers who have the condition. In Cambridgeshire in 2014/15 there were 72 people diagnosed with an autistic spectrum condition and 52 on the waiting list for an appointment. This equates to a rate of diagnosis of 14.3 people diagnosed per 100,000 adult population and compares favourably to an average rate of 7 per 100,000 population in the Eastern region and is on a par with the rate of 14.4 in England as a whole. In 2015/16 there were 130 people diagnosed which presents a significant increase in the rate of diagnosis. The waiting time for diagnosis in the period 2015/16 was between 5 and 6 months although this has recently increased to nearly a year. Accessing diagnostic services can be problematic for young people aged 12-17 years who do not have significant mental health needs. The waiting list for diagnosis carried out by community paediatricians employed by Cambridgeshire Community Services has recently been re-opened but assessments have yet to begin and waiting times are likely to be lengthy.

2.2. The NAS estimates that only 15% of adults with autism in the UK are in full-time paid employment (NAS 'Autism and Asperger's Facts and Figures 2014' at: <http://www.autism.org.uk/about-autism/myths-facts-and-statistics/some-facts-and-statistics.aspx> .) Applied to the 4160 people of working age with autism in Cambridgeshire in 2012 this means that over 3500 (85%) people of working age with autism are not in full time employment.

2.3. It has been estimated by NAS that between 25% and 33% of people with learning disabilities are also on the autistic spectrum. Cambridgeshire's Joint Strategic Needs Assessment (2013) <http://www.cambridgeshirejsna.org.uk/physical-disabilities-and-learning-disabilities-through-life-course-2013> estimated that in 2012 there were about 11,000 adults in Cambridgeshire with some kind of learning disability, ranging from moderate to severe. Therefore there are likely to be between 2730 and 3630 people in the county with a learning disability who are also on the autistic spectrum. This group are more likely than their non-disabled peers to:

- be socially excluded;
- have poorer physical and mental health;
- have difficulties in accessing healthcare;

- be at risk from abuse;
- be discriminated against;
- need support to access housing, health, employment and independent living;
- be at greater risk of ending up in prison.

2.4. Learning disability of any kind is more common in poorer households and mild learning disability is also more common in poorer communities. There are proportionally more people with learning disabilities in Fenland compared to other districts. As the population with learning disabilities as a whole is predicted to increase in Cambridgeshire in the coming years, there will be a proportionately higher increase in the numbers in Fenland and this will include those with complex needs and multiple disabilities.

2.5. The mental health needs of adults with autism, personality disorder and dual diagnosis are complex. People with these conditions often experience more than one disorder or disease (both mental and physical), behaviour difficulties, social exclusion and unemployment. Some may have contact with the criminal justice system, as either victims of crime or offenders. Some may also have been excluded from accessing health or social care services because of their diagnosis. There are often significant implications for family and carers.

2.6. Adults with mental illness have a substantially reduced life expectancy due to both mental and physical ill health with a significant proportion of excess deaths being associated with physical conditions. There is often inequality of access to health services for physical illness for people who use mental health services. People with mental illness need equal access in order to improve their physical health problems and reduce their risk factors. This would result in improvements to both their physical and mental health.

2.7. For adults aged 18 or over with autism, a high-quality diagnostic service is available from Cambridgeshire and Peterborough Foundation Trust (CPFT). However, services to support adults with autism and their carers in the community are sometimes fragmented and difficult to access.

2.8. Adults with personality disorder, dual diagnosis and autism sometimes experience mental health crises and need help quickly to stop them harming themselves or others. The Crisis Care Concordat is aimed at making sure that people

experiencing a mental health crisis receive an appropriate emergency mental health service. It reflects a new requirement for the NHS that “every community has plans to ensure no one in mental health crisis will be turned away from health services”. Effective local implementation of the Crisis Care Concordat is critical to ensuring that adults in mental health crisis are able to recover, and that admissions to hospital or to prison might be avoided. Action has been taken in developing the Crisis Concordat and this was signed by statutory agencies in Cambridgeshire in November 2014.

2.7. It was found in Cambridgeshire that people with autism who have a need for support can fall through the gap created by traditional learning disability and mental health boundaries of both health and social care. Therefore Cambridgeshire County Council decided to create a Vulnerable Adults Team, renamed the Autism and Adult Support Team (AAST) in November 2014 and the Adults and Autism Team (AAT) in April 2015. This team has responsibility for undertaking statutory social care assessments for people on the Autistic Spectrum, where primary need is not Mental Health, Learning or Physical Disability. The team also arrange ongoing support for people who meet Adult Social Care eligibility criteria. The team has 0.5 Senior Care Manager and 1.75 Care managers and has had a stand alone budget since 1st April 2015.

2.8. There is a need to ensure that team members have the skill and knowledge to undertake their work and ongoing training will remain a priority. Training has been identified and some of this has already taken place. Staffing levels will also need to be monitored to ensure that it is adequate to meet service needs. The team work closely with Children’s Services, the National Autistic Society and other partner agencies.

2.9. The team will be working with the Learning Disability Partnership Young Adults Team to incorporate the changes in line with Special Education Needs & Disabilities (SEND) reforms within the Children and Families Act and the Care Act (2014). Processes to prepare people for adulthood are being developed jointly across children’s and adult health, education and social care services. AAT will fully involve young people with autism and their families in multi-agency planning for preparation for adulthood.

2.10. Recent years have brought new statutory guidance and guidelines for local authorities and NHS bodies, which are contained in the following documents;

- The Autism Act (2009)

- Fulfilling and rewarding lives - the national strategy for autism (2010). Statutory guidance for implementing the national strategy (DOH Best Practice Guidance, Gateway 15204, 2010)
- In June 2012 the National Institute of Health and Clinical Excellence (NICE) produced clinical guidelines on the recognition, referral, diagnosis and management of people with autism. A key purpose of these guidelines was to provide evidence based recommendations to support the further implementation of the national autism strategy.
- Think Autism (2014) – the governments update of Fulfilling and Rewarding Lives
- Adult Autism Strategy Statutory Guidance (2015)

2.8. Locally Cambridgeshire aims to help people to live independent lives in the community; protect the most vulnerable in our society and provide support to people when they need it most. In 2010 Cambridgeshire commissioned a project development worker to support people with autism and their families. Information was gathered on 41 people with autism aged between 14 and 50 years old. It was found that access to diagnosis; employment and support through transition to adulthood were the main areas where help was needed.

2.9. It is also the case that people with learning disabilities who have autism have traditionally been placed out of county, as it is generally this group of people and those with mental health difficulties who have very complex and specialist health and social care support needs which pose a challenge to existing services. Being placed out of county can mean they are living a long way from their families and support networks and may be more likely to receive inadequate support in the long term. In view of this the Learning Disability Partnership established an Out of County project team to settle people in community based facilities within Cambridgeshire and as a result the vast majority of people in ‘Winterbourne’ type hospital placements have now been brought back in county. In addition six students who were in an out of county residential establishment providing education and care have been successfully moved back into Cambridgeshire.

2.10. Following the publication of ‘Fulfilling and Rewarding Lives’ Cambridgeshire established a strategic autism consortium in 2011 which drew up an action plan to implement the government’s strategy. This consortium has several active members who are on the autistic spectrum or who are family carers. As a result of the work of this group and others the outcomes listed in 3.1 below were achieved:

2.11. There is still much more work to be done – data from the support manager posts mentioned above shows that people still require support around social isolation, housing and employment. There is a need for more information about what outcomes are being achieved by the above measures. There are growing numbers of children who will progress into adulthood and increase the demand for services in this area.

2.12 However there are also opportunities in Cambridgeshire such as the introduction of Transforming Lives, which is a new model of social care which aims to help people progress to greater independence, choice and control within their local communities. Transforming Lives adopts a tiered approach to providing support to people, rather than a ‘one size fits all’ approach. The graphic below explains these different tiers:



personalised support which will benefit groups with a range of different needs, such as those on the autistic spectrum. Improved access to community services as described in the action plan below will assist people in Tier One

2.14 In addition to Transforming Lives, the Care Act (2014) places an obligation on Cambridgeshire to provide advice and information to a wider range of people in the county other than those who are eligible for social care. Both these initiatives should have a beneficial impact on people with autism in Cambridgeshire.

3. Where do we want to be?

3.1. In Cambridgeshire we are committed to implementing the government's 'Think Autism' strategy. This revised strategy contains 15 priorities that should be met locally. These 15 priorities fall into 3 broad areas;

- An equal part of my local community (priorities 1 to 6)
- The right support at the right time during my lifetime (7 to 13)
- Developing my skills and independence and working to the best of my ability (14 and 15)

A web link to the revised strategy can be found at:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf

Cambridgeshire also aims to comply fully with the statutory guidance issued in March 2015 and which can be found at:

<https://www.gov.uk/government/publications/adult-autism-strategy-statutory-guidance>

Cambridgeshire already complies with much of the statutory guidance in the following respects:

1. Autism awareness training is available for staff working in health and social care and there is a strategy in place to deliver this. The specific needs of people with autism are featured as part of local Care Management training and there is specialist autism training that is relevant for those working in Learning Disability Services.

2. There is a diagnostic pathway for adults and a local diagnostic service
3. A social care and support pathway has been established in addition to a children's pathway
4. Two part time Autism Support Managers based at the Chitra Sethia Centre for Autism provide a link from diagnosis to support, care and assessment. They support people with a range of needs and aim to prevent or delay the development of care and support needs.
5. The Adult and Autism Team (AAT) provides social care assessments for people with autism who do not have a diagnosed learning disability or mental health condition
6. Local health and social care data systems have a field to indicate whether a diagnosis of autism has been established for people with autism only and people with autism and a learning disability.
7. A meaningful Autism Consortium is in operation that includes people with autism and family carers and other partners such as health, the police, Job Centre Plus and third sector providers
8. A 'Speak Up Spectrum' has been established so that people with autism and family carers can be more involved in co-production
9. There is a named autism lead in Cambridgeshire County Council
10. There is senior level sign off for the autism self assessment process
11. The Joint Strategic Needs Assessment includes autism
12. The numbers and length of stay in hospital placements have been reduced in line with the Winterbourne Concordat
13. The Learning Disability Partnership has developed a combined residential, educational and care resource in Cambridgeshire for younger people with learning disabilities who are also likely to be on the autistic spectrum. This has resulted in seven people returning to the county to complete their education and means people are less likely to go out of county in the future
14. A county wide advocacy service is available and accessible to people with autism
15. Employment is a key focus of the Speak Up Spectrum and 'Think Autism' funding is aimed at improving employment opportunities. Employment Fair held to persuade employers of the advantages of employing people with autism.
16. Red2Green's Aspirations programme helps people with autism develop social skills and enhances links with schools and local communities e.g. 'War Detective' DVD project
17. Adult Safeguarding Board established in line with the Care Act and Multi Agency Safeguarding Hub (MASH) in place
18. The Autism Consortium is represented on the county wide Hate Crime Group
19. Carer's Assessments now available under Care Act even if the cared for person is not eligible for social care

However further work is needed in the following areas:

1. Specialist training to be provided for frontline staff, including staff carrying out social care assessments
2. Clearer links between the pathways for diagnosis, care and support and children's services
3. Implementation of Children's and Families Act requirements for children with special educational needs and disability (SEND)
4. Implementation of Care Act responsibilities in terms of assessment of needs for children and young people under 18 years of age
5. Greater integration and co-operation between social care, health, housing and other relevant partners in line with the Care Act
6. Collection of more data on autism locally including children, older people and minority ethnic groups
7. Using a variety of methods to obtain feedback from people with autism and family carers about their experiences
8. Consideration of additional preventative services in line with the Care Act responsibilities and Transforming Lives
9. Provision of clear advice and information that is accessible to people with autism and their carers in line with the Care Act
10. Ensuring that the Cambridgeshire Safeguarding Board complies with requirements under the Care Act
11. Comply fully with the Equality Act 2010 in relation to people with autism
12. Further reduction in the numbers of people placed in hospitals and ensure that the least restrictive care options are being used
13. Advocacy services to be available to support involvement in needs assessments in line with the Care Act
14. Ensuring that staff exercising functions under the MCA have regard to the Mental Capacity Act 2005; Code of Practice 2007, and in particular, how it relates to people with autism
15. Ensuring that employment is promoted as a positive outcome for the majority of children and young people with autism who have Education Health and Care (EHC) plans
16. Improve the employment prospects of adults with autism
17. Assess the care and support needs of adults who are in prison and ensure that eligible needs are met.