

Adults with Autism

Introduction

In March 2015 HM Government published Statutory Guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy – “Fulfilling and Rewarding Lives: The Strategy for Adults with Autism in England” (Department of Health 2010) – and its update – “Think Autism” 2016.

This needs analysis covers young people and adults, aged 18+, with autism.

The International Classification of Diseases (ICD-10) classifies Autistic Spectrum Disorder as:

“A pervasive developmental disorder defined by the presence of abnormal and/or impaired development that is manifest before the age of 3 years, and by the characteristic type of abnormal functioning in all three areas of social interaction, communication, and restricted, repetitive behaviour. The disorder occurs in boys three to four times more often than in girls.”

The terminology “autism” is used as an umbrella term for all conditions on the Autistic Spectrum, including Asperger’s Syndrome.

Autism is known as a spectrum condition because the difficulties it causes can range from mild to severe. The three main areas of difficulty shared by all people with autism are known as “the triad of impairments”,(Wing and Gould, 1978) and these are:

- Social communication (e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice)
- Social interaction (e.g. problems in recognising and understanding other people’s feelings and managing their own)
- Social imagination (e.g. problems in understanding and predicting other people’s intentions and behaviour and imagining situations outside their own routine)

People with autism may experience heightened or reduced sounds, touch, tastes, smells, light or colours. They often prefer to have a fixed routine and can find it difficult to cope with change. Many people with autism may also have other conditions such as attention deficit hyperactivity disorder (ADHD), a learning disability or dyspraxia.

The characteristics of autism vary from one person to another. As a result of interaction between the three main areas of difficulty, the sensory issues and the environment, people with autism may have:

- increased anxiety levels
- need for routines, sometimes having a compulsive nature
- difficulties transitioning to a new activity
- difficulties generalising skills learnt in one situation to another
- special interests
- the ability to be highly focussed when on a specific task,
- difficulties with self-awareness, understanding and expressing their own needs.

Leo Kanner (1943) was the first person to describe and name a pattern of behaviour he observed in a small group of young children, which he termed early infantile autism. A person given this diagnosis will be on the more severe end of the spectrum and will probably (but not always) have learning disabilities too.

Asperger syndrome (also known as Asperger's disorder or simply Asperger's). Asperger's syndrome is mostly a 'hidden disability', and people with Asperger's will very often fail to display any visible signs of autism, and yet present the same Triad of Impairments. People with Asperger's syndrome have fewer problems with speaking and are often of average, or above average, intelligence. They do not usually have the accompanying learning disabilities associated with autism, but they may have specific learning difficulties. These may include dyslexia and dyspraxia or other conditions such as attention deficit hyperactivity disorder (ADHD) and epilepsy.

What do we know?

Facts, Figures, Trends

There have been no epidemiological studies into autism in adults, hence no prevalence data specifically for adults. The prevalence rates established over the years from epidemiological studies have been only for children and this have been applied in this section. However this is unlikely to give the exact prevalence as many adults are not in contact with services and remain unknown. Also in the past, due to a lack of understanding about autism, adults over a certain age may have been given an incorrect diagnosis as having learning disabilities or behavioural problems.

The variation in defining the borderlines of the sub-groups on the autistic spectrum may also influence the prevalence rate (Wing 1996). The ICD-10 definition is used by clinicians to diagnose people with the Triad of Impairments as having either autism or atypical autism. This means that an investigation into the number of people with Asperger or Kanner syndrome is problematic.

As there are no clear boundaries between typical autism from other autistic spectrum disorders, including Asperger's syndrome, the best estimates of prevalence of autistic spectrum disorders are those based on studies focussing on the whole spectrum and not just specific sub-groups. The National Autistic Society states that the best estimate of prevalence rates is 1 per hundred children, regardless of functionality and including people with Asperger's syndrome.

Using figures from Office for National Statistics (ONS) represented in Table1 below shows the estimated figures for the current numbers of adults, aged between 18+, with autism in England, the East of England and Bedford Borough plus an estimate of how many of those may have Asperger syndrome, and higher functioning autism, using the Ehlers and Gillberg criteria:

Table 1

	Age	Population	Autism (1:100)	Asperger's Syndrome (36:10,000)	Higher Functioning Autism (35:10,000)
England	All ages	54,227,900	542,279	195,220	189,798
	18-64	33,158,100	331,581	119,369	116,053
	65+	9,530,900	95,309	34,311	33,358
East of England	All ages	6,001,100	60,011	21,604	21,004
	18-64	3,577,600	35,776	12,879	12,522
	65+	1,140,800	11,408	4,107	3,993
Bedford Borough	All ages	163,924	1,639	590	574
	18-64	98,634	986	355	345

Source: PANSI, 2014

Projecting Adult Needs and Service Information (PANSI) and Projecting Older People Population Information System (POPPI) has estimated future prevalence rates of autism in adults, by applying ONS population projections to the 18 + age group, and table 2 below summarises the future trend in Bedford Borough:

Table 2

Age	Years				
	2014	2015	2020	2025	2030
18-24	144	144	140	136	154
25-34	202	203	218	224	218
35-44	215	215	219	229	242
45-54	231	235	232	223	227
55-64	180	182	207	226	225
65-74	145	150	161	167	191
75 and over	114	116	134	170	194
Total	1231	1245	1311	1375	1451

Source: PANSI and POPPI, 2014

The biggest increase will come from people who are 65 and older, increase of 70% for 75 years and older between 2014 and 2030.

Gender

Using the criteria outlined above, PANSI and POPPI have also estimated the prevalence of autism in Bedford Borough by gender to 2030, as shown below:

Table 3: Estimated prevalence of Autism in Bedford Borough by Gender

Gender	Age	Years				
		2014	2015	2020	2025	2030
Male	18-64	871	878	913	932	958
	65+	229	236	261	299	342
Female	18-64	100	101	104	106	108
	65+	30	31	34	38	43

Source: PANSI and POPPI, 2014

The data from PANSI and POPPI supports the evidence that the prevalence of autism is higher in males than in females, although the reason for this remains unclear. In an epidemiological research Wing (1981) found that among people with high-functioning autism or Asperger syndrome, there were as many as fifteen times as many males as females. The reasons for the difference in male and female prevalence may be genetic, male susceptibility to organic damage from disease, or simply that females have “coping” mechanisms which mean that many females are never diagnosed with autism.

Ethnicity

No evidence is available to suggest that autism is more prevalent in any particular ethnic group, but there do appear to be disparities between different ethnic groups. In the documentation of autism (Mandell et. al, 2009). Goodman (2010) argues that social and cultural influences on epidemiological assessment measures are the most likely explanation for any observed racial and ethnic variations in autism prevalence and diagnosis.

Given general demographic information (28.5% BME population) we can estimate that around 363 adults aged 18 and over from ethnic minorities will have autism. Issues of diagnosis, cultural attitudes toward autism, culturally sensitive services need to be considered in implementing the strategy

Learning Disability and Autism

People with autism can have different 'degrees' of learning disability, affecting all aspects of their life. Some people will be able to live fairly independently - although they may need a degree of support to achieve this - while others may require lifelong, specialist support.

It is estimated that there were a total of 16,427 adults with a learning disability within the partnership area (Bedford, Central Bedfordshire, Luton and Milton Keynes) in 2015. The breakdown of estimated and projected prevalence of learning disability, autistic spectrum conditions for adults is provided below in Table 4, along with projected figures for 2030.

Table 4: Transforming Care Partnership (TCP) - Prevalence Estimates for 2015

(Source: POPPI and PANSI)

Area	Learning Disability Baseline (18 years and above)	Autistic Spectrum Conditions (ASCs) (18 years and above)	Challenging Behaviour (18- 64 yrs. only)
Bedford	3,003	1,246	45
Central Bedfordshire	4,956	2,078	74
Milton Keynes	4,664	1,935	73
Luton	3,804	1,597	60
Total	16,427	6,856	252

There will be increases in the number of people with a moderate or severe learning disability, behaviours that challenge and autistic spectrum conditions over the next 15 years.

Table 5: Transforming Care Partnership (TCP) - Prevalence Estimates for 2015

(Source: POPPI and PANSI)

Area	Learning Disability Baseline (18 years and above)	Autistic Spectrum Conditions (ASCs) (18 years and above)	Challenging Behaviour (18- 64 yrs. only)
Bedford	3,003	1,246	45
Central Bedfordshire	4,956	2,078	74
Milton Keynes	4,664	1,935	73
Luton	3,804	1,597	60
Total	16,427	6,856	252

Table 6: Transforming Care Partnership (TCP) - Projected population in 2030

(Source POPPI and PANSI)

Area	Learning Disability Baseline (18 years and above)	Autistic Spectrum Conditions ASCs) (18 years and above)	Challenging Behaviour (18- 64 yrs. only)
Bedford	3,456	1,451	48
Central Bedfordshire	5,796	2,446	80
Milton Keynes	5,541	2,312	80
Luton	4,410	1,892	67
Total	19,203	8,101	275

Table 7: Transforming Care Partnership (TCP) - Predicted percentage increase in estimated cohort between 2015 and 2030.

(Source – based on POPPI and PANSI data)

Area	Learning Disability Baseline (18 years and above)	Autistic Spectrum Conditions ASCs) (18 years and above)	Challenging Behaviour (18- 64 yrs. only)
Bedford	15.08%	16.45%	6.67%
Central Bedfordshire	16.95%	17.71%	8.11%
Milton Keynes	18.80%	19.48%	9.59%
Luton	15.93%	18.47%	11.67%
Total	16.90%	18.16%	9.13%

Bedford Borough Council's internal data collection for the Autism Self-Assessment Framework (2015/16) identified a total of 44 people in Bedfordshire (not specific to Bedford Borough) who received an autistic diagnostic assessment provided by East London NHS Foundation Trust (ELFT) Of these 44 people, 16 people went on to receive a diagnosis of Autism.

In 2015/16 a total of 16 adults were assessed as being eligible for social care by Bedford Borough Council. Of those 16, 14 had a diagnosis of Autism AND a learning disability with only 2 having Autism alone.

Transitions from children and adult services – Children and Families Act 2014

Managing transitions from children’s to adult services is critical to minimising new residential placements as significant demand is anticipated in the next few years.

The Adult Learning Disability Team reports that 65 children with LD aged 14-18 are expected to move to adult services i.e. a minimum of 10 per year for the next 5 years (2014-2019).

Many of these are supported in specialist residential educational settings. These are at high risk of becoming new high cost residential clients unless their transitions are carefully planned and managed.

Out of 65 young people transitioning to adult services, following Table 6 identifies young people known to services who have autism.

Table 8 - Known young people who have autism transitioning to adult services

Year	Know Autism Cases	Predicted Needs Summary
2014/2015	9	respite and accommodation
2015/2016	8	homecare
2016/2017	11	respite , homecare
2017/2018	11	home care, accommodation, education
2018/2019	6	not identified yet

Forward planning for transition is already critical and this must remain a priority for the future.

Summary of Facts and Figures

1. Available data indicates that total number of adults with autism in Bedford Borough is in the range of 1231-1262, with a projected increase to 1451 by 2030, in line with demographic increase.
2. The biggest increase will come from people who are 65 and older, increase of 70% for 75 years and older
3. There is a disproportion in diagnosis between males and females. Because of male gender bias, females are less likely to be identified with autism.
4. There is a significant gap between the number of people who are know to BBC 65+ social work team (0) and expected level of autism in this cohort (278).
5. It is important that the services do not overlook people with autism who come from BME group, given the ethnic make-up of local population.
6. Although numbers of young people with autism who are/will be transitioning to adult services is comparatively low, the specialist level of support required for those young people should not be underestimated.

Health needs

Autism is a developmental disorder; it is not a learning disability or a mental illness. However, some people with autism will have an accompanying learning disability and/or a mental health condition.

A large number of medical conditions, psychiatric disorders and behavioural and motor dyscontrol symptoms are associated with autism and Asperger's Syndrome. These include:

- Estimated rates of schizophrenia are around 3% compared with 1% of the general population and which can be caused by depression and isolation suffered by many people with autism;
- Sensory sensitivity or under-sensitivity to sound, touch, taste, smell, light or colour;
- High levels of anxiety related to changes in routine;
- Obsessive compulsive behaviour;
- Challenging behavioural problems, such as aggression and self-injury, linked to Attention Deficit Hyperactivity Disorder (ADHD) or dyspraxia;
- Sleep disorders, such as insomnia;
- Epilepsy;
- Gastro-intestinal problems;

We can also assume that adults with autism and a learning disability share some of the same co-morbid conditions as adults with a learning disability, which are:

- Cancer - increasing in people with learning disabilities, but with a higher risk of tumours of the oesophagus, stomach, gallbladder reportedly linked to the higher prevalence of, for example, gallstones and oesophageal reflux (NHS Scotland 2004);
- Coronary heart disease - on the increase now that more people live in the community and have more opportunities to access unhealthy lifestyles;
- Respiratory disease, linked to pneumonia, swallowing and feeding problems and gastro-oesophageal reflux disorder (NHS Scotland 2004), as well as constipation and incontinence;
- Oral health - the findings from a review of the literature related to the oral health of people with disability, confirm that people with learning disability or mental health problems have similar oral diseases but poorer oral health and poorer health outcomes from care than the general population (Fiske et al 1999; BDA, 2003 in BSDOH, 2006);
- Cerebral palsy - up to a third of people with learning disabilities have an associated physical disability, most often cerebral palsy which puts them at risk of postural deformities and hip dislocation;
- Osteoporosis - develops in people with learning disabilities at a much younger age than the general population, and they suffer more fractures, particularly in people with learning disabilities and epilepsy (Jancar and Jancar, 1998);
- Dementia - the prevalence of dementia is much higher amongst older adults with learning disabilities compared with the general population (21.6% vs 5.7% aged 65+ (Cooper, 1997).

The National Institute for Clinical Excellence (NICE) Quality Standard on autism (QS51) describes the following eight quality standards which apply to autism services:

- People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral.
- People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.
- People with autism have a personalised plan that is developed and implemented in a partnership between them and their family and carers (if appropriate) and the autism team.
- People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.
- People with autism have a documented discussion with a member of the autism team about opportunities to take part in age-appropriate psychosocial interventions to help address the core features of autism.
- People with autism are not prescribed medication to address the core features of autism.
- People with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.
- People with autism and behaviour that challenges are not offered antipsychotic medication for the behaviour unless it is being considered because psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour.

Current Activity and Services

1. Universal services

Many people with autism may not be eligible for specialist health care or social care support, and live independently within the community. It is important that general community services (universal services) are equipped with the knowledge and skills to support all members of community, people with autism included.

2. Specialist and support services

ELFT is the provider of mental health and learning disability services in Bedford Borough.

Small numbers of adults with a learning disability and autism may access these services:

Name	Description	Location
IST (Intensive Support Team)	IST provides a predominantly community based service for people with a learning disability and who have additional mental health needs or present with challenging behaviour. In addition, to the community outreaching support, there are 7 inpatient beds, based at The Coppice, Bromham, that are staffed as part of the service	The Coppice, 2 The Glade, Bromham
Specialist Community Health Care Team	This service provides a range of therapies to people with a learning disability. The service has a single point of access which	Clinical Resources Centre, Twinwoods

	then agrees a treatment pathway. The team includes speech and language therapy, dietetics, arts psychotherapies, psychology, sensory		
Health Facilitation Team (HFT)	A team which provides support for people to access generic health care services. Staff are co-located with the Adult Learning Disability Team at Bedford Borough Council, and staff based in Bedford General Hospital.	Clinical Resources Centre, Twinwoods	
Specialist Medical Department	The medical team works as part of the inpatient services, the specialist community health care team, and provides outpatient services to people with a learning disability.	Clinical Resources Centre, Twinwoods	
Wood Lea Clinic Provided by South Essex Partnership NHS Trust (SEPT)	Low secure unit. 10 bedded forensic unit commissioned through Specialist Commissioning Group, East of England	5 The Glade, Bromham	

Bedfordshire Adult Autism Service (AAS) provided by ELFT

NICE Guidance (CG142, Autism in Adults: Diagnosis and Management, 2012) recommends that specialist community-based multidisciplinary teams for adults with autism should include:

- clinical psychologists
- nurses
- occupational therapists
- psychiatrists
- social workers
- speech and language therapists
- support staff (for example, staff supporting access to housing, educational and employment services, financial advice, and personal and community safety skills).

The specialist autism team should have a key role in the delivery and coordination of:

- specialist diagnostic and assessment services
- specialist care and interventions
- advice and training to other health and social care professionals on the diagnosis, assessment, care and interventions for adults with autism (as not all may be in the care of a specialist team)
- support in accessing, and maintaining contact with, housing, educational and employment services
- support to families, partners and carers where appropriate
- care and interventions for adults with autism living in specialist residential accommodation
- training, support and consultation for staff who care for adults with autism in residential and community settings.

The AAS provided by ELFT became operational with effect from 10th July 2013 with an interim multi-disciplinary team, the team recruited to full establishment in September 2014 and consists of:

Consultant Psychiatrist	0.3 whole time equivalent
Specialist Nurse/ Team Manager	1.0 whole time equivalent
Clinical Psychologist	0.6 whole time equivalent
Occupational Therapist	0.5 whole time equivalent
Autism Support Worker	2.0 whole time equivalent
Administrator	0.5 whole time equivalent

The immediate aim was to develop the service to be compliant with statutory requirements of the Autism Act 2009 and support the values and aims of Fulfilling and Rewarding Lives (Department of Health 2010).

This was achieved through the provision of local assessment, diagnostic and post diagnostic services for adults who may have autism and through effective collaboration with local commissioners and other service providers to help improve outcomes for people with autism in accessing generic services.

The AAS provides services for adults who are registered with a Bedfordshire & Luton General Practitioner by:

- Undertaking comprehensive diagnostic assessments to confirm / exclude Autism Diagnosis.
- Suggest recommendations to General Practitioner/ referrer with regards to appropriate services for individuals who are not diagnosed as being Autistic.
- Provide comprehensive post diagnostic assessments and short term clinical interventions for people with Autism who are unable to access mainstream health and social care provision for example:
 - Sensory Processing
 - Anxiety Management
 - Psycho-education
 - Activities of daily living
 - Mental Health Monitoring
- Supporting people with Autism to enable access to appropriate local mainstream services, to include signposting to other agencies.
- Work with existing learning disability and mental health services to ensure that there is adequate recognition of Autism in their client groups, providing specialist consultation, training and awareness.

Bedfordshire data from 1st April 2015 to 31st March 2016.

Table 9: AAS activity 2015/16

Referred for a diagnostic assessment but yet to be completed	Diagnostic assessments Completed	Autism Diagnosis Confirmed from Assessment
27	44	16

Source: ELFT Diagnosis service for Autism SAF 2015/16

NICE Gap Analysis

The service has recently undertaken a gap analysis of local service provision against recommendations set within NICE Guidance CG142 Autism in Adults and CG170 Autism in under 19's:

- Primary Care -Training, advice & consultation to primary care services, in particular General Practitioners to support the awareness of ASD and to enable practitioners to identify and symptoms using recommended evidence based tools, for example AQ10.
- Risk Management - Participate in developing 24 hour Crisis Management plans where appropriate in partnership with other Mental Health service, by providing ASD awareness, training and suggesting reasonable adjustments to care.
- Mainstream services- to provide intense support, training and consultation to mainstream health services in order to make reasonable adjustments to planned care.
- Management- Provision of medium to long term post diagnostic therapy, for both service users with a new or an existing diagnosis to include:
 - i. ASD specific anger management
 - ii. Anti- victimization
 - iii. Holistic life skills
 - iv. CBT for OCD/challenging behaviour/depression
 - v. Psycho- social interventions i.e. Mindfulness
- Family/ carer support - Development of local ASD specific support for family and carers including psycho-social education, individual and group work in partnership with local voluntary sector.

3. Autism Bedfordshire

Autism Bedfordshire is an independent charity that provides emotional and practical assistance and support to people with autism and their families in Bedford Borough. Autism Bedfordshire provides the following services:

- Adult Skills Course in Bedford to teach employment skills, social communication skills, life and leisure skills;
- Adult Social Group to offer social activities which will develop social skills and confidence, encouraging the individuals to take up these activities outside of the group;
- Supported volunteering and work experience for adults with autism;
- Extended telephone helpline to support adults with autism, their families and professionals;
- Training for organisations, schools and businesses so they can support and work with people with autism;
- Developing and maintaining a directory of services for adults with autism, offering signposting and information on a variety of services that the adults can access themselves.

Local Views

Since the introduction of the Autism Act in 2009 there has been constant local stakeholders' engagement led by the Local Authorities through the Think Autism Partnership Board (TAPB) which aims to:

- Review national legislation, guidance, policy and best practice (e.g. Autism Act 2009, Care Act 2014)
- Review local information to support needs assessments (e.g. Autism Strategy 2010, refresh 2014)
- Provide a gap analysis to inform commissioning decisions (Autism Self-Assessment framework 2015/16, facilitated themed table discussions at each TAPB).

In order to agree and implement the priorities across the following areas:

- Diagnosis and post support
- Preventative support
- Safeguarding
- Equality
- Criminal justice
- Comprehensive training and awareness
- Employment,
- Accommodation and housing

National & Local Strategies (Current best practices)

1. **Valuing People – A New Strategy for Learning Disabilities for the 21st Century (Department of Health, 2001)** - the Government's national strategy for people with learning disabilities, but which makes key references to the barriers faced by people with autism
2. **I Exist** the message from adults with autism in England (The National Autistic Society, February 2008)
3. **The Autism Act 2009** - sets out the Government's commitment to improve inclusion and ensure adults with autism are able to participate fully in society.
<http://www.legislation.gov.uk/ukpga/2009/15>

4. **Fulfilling and Rewarding Lives (Department of Health, 2010)** – the Government’s strategy for adults with autism in England
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369
5. **Implementing Fulfilling and Rewarding Lives (Department of Health, 2010)**- Statutory guidance for local authorities and health to support implementation of the autism strategy
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122847
6. **Towards Fulfilling rewarding lives (Department of Health, 2010)** - the first year delivery plan for adults with autism in England
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_115115
7. **Think Autism Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update.**https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf
8. **Personalisation briefing: Implications for people with autistic spectrum conditions and their family carers** (National Autistic Society/SCIE, 2010)
<http://www.scie.org.uk/publications/ataqlance/ataqlance21.asp>
9. **Good practice in supporting adults with autism: guidance for commissioners and statutory services** (Government Office South West/NHS South West, 2009)
<http://www.autism.org.uk/Working-with/Social-care-and-support.aspx>
10. **Supporting adults with autism: a good practice guide for NHS and local authorities** (National Autistic Society, 2009) <http://www.autism.org.uk/Working-with/Social-care-and-support.aspx>
11. **NICE Guidance** (3 clinical guides, and quality standard) <http://www.nice.org.uk>
12. **Transforming care: a national response to Winterbourne View hospital** (Department of Health, 2012) <https://www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response>
13. **Autism: a guide for criminal justice professionals** (NAS, 2005)
<http://www.autism.org.uk/working-with/criminal-justice/autism-a-guide-for-criminal-justice-professionals.aspx>
14. **Green Light Toolkit** (A guide to auditing and improving your mental health services so that it is effective in supporting people with autism and people with learning disabilities, NDTI, 2013)
<http://www.ndti.org.uk/news/national-news/green-light-toolkit/>

**What is this telling us? What are the key inequalities?
What are the unmet needs/ service gaps?**

Autism remains national and local priority.

Nationally, there have been a number of best practice guides, NICE guidelines and associated training packages developed in the course of last three years which could and must (NICE) inform local work.



Back in 2009 we finally won the battle for a law to transform the lives of adults with autism...

2009 The Government recognised that adults with autism were being denied the support that they needed...
 ...because services were simply not designed to meet their needs.
 So the Autism Act was passed
 The Autism Act put a duty on local authorities and the NHS to solve this.

Four years on... how is the Autism Act being implemented?
2013 Local Authorities have now appointed an Autism Lead responsible for implementing other aspects of the strategy.
145 OUT OF 152
BUT!

Progress is slow and patchy and too many are still waiting for the everyday support that they need.

ONLY 23% of people with autism told us that the social workers they'd come into contact with had **A GOOD UNDERSTANDING OF AUTISM**

63% of people with autism said they **NEED HELP TO PREPARE A MEAL**
 But **ONLY 6%** get this support from social services.

77% of people with autism said they **NEED HELP TO MANAGE MONEY**
 But **ONLY 4%** get this support from social services.

53% of people with autism said they **WANT HELP TO FIND WORK**
 But **ONLY 10%** get this support.

36% of people with autism said they **NEED HELP TO WASH AND DRESS**
 But **ONLY 7%** get this support from social services.

Now it's time for everyone to put the law into action and end that wait.

This year the government will review the Autism Act
 Providing a second chance for **300,000** adults with autism to be heard

NATIONAL GOVERNMENT MUST:
 Provide funding to help with new services
 DEFENDING SERVICES
 DIAGNOSTIC SERVICES
 TRAVEL TRAINING
 EMPLOYMENT SUPPORT
 Monitor what local areas are doing
 Keep their commitment to train key professionals in autism
 Publish guidance to clearly explain what local areas should do

COUNCILS AND THE NHS MUST:
 Take the actions outlined as a result of the Autism Act

These commitments WILL make a difference to the everyday lives of adults with autism.

You can make a difference. Join our campaign today **PUSH FOR ACTION**

The National Autistic Society www.autism.org.uk/push

Local main strategic documents fully support autism via associated work streams (mental wellbeing, lifestyles, wider determinants of health, and 5 out of 6 aims of Healthy Borough work theme).

Valuing People Now, the Government's strategy for people with learning disabilities, recognised that people with autism are some of the most excluded and least heard people in society, with poor health outcomes. Whilst action taken forward under Valuing People Now will benefit adults with autism who also have a learning disability, more needs to be done to support the health needs of adults across the whole spectrum. According to the National Autistic Society report I exist: the message from adults with autism in England (2008), this lack of support has serious consequences:

- Two third of adults (67% say they have experienced anxiety because of a lack of support;
- One third of adults (33%) say they have experienced serious mental health problems because of a lack of support.

Push for Action clearly identified areas where people with autism were not supported:

- Lack of awareness and understanding of autism
- Lack of social care support in areas such as meal preparations, money management, personal care
- Lack of employment opportunities
- Lack of central government financial support to implement the Autism Strategy

Think Autism encourages Autism Aware Communities - Think Autism community awareness projects should be established in local communities and there will be pledges/awards for local organisations to work towards.

Think Autism show three areas where people with autism needs support:

Equal part of local community
Right support at the right time
Developing independence

The Government's and local vision for adults with autism is that:

"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 when 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."

Local Progress

Since 2016, there has been excellent progress in Bedford Borough, in cooperation with the two Bedfordshire Councils, which improved services for people with Autism in response to the national autism strategy in 2010. With an identified Commissioning lead for Autism within Bedford Borough Council an action plan/strategy refresh will be completed for 2017/18 in partnership with all key stakeholders along with a new framework for monitoring support services that is based on outcomes.

Training

- Workforce Development departments worked with commissioners and colleagues across Bedfordshire in designing the training pathway.
- Three tiers of training are in place.
- A wide range of external Private, Voluntary and Independent care provider organisations and ELFT have had access to the training programme supported through the Council's and NHS funding (compared to almost non-existent Autism training before the strategy).
- Feedback received from training evaluations indicates a consistent high standard of delivery with "excellent" rated assessment. All evaluations are regularly and closely monitored to ensure that the quality of the training provided is maintained.
- ELFT provide their own comprehensive training to clinical staff through the AAS, lead nurse specialist. Approximately 65 clinical staff have attended this training in 2015/16 from across the CMHTs, CLDT and CRHT.
- 3 Autism Awareness workshops have been facilitated by ELFT since June 2016 as part of the Mental Health Recovery College with a further 2 workshops planned for November & December 2016.

Diagnosis and Assessment

- The comprehensive local diagnostic and personal support pathway provided by ELFT has been operational since July 2013. This has mitigated the previously high number of referrals going out of area to just 1 in 2015/16 for a condition not recognised on the ASD.

As part of the assessment pathway, all individuals for whom an autism diagnosis is confirmed are offered a follow-up appointment. This is to assess the individual's post-diagnostic needs, provide signposting information and help facilitate access to other appropriate local services.

The post-diagnostic assessment also helps to identify whether further specialist clinical intervention is required from the adult autism service through a short-term treatment plan developed with members of the multi-disciplinary team.

Support Services

- Bedford Borough, Central Bedfordshire and Luton Borough have jointly agreed a new performance management framework based on outcomes with Autism Bedfordshire, effective from Qtr 4 2016/17. The new framework captures 'Istatements' based on peoples experiences of being offered choice, opportunities, involvement in their care, being listened to and having confidence in the services that are being provided.
- Advocacy services are currently provided by PowHER who have staff fully trained in Autism Awareness. Further opportunities are made available to all staff to attend more in-depth training. A joint performance monitoring framework based on the outcomes listed above will be effective from the 1st April 2017 through a joint tendering process with Central Bedfordshire.
- All social work teams from Bedford Borough have access to specialist knowledge of Autism Bedfordshire.
- Carers in Bedfordshire in partnership with Autism Bedfordshire provide carer's training sessions.

Bedford Prison

- Through the in house surveys Bedford Prison identified that there is a higher percentage of prisoners housed at Bedford that fall into the Autistic Spectrum, than nationally predicted.
- In response Bedford Prison put into place to identify the people who require further investigation. The prison also devised systems where by those identified are provided with a support mechanism by which they can be helped.
- This work has been recognised in the national strategy Think Autism 2014.
- Health and social care collaborative partnership arrangements are ongoing through the Prison Health Partnership Board (PHPB) for Bedfordshire and Hertfordshire.

Criminal Justice System

- In 2013 Central Bedfordshire Council Autism Lead hosted two workshops with Bedfordshire Criminal Justice System Agencies to raise a profile of autism strategy and map local areas which could be improved in order to support people with autism better. This understanding will support further work.

What should we be doing next?

Local Autism Strategy 2011-2014 should be reviewed, with a view to build on the excellent work so far, and continue with the following priorities:

Continue with Increasing awareness and understanding of autism among frontline professionals

Failing to understand autism, and its implications for adults with autism, mean that many do not trust public services, and will therefore fail to access them. This may increase a sense of isolation and lead to physical and mental problems that will only be treated once those problems have reached crisis point.

Recommendations

- Continue improving autism awareness training for all frontline public service staff which will provide them with a better understanding of the individual needs of the person concerned
- Training for all statutory agency staff who will come into contact with adults with autism. This will help staff with a greater understanding of autism, and to determine the levels of individual support required.

It will also help with communication problems which may arise when frontline staff meet someone with autism, and ultimately assist with the identification of potential signs of autism

- Autism awareness training to be included within general inequality and diversity training delivered to staff within Bedfordshire Clinical Commissioning Group.

Developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a professional needs assessment

Better Services for People with an Autistic Spectrum Disorder reported that many people with autism and their families found that a diagnosis of autism was helpful in understanding the support needed by an individual. Fulfilling and Rewarding Lives suggests:

Diagnosis is particularly important for adults who have not previously had their condition recognised ... it is equally important for their families and carers ... it can be an important step in ensuring that support takes account of how autism can affect the whole family.

Recommendations

- Enhance the existing capacity of the AAS in Bedfordshire to ensure NICE compliance to:
 - 1 Band 8a Clinical Psychologist
 - 1 Band 4 Assistant Psychologist
 - 0.5 Band 6 Occupational Therapist
- Continuously review local diagnostic and support pathway in line with NICE guidelines service feedback
- Once autism is diagnosed, then a comprehensive assessment of need by trained practitioners will automatically follow. The assessment will be used to inform care decisions, and/or support applications for additional services

- A diagnosis of autism should also be followed by information about autism and the resources available to a person with autism and their carers

Improving access for adults with autism to the services and support they need to live independently within the community

Since 2006, under the Disability Equality Duty, all public sector organisations have been required to make reasonable adjustments to their services to cater for the needs of disabled people, and this should include needs of adults with autism, particularly for those with physical and sensory impairments.

Recommendations

The Standard Contract for Mental Health and Learning Disabilities makes specific references to adults with autism, and demonstrate how reasonable adjustments for adults with autism are made.

For frontline staff dealing with patients with autism this could mean:

- Provision of lower-light areas or quiet areas for adults with autism with sensory impairments in healthcare settings
- Provision of appointments for adults with autism at less busy times, and providing them with additional appointment time in order to assist with communication problems
- Awareness by frontline staff of how to respond to those communication problems demonstrated by adults with autism
- Providing an opportunity for adults with autism to visit an unfamiliar hospital setting, or be made aware of what they can expect from an unfamiliar situation

Improve transition experience for young people with autism at 16+ in line with the recent legislation

Recommendations

- In consultation with parents in Bedford Borough, the need for planned transition in an acceptable time frame is essential. Many families encounter situations where they are unable to support their child through transition because of a lack of information or decisions, resulting in changes having to be made quickly and in a manner that failed the person with autism.

Concentrate on priorities as identified by the local ongoing consultation in order to create more autism friendly community in Bedford.

Recommendations

Social Care Assessments

More work is required to ensure that diagnostic and support services are firmly linked to social work assessments.

Employment, Education and Training

Bedford Borough Council has supported employment services with various projects to support people who are eligible for social care support and want to get to employment. Local Job Centre Plus disability advisors received Autism Awareness training. More work is required on strategic level around supported employment for all vulnerable groups (autism included). Autism Partnership will need to make recommendations on how this work can progress.

Work with Criminal Justice System

Bedford Prison provided examples of fantastic awareness raising for its staff and among inmates in 2012. The Autism Strategy must continue to engage with other partners from criminal and justice system such as Probation Services, Bedfordshire Police, and the Courts.

Accommodation and housing support

People with autism (including Asperger syndrome) vary greatly in their housing needs. Some live independently while others may require support with certain tasks or, in some cases, 24-hour specialist support. A better understanding of the range of existing need and provision is needed. An improvement in the choice available as the information and help for people and their families seeking to plan for the future is required.

Sustainability

It is important that local Autism Partnerships continues cooperation with the local authorities and the NHS to ensure that autism agenda locally continues with the same passion as it did in the period of 2011-2014. Appropriate commissioning and staff resource is critical in order to continue delivering identified priorities.

2015 Update

The above recommendations were proposed in the strategic delivery plan for 2015 -2020.

Employment

The Think Autism Partnership Board adopted the action plan to deliver the first priority. A copy of the action plan is available here:

http://www.bedford.gov.uk/health_and_social_care/help_for_adults/autism/think_autism_partnership.aspx

Social Care Assessments

This priority is planned to be discussed at the 17/11/2015 Think Autism Partnership Board. Result of the meeting will be the action plan to support social care assessments, and will be available as per the above link.

Remaining priorities will be discussed and action planed in turn during the quarterly Autism Partnership Meetings.

References

British Society for Disability and Oral Health (2006). *A Commissioning Tool for Special Care Dentistry*. Department of Health, 2006. Available at:

http://www.bsdh.org.uk/misc/commissioning_tool_for_special_care_dentistry.pdf

Brugha. T, McManus. S, Meltzer. H, Smith. J, Scott. FJ, Purdon. S, Harris. J, Bankart .J (2009), *Autism Spectrum Disorders in adults living in households throughout England - Report from the Adult Psychiatric Morbidity Survey 2007*, The Health & Social Care Information Centre, Social Care Statistics. Available at:

http://www.ic.nhs.uk/webfiles/publications/mental%20health/mental%20health%20surveys/APMS_Autism_report_standard_20_OCT_09.pdf

Cooper, S.A. (1997) *High prevalence of dementia among people with learning disabilities not attributable to Down's syndrome*. *Psychological Medicine*, 27, 609-616.

Cooper. SA, Smiley. E, Morrison, J, Williamson. A, Allan L. (2007) *Mental ill-health in adults with intellectual disabilities: prevalence and associated factors*. *Brit J Psychiatry*: 190:27-35

Ehlers, S. & Gillberg C. (1993) *The epidemiology of Asperger syndrome, a total population study*. *Journal of Child Psychology and Psychiatry*

Goodman. E, (2010) *Race, Ethnicity, and Autism: Evaluating the Epidemiological, Genetic, Neurological, and Social Evidence*, Princeton Neuroscience Unit, Princeton University. Available at: <http://www.princeton.edu/ghp/research/senior-thesis-research/Betsy-Goodman-Thesis-Abstract.pdf>

Jancar, J. & Jancar, M.P. (1998) *Age-related fractures in people with intellectual disability and epilepsy*. *Journal of Intellectual Disability Research*, 42, 429-433

Mandel. DS, Wiggins. LD, Carpenter. LA, Daniels. J, DiGuseppi. C, Durkin. MS, Giarelli. E, Morrier. MJ, Nicholas, JS, Pinto-Martin. JA, Shattuck. PT, Thomas. KC, Yeargin-Allsopp. M, Kirby. RS, (2009), *Racial/ethnic disparities in the identification of children with autism spectrum disorders*, *American Journal of Public Health* , 2009 Mar;99(3):493-8. Epub 2008 Dec 23. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/19106426>

NHS Health Scotland, (2004) *Health Needs Assessment Report - People With Learning Disabilities In Scotland* NHS Health Scotland. Available at: http://www.gla.ac.uk/media/media_63872_en.pdf

Projecting Adult Needs and Service Information (PANSI) (2011), Available at: <http://www.pansi.org.uk/index.php?pageNo=383&areaID=8640&loc=8640>

The National Autistic Society (2011), *How Many People have Autism?* <http://www.autism.org.uk/About-autism/Some-facts-and-statistics/Statistics-how-many-people-have-autism-spectrum-disorders.aspx>

Office for National Statistics, (2009) *Survey feedback for Bedford Borough*

Office for National Statistics, (2011) *Mid Year Population Statistics 2010*. Available at:
<http://www.ons.gov.uk/ons/publications/all-releases.html?definition=tcm:77-22371>

Wing, L. (1993) *The Definition and Prevalence of Autism: A Review*, *European Child and Adolescent Psychiatry*, Vol.2, Issue 2, April 1993, pp.61-74. Available at:
<http://www.mugsy.org/wing.htm>

Appendices

Name and contact details of author: