



BEDFORD
BOROUGH COUNCIL

NHS
Bedfordshire

Central
Bedfordshire

***Fulfilling And Rewarding Lives
In Bedfordshire***

***Autism Strategy
For Bedfordshire***

2011-2014

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1. Executive Summary

- 1.1 This joint commissioning strategy to improve outcomes for people with Autism in Bedfordshire demonstrates the partnership approach being taken by Bedford Borough Council, NHS Bedfordshire and Central Bedfordshire Council. All three organisations are committed to support fulfilling and rewarding lives for people with autism in accord with the government's vision 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 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.'

(Fulfilling and rewarding lives - The strategy for adults with autism in England, Department of Health, 2010)

- 1.2 Recent years have brought new statutory duties to local authorities and NHS bodies through;
- 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)
- 1.3 This strategy to meet our duties has benefited from the concurrent development of the Bedfordshire Autism Partnership Group. As suggested by the national strategy this group brings together relevant local organisations, services and stakeholders to set clear direction for improved local services. The Autism Partnership Group is a pan-Bedfordshire entity that feeds into the appropriate governance structures in each local authority area.
- 1.4 As well as working through the Autism Partnership Group, a series of local workshops have been held to consult and confirm agreement with this strategy. As a result, our joint strategic objectives are now clarified below. They encompass all relevant statutory duties and national guidance. Implementation will be locally driven over the next three years.
- 1.5 **Strategic Priorities**

1. Increase awareness and understanding of autism among frontline staff across the whole community.
2. Develop a clear consistent pathway for diagnosis in every area, which will be followed by the offer of a personalised needs assessment and considerations for appropriate community services.
3. Plan in relation to the provision of services to people with autism in transitions.
4. Enable local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.
5. Help adults with autism with work.

These strategic priorities will be delivered through a three year action plan. During the life of the strategy we will continue to consult and invite feedback to ensure annual action plans reflect any changes to local or national priorities.

2 Introduction

2.1 There is a developing body of evidence¹ that adults with autism, and their families, face many barriers in their everyday lives and in accessing the services and support that they need, including:

- their condition being overlooked or misunderstood by professionals and by society
- difficulties with the services and support they need to live independently within the community
- difficulties in gaining long-term, meaningful employment.

2.2 The Autism Act 2009² required the government to develop ‘a strategy for meeting the needs of adults in England with autistic spectrum conditions by improving the provision of relevant services to such adults by local authorities, NHS bodies and NHS foundation trusts.’

That requirement was met by ‘Fulfilling and rewarding lives: the strategy for adults with autism in England, 2010³.’

Statutory guidance for implementing the national strategy was also issued in 2010⁴.

Bedford Borough Council, NHS Bedfordshire and Central Bedfordshire Council have worked in partnership to produce this local strategy in response to the national autism strategy and statutory guidance.

2.3 This document:

- Identifies gaps in provision of services for people with autism and actions to address those gaps
- Sets out how the health and social care commissioners in Bedfordshire will work in partnership to improve services for people with autism

¹ National Audit Office (2009). Supporting people with autism through adulthood.

² Great Britain. The Autism Act. London : The Stationery Office

³ Department of Health (2010) *Fulfilling and rewarding lives - The strategy for adults with autism in England*, Department of Health, 2010. London: The Stationery Office

⁴ Department of Health (2010) Implementing “Fulfilling and rewarding lives”. Statutory guidance for local authorities and NHS organizations to support implementation of the autism strategy. London: The Stationery Office

- Sets out relationships and responsibilities of statutory organisations and partners involved in service provision for adults with autism to make the best and most effective use of resources

3. What Is Autism?

Terminology

- 3.1 'Autism' can mean many things to many people. There are a number of terms that different people and groups prefer to use, including autistic spectrum disorder, autistic spectrum condition, autistic spectrum difference and neuro-diversity.

In this strategy, we use 'autism' as an umbrella term for all such conditions, including Asperger's syndrome. This is in line with the terminology adopted by the National Autistic Society and the Department of Health in 'Fulfilling and rewarding lives, the strategy for adults with autism in England' (2010).

Definition

- 3.2 Autism is known as a spectrum condition because of the range of difficulties it causes and because people can experience those difficulties along a range from mild to severe. Many people with autism are able to live with minimal 'specialist' support; others need a lifetime of specialist services to maximise independence, choice and control.

For the purposes of this strategy, autism is defined as:

"A lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them."

- 3.3 The three main areas of difficulty, which all people with autism share, are known as the 'triad of impairments'.

They are difficulties with:

- 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)

- 3.4 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.

3.5 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.

Asperger's Syndrome⁵

3.6 Asperger's syndrome is a form of autism. People with Asperger's syndrome often find it difficult to express themselves emotionally and socially. For example, they may:

- have difficulty understanding gestures, facial expressions or tone of voice
- have difficulty knowing when to start or end a conversation and choosing topics to talk about
- use complex words and phrases but may not fully understand what they mean
- be very literal in what they say and can have difficulty understanding jokes, metaphor and sarcasm. For example, a person with Asperger's syndrome may be confused by the phrase 'That's cool' when people use it to say something is good

3.7 People with Asperger's syndrome do not usually have learning disabilities but despite average or above average intelligence they can experience specific learning difficulties. These can include dyslexia and dyspraxia or other conditions such as attention deficit hyperactivity disorder (ADHD) or attention deficit disorder (ADD) and epilepsy.

3.8 People with Asperger's syndrome may learn masking behaviours and coping strategies that hide their difficulties from immediate view. The coping strategies can lead to diagnosis not occurring in a timely way and behavioural labels being inappropriately applied. As a result, it is not unusual for a person with Asperger's Syndrome to reach adulthood without a diagnosis or understanding why he/she may have differences.

⁵ Adapted from National Autistic Society 'What is Autism?' Available at www.autism.org.uk (Accessed on 01/07/2011)

4. Improving Outcomes For People With Autism

4.1 Our vision is the same as the vision in the national autism strategy

'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.'

(Fulfilling and rewarding lives - The strategy for adults with autism in England, Department of Health, 2010)

We are committed to involving adults with autism and carers in all aspects of strategy planning, delivery, monitoring, and reviewing.⁶

4.2 In common with personalisation across all client groups this strategy places people with autism at the centre of planned improvements.⁷

This strategy understands autism not necessarily as deficit, but valuing it as difference.

"Autism traits can be valued and channelled into important employment and lifestyle opportunities for people with autism if they wish. We recognise that there are many inequalities experienced by people with autism. We would like to suggest that with adequate support people with autism may be able to use their unique skills effectively.

By including the wider views of people with autism in professional representation a less stigmatised view of autism can be presented.⁸

4.3 This strategy adopts a life span approach to supporting people with autism and aims to link with children and young people's services.

Through implementation of this strategy more people with autism will be diagnosed and come to the attention of local services. Newly diagnosed children will be supported by children's health and social services until they enter adult services. It is therefore important that both children and adult services have effective transition systems in place to enable a seamless experience for those who need support. The transition chapter of this strategy looks at transition arrangements, the exchange of information for the purposes of planning, and the need for commissioning overlaps.

⁶ Services for Adults with autistic spectrum conditions (ASC) – Good practice advice for primary care trust and local authority commissioners. DH, 2009

⁷ Putting people first: a shared vision and commitment to the transformation of adult social care, DH, 2007

⁸ Brownlow, Ch, and O'Dell, L (2007). Representations of autism: implications for community healthcare practice. *Community Practitioner*, Vol.82, Num 7, pp. 18-21

- 4.4 Translating the aims of ‘Fulfilling and rewarding lives: the strategy for adults with Autism in England’ into better outcomes for people with autism across Bedfordshire is what this strategy is all about.

The Bedfordshire Autism Partnership draws membership from a wide range of stakeholders (see paragraph 16.4) and will:

- Increase awareness and understanding of autism among frontline staff across the whole community
- Develop a clear consistent pathway for diagnosis in every area, which will be followed by the offer of a personalised needs assessment and considerations for appropriate community services
- Plan in relation to the provision of services to people with autism in transitions
- Enable local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.
- Help adults with autism with work

Following these five strategic areas through the development of local authority implementation plans will ensure there is a positive improvement to the lives of adults with autism, their families and carers.

Bedford Borough Council⁹

- 4.5 This autism strategy complements the Borough’s Sustainable Community Strategy, NHS Bedfordshire’s A Healthier Bedfordshire Strategy, the joint Healthy Bedford Borough Strategy, the Bedford Borough Adults Services Plan, the Bedford Borough Children and Young Peoples Plan, by providing a broad overview of the strategic direction which the Borough Council, NHS Bedfordshire and partners must follow in order to impact on and improve the health and wellbeing of people with autism needs in the Borough.

Central Bedfordshire Council

- 4.6 This autism strategy complements the Central Bedfordshire Healthier Communities Strategy and NHS Bedfordshire’s A Healthier Bedfordshire Strategy, while linking with Central Bedfordshire Council’s focus on an integrated approach to service delivery, emphasising prevention and choice in providing high quality services to enhance the wellbeing of all Central Bedfordshire residents. A key driver is the Government’s emphasis on individual choice and control which is reflected in our “Transforming Peoples Lives” programme, working in partnership with our NHS colleagues to empower and support people to shape their own lives and services.

For NHS Bedfordshire

⁹ For more details please refer to :

www.bedford.go.uk , <http://www.bedfordboroughpartnership.org.uk/home.aspx>

- 4.7 NHS Bedfordshire's "A Healthier Bedfordshire" plan identified the need to develop a strategy for people with autism to address the health inequalities that can exist when health professionals do not understand autism and are unable to support people appropriately to access health care services. NHS Bedfordshire is committed to working in partnership with the local authorities to improve the health outcomes for people with autism through local services which are able to meet their needs.

5. Local Picture - Bedford Borough¹⁰

Bedford Borough has a growing and rapidly ageing population, which increased by 6.1% from 147,900 in 2001 to 157,100 in 2008, including a 23% rise in the numbers aged 85+.

This strong growth is projected to continue, with the population reaching 172,000 by 2021 as a large part of the Borough is situated in one of the growth areas of the Milton Keynes and South Midlands sub-region. More than 1,000 new homes are planned each year.

- 5.2 Bedford Borough is characterised by great diversity, with major differences between the profiles of the Borough's urban and rural areas. The population of Bedford and Kempston towns is younger on average and more ethnically diverse than the rural area, and the areas of highest deprivation are all within the urban area.
- 5.3 In 2001, 19.2% of the population was from non-'White British' minority ethnic groups (BME), compared to 13% nationally. The BME population has increased further since 2001 due to significant international in-migration, particularly the large number of migrants in 2004-2008 arriving from the EU Accession countries, primarily Poland and Lithuania.
- 5.4 Recent years have also seen the growth of significant communities from countries not previously represented to a major degree in the Borough's ethnic mix, such as new arrivals from Afghanistan and Zimbabwe. The latest estimates are that the non-'White British' population rose to 21.6% in 2007, and it is likely that it has increased further since that time.

The BME population is concentrated in the urban areas, 58% of Queens Park and 44% of Cauldwell residents are from BME groups.

- 5.5 This growth in the BME population contributed to a substantial rise in the number of births in 2008-2009 compared to earlier years, with the increase in births in the Borough largely attributable to mothers born outside the U.K.

¹⁰ NHS Bedfordshire and Bedford Borough Council (2010) *Bedford Borough, Joint Strategic Needs Assessment 2010. Executive Summary*. Available at http://www.bedfordshire.nhs.uk/downloads/bedford_borough_1_exec_summary_jsna_20110111B.pdf. (Accessed: 04/07/2011)

Key demographic challenges facing Bedford Borough include:

- Continued strong growth in population with a major increase in the numbers of older people, particularly those aged 85+
- An increasingly diverse population with strong growth in the non-‘White British’ Black Minority Ethnic (BME) population
- A rising level of births, with the increase largely attributable to births among mothers born outside the UK

5.6 While Bedford Borough has an overall level of deprivation which places it midway among English authorities (ranking 183rd of 354 authorities on the 2007 Index of Multiple Deprivation) this masks pockets of significant deprivation in the Borough.

Three areas in Bedford town are among the 10% most deprived areas in England and a further 6 areas in Bedford and Kempston towns are among the 20% most deprived. Parts of these areas also have unhealthy lifestyle behaviours, poor health outcomes, high levels of unemployment, and poor performance on a wide range of well-being indicators.

5.7 One of key socio-economic and environmental challenges facing Bedford Borough is:

- areas of significant deprivation in parts of Bedford and Kempston towns, including high levels of deprivation among children and older people

6. Autism In Bedford Borough

6.1 The estimated number of people with autism is increasing as a result of better understanding and diagnosis of autism. The indication from recent studies is that a prevalence rate of around 1 in 100 is a best estimate of the prevalence in children, which we also apply to adults.¹¹

6.2 In 1993, Stephan Ehlers and Christopher Gillberg¹² published results of their Gothenburg study. They examined children in mainstream schools to find the prevalence of Asperger’s syndrome and other autistic spectrum disorders in children with IQ of 70 or above. They calculated a rate of 36 per 10,000 for

¹¹ Health and Social Care Information Centre (2009). *Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey*

National Autistic Society (2011) Statistics: how many people have autistic spectrum disorders?

Available at: <http://www.autism.org.uk/en-GB/About-autism/Some-facts-and-statistics/Statistics-how-many-people-have-autism-spectrum-disorders.aspx>. (Accessed: 04/07/2011).

¹² Ehlers, S. & Gillberg C. (1993) The epidemiology of Asperger’s syndrome, a total population study. *Journal of Child Psychology and Psychiatry*.vol4, Issue 8, pp. 1327–1350.

those who definitely had Asperger's syndrome and another 35 per 10,000 for others with similar social impairments. Some of the latter may have fitted Asperger's description if more information had been available. The children who were identified were known by their teachers to be having social and/or educational problems but the nature of their difficulties had not been recognised prior to the study.

6.3 The table below summarises the estimated current population of adults with autism in Bedford Borough, with an estimated 98,700 people aged between 16 and 64.¹³

	Age	Population	Autism (1:100)	Asperger's Syndrome (36:10,000)	Higher Functioning Autism (35:10,000)
Bedford Borough	All ages	159,000	1590	572	556
	18-64	98,700	987	355	345

Table 1: Number of people with autism in Bedford Borough.

The data for adults with autism aged 18-64 corresponds with the estimates of PANSI, as illustrated in the table 2.

Years	2010	2015	2020	2025	2030
People aged 18-24 predicted to have autistic spectrum disorders	138	134	126	126	137
People aged 25-34 predicted to have autistic spectrum disorders	199	211	215	207	201
People aged 35-44 predicted to have autistic spectrum disorders	239	216	214	231	237
People aged 45-54 predicted to have autistic spectrum disorders	227	249	241	221	223
People aged 55-64 predicted to have autistic spectrum disorders	180	182	208	230	225
Total population aged 18-64 predicted to have autistic spectrum disorders	983	992	1,004	1,016	1,023

¹³ Projecting Adult Needs and Service Information System (PANSI), Available at: <http://www.pansi.org.uk/index.php?pageNo=392&areaID=8645&loc=8645> (Accessed: 04/07/2011)

Table 2: People aged 18-64 predicted to have autistic spectrum disorders, by age and gender, projected to 2030

Conclusion 1: Available data indicates that total number of adults with autism in Bedford Borough is in the range of 983-987, with a projected increase to 1,023 by 2030.

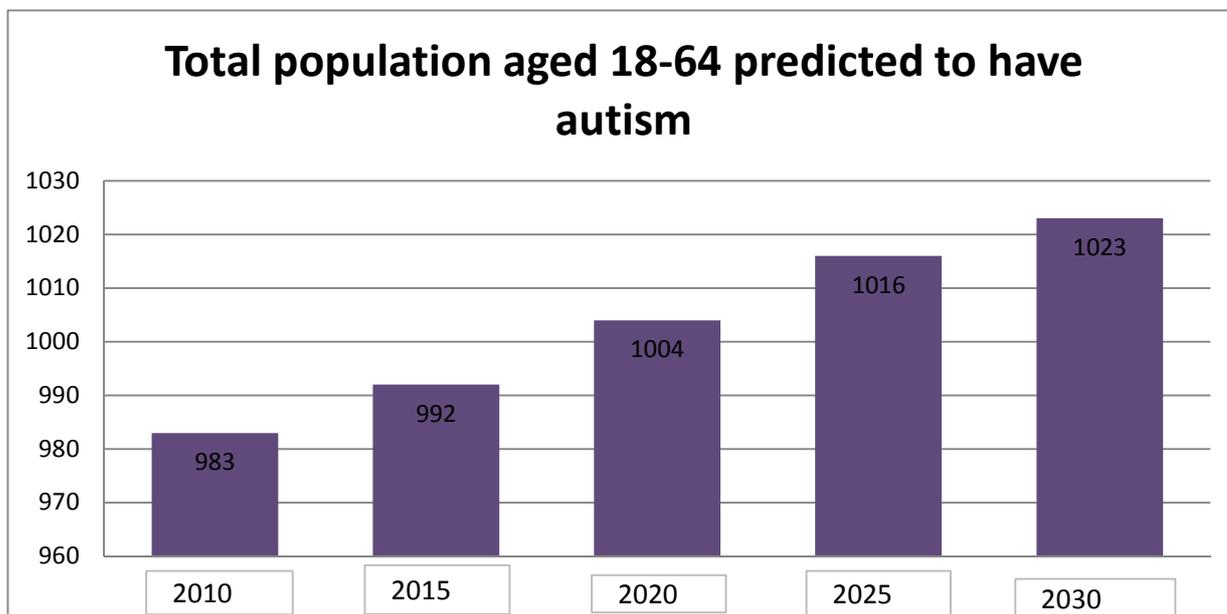


Figure 1: Increase of people with autism in Bedford Borough in the period of 2010-2030.

6.4 Males and females

Various studies, together with anecdotal evidence, have come up with male/female ratios ranging from 2:1 to 16:1. Whatever the true ratio, clinical referrals to a specialist diagnostic centre such as The National Autistic Society’s Lorna Wing Centre have seen a steady increase in the number of girls and women referred. Because of the male gender bias, girls are less likely to be identified with autism, even when their symptoms are equally severe. Many girls are never referred for diagnosis and are missed from the statistics.

	Age	Population	Autism (1%)	Males/ Females (2:1) minimum ratio range	Males/ Females (16:1) maximum ratio range
Bedford Borough	All ages	159,000	1590	1060/530	1491/99
	18-64	98,700	987	658/329	925/62

Table 3: Minimum and maximum males/females ratio range.

Conclusion 2: There is a disproportion in diagnosis between males and females. Because of male gender bias, females are less likely to be identified with autism.

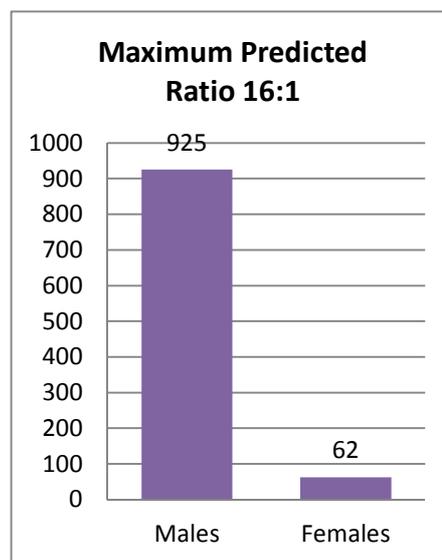
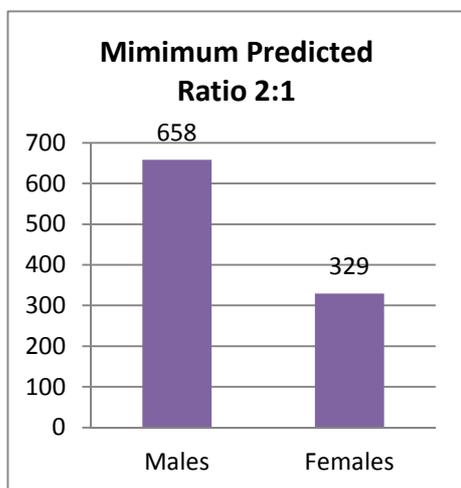


Figure 2: Minimum predicted males: females ratio for Bedford Borough, aged 18-64.

Figure 3: Maximum predicted males: females ratio for Bedford Borough, aged 18-64

6.5 Learning Disability and Autism

6.5.1 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.

The report *Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)* found that 55% of those with autism have an IQ below 70%.¹⁴

Table 4 shows local number of people with autism who have learning disability based on the above assumption.

	Age	Population	Autism (1%)	Autism with learning disability (55%)
Bedford	All ages	159,000	1590	875

¹⁴ Baird, G. et al (2006). *Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)*. The Lancet, 368 (9531), pp. 210-215

Borough				
	18-64	98,700	987	543

Table 4: Number of people with autism who have learning disability in Bedford Borough.

6.5.2 Office of National Statistics 2009 Survey Feedback for Bedford Borough¹⁵ presents following figures for people with autism known to social services:

Adults with autism receiving services with a learning disability 131.

Adults with autism receiving services without learning disability 3.

There is clearly a gap between the actual number of people with autism who have learning disability and those who are known to Bedford Borough Council social services.

6.5.3 The National Autistic Society states that 'estimates of the proportion of people with autism spectrum disorders (ASD) who have a learning disability, (IQ less than 70) vary considerably, and it is not possible to give an accurate figure. Some very able people with ASD may never come to the attention of services as having special needs, because they have learned strategies to overcome any difficulties with communication and social interaction and found fulfilling employment that suits their particular talents. Other people with ASD may be able intellectually, but have need of support from services, because the degree of impairment they have of social interaction hampers their chances of employment and achieving independence.¹⁶

Conclusion 3: There is a significant gap between amount of people with autism who have learning disability and are known to Bedford Borough social services (as of 2009), and total estimated amount of people who have autism and learning disability.

6.6 Ethnic Minorities

No evidence is available to suggest that autism is more prevalent in any particular ethnic group.

Given general demographic information (21.6% BME population) we can estimate that around 213 adults aged 18-65 from ethnic minorities will have autism. Issues of diagnosis, cultural attitudes toward autism, culturally sensitive services need to be considered in implementing the strategy.

¹⁵ National Audit Office (2009). Supporting people with autism through adulthood. Bedford Borough Council, Feedback report

¹⁶ National Autistic Society (2011). *Estimated population of autism spectrum disorders in the UK*. Available at: <http://www.autism.org.uk/About-autism/Some-facts-and-statistics/Statistics-how-many-people-have-autism-spectrum-disorders.aspx> (Accessed: 04/07/2011)

Conclusion 4: It is important that this strategy does not overlook people with autism who come from BME group, given the ethnic make up of local population, as shown in Figure 2.

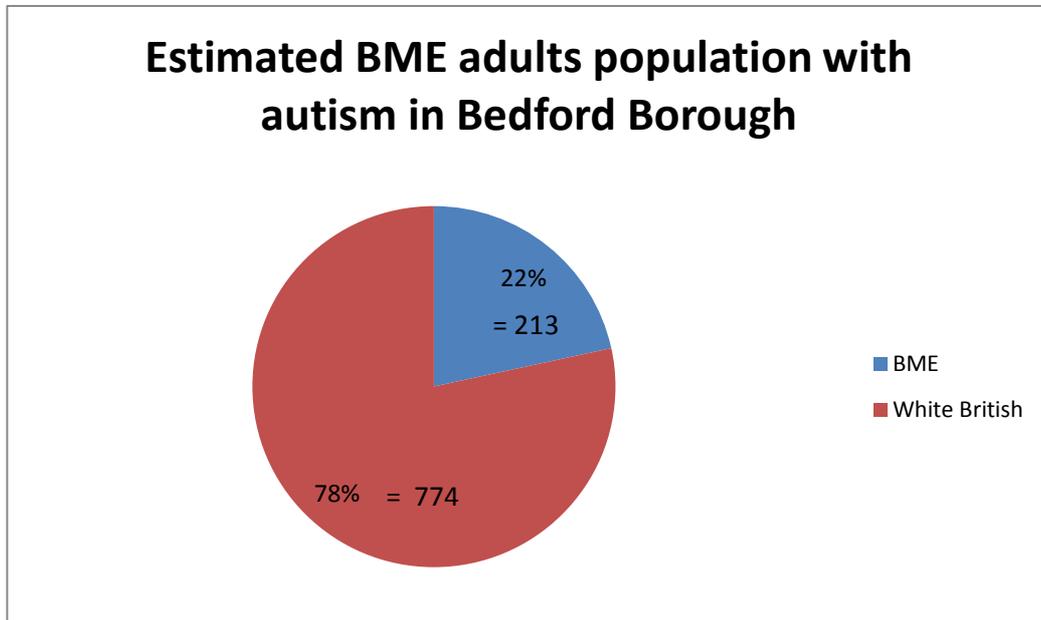


Figure 2: Estimated proportion of people with autism from BME groups in Bedford Borough.

Note: Minority ethnic groups (BME) are defined as all ethnic groups other than 'White British'

6.7 Autism in Bedford Borough: Summary of Conclusions

1. Available data indicates that total number of adults with autism is in the range of 983-987, with a projected increase to 1,023 by 2030
2. There is a disproportion in diagnosis between males and females. Because of the male gender bias, females are less likely to be identified with autism.
3. There is a significant gap between amount of people with autism who have learning disability and are known to Bedford Borough social services (as of 2009), and total estimated amount of people who have autism and learning disability.
4. It is important that local strategy does not overlook people with autism who come from BME group (estimate of 213), given the ethnic make up of local population.
5. We currently do not have exact data of people with autism in Bedford, and as one of the actions in this strategy suggests, we need to get better at understanding our local numbers, thus move from estimates as much as possible towards empirically based local data.

7. Local Picture – Central Bedfordshire

- 7.1 Central Bedfordshire has a growing and ageing population, currently estimated to be 252,900 and expected to increase to 282,400 by 2021. The biggest increase is in the number of people aged 65 and above, with the number of people aged 85+ doubling by 2021.
- 7.2 Life expectancy in Central Bedfordshire is estimated to be 79.1 years for men and 82.5 years for women, based on statistics for 2006-8. There is evidence that life expectancy is increasing at a faster rate than healthy life expectancy. If current trends continue, people are likely to spend a greater proportion of their life living with a disability or long-term illness.
- 7.3 The population in Central Bedfordshire has a lower proportion of people from minority ethnic groups (BME) at 6.8%, compared to 13% nationally. The number of national insurance registrations to overseas nationals has increased in recent years from 430 in 2002 to 840 in 2008, of whom 40% were from the new EU accession countries, 19% from Asia and the middle east and 15% from Africa. The health and social care needs of this group are not well understood locally and work is underway to determine what these are.
- 7.4 Central Bedfordshire is predominantly rural with just over half of the population living in rural areas.
- In terms of deprivation, no areas are in the 20% most deprived nationally. However, if deprivation is assessed at a small area level (known as Lower Super Output Areas – LSOAs) and compared with the East of England, there are nine LSOAs which fall within the 20% most deprived regionally. These are within Dunstable, Houghton Regis, Northfields, Flitwick East and Sandy.
- 7.5 27% of children in the Central Bedfordshire area live in low income households, rising to between 45% and 50% in parts of Houghton Regis and Dunstable.
- 7.6 Looking to the future there are a number of challenges facing Central Bedfordshire. Amongst these, people with a learning disability are likely to suffer from poorer health than the rest of the population and there are approximately 4,000 people aged between 18 and 64 years with a learning disability in Central Bedfordshire.

8. Autism In Central Bedfordshire

- 8.1 There is no exact data available on adults with autism.

Using the Ehlers and Gillberg/Wolff criteria, the estimated current population of adults with autism, Aspergers and higher functioning autism is illustrated below:

	Age	Population	Autism (1:100)	Asperger Syndrome 36:10,000)	Higher functioning autism (35:10,000)
Central	All Ages	252,900	2529	910	885

Bedfordshire					
	16-64	165,200	1652	595	578

8.2 The following table forecasts the increase in prevalence of adults with autism to 2031, based on population forecasts:

	Age	Population	Autism (1:100)	Asperger Syndrome (36:10,000)	Higher functioning autism (35:10,000)
Central Bedfordshire 2021	All Ages	292,100	2921	1051	1022
	16-64	181,000	1810	651	633
Central Bedfordshire 2031	All Ages	335,000	3350	1206	1172
	16-64	201,000	2010	723	703

8.3 Using the data available from Projecting Adult Needs and Service Information System (PANSI), total population aged 18-64 predicted to have autistic spectrum disorders is 1611.

Autistic spectrum disorders – all people	2010	2015	2020	2025	2030
People aged 18-24	199	188	176	182	198
People aged 25-34	307	344	354	339	436
People aged 35-44	401	371	384	421	436
People aged 45-54	392	422	405	375	392
People aged 55-64	313	319	369	401	385
Total population aged 18-64 predicted to have autistic spectrum disorders	1611	1643	1687	1718	1737

8.4 There is a difference between estimates of adults with autism and a learning disability using the PANSI projected prevalence, and the Ehlers and Gillberg/Wolff criteria of approximately 1:100 people with autism, based on 2009/10 population figures. However, it is clear that predicted numbers of adults with autism in Central Bedfordshire are expected to increase across all age groups over the next 20 years.

8.5 Using data from the Projecting Adult Needs and Service Information (PANSI), the table below shows the estimated projected prevalence of adults with autism and a learning disability in Central Bedfordshire:

	2010	2015	2020	2025	2130
Central Bedfordshire	1611	1643	1687	1718	1737

Autism in Central Bedfordshire: Summary of conclusions

1. Available data indicates that the number of people with autism is expected to rise significantly.
2. There is a disproportion in diagnosis between males and females – for example, using data from the Projecting Adult Needs and Service Information (PANSI), against a current estimate of 1611 people aged 18-64 with autism, only 160 are estimated to be female.
3. Accurate data needs to be collated on the number of people with autism in Central Bedfordshire so that we are best able to plan and deliver meaningful services.

9. Local Services For People With Autism In Bedford Borough And Central Bedfordshire

Universal Services

- 9.1 Putting People First¹⁷ defines universal services as local services and supports that are important in everyone's life, not just those with social care needs and include things like higher education, transport, leisure activities, and health services.

Many people with autism might not be eligible for specialist social services support, therefore 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.

Higher Education

- 9.2 There are procedures in place in children's services that cater for the needs of children with autism. The provision and support changes once they leave statutory school age. There few opportunities available if a person with autism wishes to continue into higher education.
- 9.3 For people with autism to be able to cope in higher education they may need support with elements such as organising tasks, day to day living skills, and the communication skills necessary to participate in the academic life of the university.

9.3.1 Bedford College

All staff at Bedford College have attended staff development on disabilities incorporating autism.

The Foundation Team, consisting of 20 members of both teaching and support staff have annually attended training on autism over the last four years; this has

¹⁷ Putting people first: a shared vision and commitment to the transformation of adult social care, DH, 2007

included Understanding Autistic Spectrum Condition, Practical Communication Strategies in ASC. Within the provision six students in 2010-11 have been supported in work placements or trials.

Cross college the Additional Support Team have worked with 23 students with ASC from entry level to level three in 2009-2010 and 28 in 2010-11.¹⁸

9.3.2 Central Bedfordshire College

Central Bedfordshire College in Dunstable has a Pathways Team which co-ordinates opportunities in further education for students with special educational needs, including people with autism and Asperger's syndrome. The staff employed in the Pathways Team are trained and experienced in supporting people with disabilities, including autism.

Each student has an individual programme tailored to their needs and they work towards accredited certificates through Edexcel, NCFE, and ASDAN. Courses are designed to increase their independence, help prepare for work or to move on to a higher level course. Subjects include: Communication skills, IT, hair & beauty, floristry, woodwork and the college arranges voluntary work in the community to compliment their studies. Students have the opportunity to run their own small enterprise.

Students with Asperger's syndrome are supported to access mainstream courses. Where this might prove a challenge for the individual student, the Pathways course will be used to prepare them for the move on to mainstream study.

Employment

- 9.4 The National Autistic Society stated that only 15% of adults with autism were in employment, a situation that needs to be rectified. Employment support needs to include volunteering and work experience placements, together with specialised 1:1 support to enable the individual to learn the skills involved in going to work and how to interact appropriately when there. Individuals with autism have as much right as anyone else to secure employment or volunteering opportunities and employment projects should run appropriate services to enable this to happen and to be maintained.

- 9.5 There are some specific services available for people with autism if they have a learning disability (see 9.19.1).

For those who do not have learning disability there are services provided by Job Centre Plus.

9.5.1 Job Centre Plus

Jobcentre Plus provides advisory support to disabled people who are looking for employment. Disability Employment Advisers are available in all Jobcentres and are specially trained to work with disabled people.

¹⁸ Information provided by Katrina O'Brien, Assistant Director - Foundation and Additional Support, Bedford College (July 2011)

9.5.2 Access to Work is a Jobcentre Plus grant scheme, which assists disabled people who are in paid employment or completing a work trial, by providing practical support in overcoming work related obstacles resulting from their disability. Accesses to Work grants contribute to the additional employment costs resulting from disability that an employer would not normally be expected to fund. In some cases, this may involve an arrangement where JCP and the employer share costs. For further information please email the Regional Contact Centre (London) at atwsu.london@jobcentreplus.gsi.gov.uk or telephone 0208 426 3110 textphone 0208 426 3133.

9.5.3 The Disability Employment Adviser may identify a customer who would benefit from Workchoice. This is a voluntary employment programme delivered by Shaw Trust in Bedfordshire. They provide support to disabled people facing complex barriers to getting and keeping a job. Work Choice is for disabled people of working age, with the highest support needs and whose disability is defined in the Equality Act 2010. For further information speak to the Disability Employment Adviser at your Jobcentre Plus office.¹⁹

Leisure

9.6 In 2008 a report commissioned by then Bedfordshire County Council concluded that “there is little available for someone with autism in order to socialise. Besides Autism Bedfordshire, the only services available are day centres that are predominantly focused towards helping people with learning disabilities”.

9.7 Since then various local developments have taken place to increase the availability of leisure services for people with autism to enjoy.

For example:

Oasis Beach Pool²⁰

Oasis Beach Pool (in Bedford) has now got the most sophisticated autism-friendly signage placed around a swimming pool within the U.K. The signage was fitted in March 2011 and was specially designed with advice from local charity Autism Bedfordshire.

9.8 The unique fittings have been provided as part of Bedford Borough Council’s ‘Aiming High’ programme to get children with disabilities accessing the universal services available within the community.

Directory of Local Services

¹⁹ Information provided by Louise Peck-Cooper, Integrated Partnership Manager, Jobcentre Plus, Jobcentre Directorate, St Albans (July 2011)

²⁰ Information obtained from Bedford Borough Council News website:

http://www.bedford.gov.uk/council_and_democracy/council_news/autism_friendly_signage.aspx
(Accessed on 08/07/2011)

- 9.9 Autism Bedfordshire is in the final stages of compiling a directory of services for adults which will have information on all local services that offer appropriate and accessible activities for those with autism. Venues will need to show themselves to be 'autism friendly' and special consideration also needs to be made to support the individual's participation in activities.

Information and Advice on Various Local Services

- 9.10 Both local authorities host websites which provide guidance on social care, health and housing services, making it easier to access information and advice.

Bedford Borough Council:

http://www.bedford.gov.uk/health_and_social_care/help_for_adults/information_and_advice.aspx

Central Bedfordshire Council:

<http://www.centralbedfordshire.gov.uk/health-and-social-care/Adult-Social-Care>

Health Needs ²¹

- 9.11 General Practice and Primary Care

General Practice is commissioned, contracted and funded by NHS Bedfordshire. GPs provide services to the local population on their practice list. Additional services may be commissioned with directed enhanced, locally enhanced, or nationally enhanced service contracts (DES, LES, NES respectively). Horizon Health is the practice based commissioning group for 26 GP practices in Bedford Borough.

- 9.12 Bedfordshire Community Health Services (BCHS)

This is the provider arm of NHS Bedfordshire. It provides community based services including smoking cessation advice, sexual health advice. During 2010/11 NHS Bedfordshire will become a commissioning body only, and transfer all its provider services to another provider body. It currently provides general health care to HM Prison Bedford.

- 9.13 Hospital Trusts

There are two hospitals in the Bedfordshire area: Bedford Hospital NHS Trust and Luton & Dunstable Hospital NHS Trust They provide accident and

²¹ Information adopted from NHS Bedfordshire (2010) Health Needs Assessment Adults with Autism in Bedford Borough.

emergency departments, outpatient and inpatient services at Bedford. Other hospital trusts in neighbouring areas are also commissioned to provide services for patients from Bedfordshire.

9.14 Dental Services

Dental Services are provided by private organisations commissioned through contracts with NHS Bedfordshire. These organisations range from individual dentists working alone to much larger partnerships or companies. Dental surgeries mix NHS and private work and charges.

9.15 South Essex Partnership University NHS Foundation Trust (SEPT)

The South Essex Partnership University NHS Foundation Trust is the provider of mental health and learning disability services in the Bedfordshire area. It took over the contract from Bedfordshire and Luton Mental Health and Social Care Partnership NHS Trust on 1 April 2010 and provides specialist adult learning disability health 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 4 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 then agrees a treatment pathway. The team includes speech and language therapy, dietetics, arts psychotherapies, psychology, sensory	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	Low secure unit. 10 bedded forensic unit commissioned through Specialist Commissioning Group, East of England	5 The Glade, Bromham
Health Facilitation Team	A team which provides support for people to access generic health care services. Available on 01/10/2011.	Based with local authorities adults with learning disabilities teams.

Name	Description	Location
Learning Disabilities Community Forensic Team	Delivering treatment programmes to people living in the community, Wood Lea Clinic, and supporting people who have committed offences.	

9.16 Autism Clinic

SEPT provide an autism clinic within their specialist learning disability services. This provides a diagnosis for people with a learning disability and autism, but does not provide a service for adults with autism with an IQ above 70. Access to treatment for people with autism without a learning disability has historically been denied by the local mental health provider as it is not deemed to be part of their contracted service.

9.17 South London and Maudsley NHS Trust (SLAM)

SLAM is commissioned to provide a comprehensive assessment of Bedfordshire people with “cognitive abnormalities and behavioural disorders with a known genetics syndrome”. The service is for Asperger’s Syndrome, Autistic Spectrum Disorder, Downs Syndrome, Fragile X Syndrome, Velo-Cardio Facial Syndrome.

Referrals to SLAM are made by a consultant psychiatrist.

9.18 Justice and Probation System

9.18.1 Bedfordshire Police

Bedfordshire Police are aware of autism and have carried out their own survey to assess if they were responding to the needs of people with autism.. National guidance was published to all police officers and police staff and copies made available within custody areas and parade rooms in 2010. Recently (2011) Bedfordshire Police commissioned Autism Bedfordshire to deliver awareness training.²²

The Autism Alert Card, produced by West Anglia Autism in conjunction with Beds, Cambs and Herts Police Constabularies, is being promoted by Autism Bedfordshire and its members encouraged to use it.

9.18.2 Probation Service²³

The Probation service deal with individual cases separately and have no specific procedures in place to help people with autism.

²² Information provided by Theresa Peltier, Head of Diversity and Inclusion, Bedfordshire Police. (July 2011)

²³ Information approved by Bedfordshire Probation Trust. (July 2011)

9.18.3 Bedford Prison

Bedford Prison has mental health nurses who could support offenders who have autism.

“In terms of what the team here at HMP Bedford provide, we do continue to support prisoners with autism/Asperger’s through whatever their individual needs may be. This may mean hospital transfer or simply supporting them while in prison and providing through care to the community upon release.

Regarding training; We would be happy for you or your team to visit us at the prison and give us a talk on autism”

Information provided by James Mullins, RGN, RMN, South Essex Partnership University NHS Foundation Trust, Mental Health Team Manager HMP Bedford.

9.19 Specialist Services Examples

9.19.1 Supported Employment

Both local authorities have supported employment services. The services are predominantly aimed at people with learning disabilities who meet local authority service eligibility criteria. The service aims to be very person centred and tailors support around each individual.

There is an opportunity to raise autism awareness within the supported employment team in order to improve employment support for people with autism, currently applies only to those known to social services.

9.19.2 Autism Bedfordshire²⁴

Autism Bedfordshire is an independent charity that provides assistance and support emotionally and practically to people with autism and their families in Bedfordshire and Luton.

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

²⁴ Information provided by Mike Osborne, Autism Bedfordshire Development Manager. (July 2011)

- 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 ASC, offering signposting and information on a variety of services that the adults can access themselves

Autism Bedfordshire also supports over 120 children and their families through various clubs, activities, telephone help line and publications throughout the county.

9.19.3 Day services in Bedfordshire

The local authorities currently provide day services for people with learning disabilities in Kempston, Biggleswade and Dunstable but these are under review as part of the wider modernisation of day opportunities. They support people with autism.

At Kempston Centre a unit has opened called Pathways which is run with a very structured approach in line with TEACHH principles. Service users with autism from Bedford Borough have shown great benefits and progress from being based within this unit.

Plans for the services provided by the Central Bedfordshire Council Learning Disability Assessment and Resettlement Team are being redesigned and it is intended that one of the priorities of the future service will manage and respond to a range of complex needs; specifically people on the Autistic Spectrum, those with profound disabilities, challenging behaviour and our most vulnerable groups.

A Shared Care Protocol has been agreed between Central Bedfordshire Council and South Essex Partnership NHS Trust (SEPT) for the purpose of the administration of depot medication.

10. NHS Health Needs Assessment for Bedfordshire

In August 2010 NHS Bedfordshire completed Health Needs Assessment for people with autism with recommendations which are aligned with Fulfilling and rewarding lives - The strategy for adults with autism in England.

Main recommendations are:

- Improve 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
- Specialist training packages to be provided for staff in NHS Bedfordshire who come into contact with adults with autism. This will help staff with a greater understanding of autism, and determine 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 NHS Bedfordshire
- Using the increased awareness of frontline staff of autism will mean that there needs to be a care pathway developed. NICE are currently developing a model care pathway for use in local areas, and which can be used by GPs, mental health practitioners and voluntary sectors
- The national strategy recommends the appointment of a local lead professional to develop local diagnostic and assessment services for adults with autism, working with local specialised commissioning group
- 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
- The Standard Contract for Mental Health and Learning Disabilities should make specific references to adults with autism, and demonstrate how reasonable adjustments for adults with autism are made. For NHS Bedfordshire staff dealing with patients with autism this could mean:
 - a) Provision of lower-light areas or quiet areas for adults with autism with sensory impairments in healthcare settings
 - b) 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
 - c) Raising awareness by frontline staff of how to respond to those communication problems demonstrated by adults with autism
 - d) 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

These recommendations are fully considered in the Bedfordshire strategy.

11. Autism Workshops

- 11.1 NHS Bedfordshire, Central Bedfordshire Council, Bedford Borough Council, and Autism Bedfordshire have held a series of consultation events and workshops to review this guidance and to develop a local strategy for the people of Bedfordshire.
- 11.2 Two autism workshops were held in October 2009 and January 2010 involving individual consultation meetings with service users, carers, interest groups and service providers.

11.3 Concerns were raised and discussed, with the following recommendations for future services:

- Quality assurance of training
- Future cohort – a post created to map services and evidence local needs
- Joint working with other counties/boroughs to seek good practice
- Work with local colleges and providers
- Trained staff with the outcome of establishing ASD specialism and provision
- Accredited services available locally
- Adult services and children's services working together or transitions
- ASD team to cover across the whole of Bedfordshire with the skills and resources to cover the whole ASD spectrum
- Diagnostic service to cover all age groups
- Directory of local information
- Co-ordinate teams/developments/work
- ASD Commissioner across Bedfordshire – developing, befriending, mentoring services
- Information and guidance for parents (parent support groups)
- ASD Team to be located within Learning Disability and Mental Health Forensic teams
- Rolling training programmes available (and engage with workforce development programmes + teams) targeting existing services
- Post diagnostic service (e.g. family support workers)
- Ongoing mapping of local population working with schools and services
- Strategically building into strategic plans; Joint Commissioning strategy.
- Development of employment support + support around transition

12. Local Strategy

12.1 This local strategy includes the findings of the NHS Health Needs Assessment and outlines the recommendations which are going to be developed across the core areas in Bedfordshire.

12.2 Strategic Objectives:

1. Increase awareness and understanding of autism among frontline staff across the whole community.

2. Develop a clear consistent pathway for diagnosis in every area, which will be followed by the offer of a personalised needs assessment and considerations for appropriate community services.
3. Plan in relation to the provision of services to people with autism in transitions.
4. Enable local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities
5. Help adults with autism into work.

13. Awareness And Training

- 13.1 Increasing awareness and understanding of autism among frontline professionals.

It has been identified that there is a lack of understanding of autism within services in Bedfordshire, this can have significant consequences. Adults with autism may not trust public services and this may lead to an avoidance of the very services they need for support. Training frontline staff will enable staff to recognise autism and be able to respond appropriately when they are working with adults with autism.

- 13.2 Autism awareness training will be delivered across the public sector as part of general equality/diversity training; this includes staff within the criminal justice sector.

The training will be developed as part of a standardised suite of training programmes, ranging from autism awareness and developing into training for specialist services. Each programme will have an identified target audience. People with autism and their carers will be identified to help facilitate these sessions.

Training departments within each local authority and The Autism Partnership will monitor the uptake of training across all public sector services.

14. Diagnosis, Assessment And Community Services

- 14.1 For many adults, receiving a diagnosis is an important step not only for the individual but for their families and carers.

We will develop a clear consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment and considerations for appropriate community services.

- 14.2 Within Bedfordshire, people with a learning disability can currently be assessed within the specialist learning disability service, but for people with Asperger's syndrome, they need to go to out of area for an assessment. This is not

acceptable and places those people with an identified need isolated and with no clear pathway for support.

14.3 Within Bedfordshire, a pathway that enables people to get a diagnosis locally which triggers a pathway of support and sign posting will be developed. The pathway will be developed that takes over 18's regardless of their cognitive ability, and supports them through diagnostic process.

14.4 The pathway from diagnosis will be part of a framework of specialist support and advice which is connected to mental health, learning disability and private and voluntary sector services.

The pathway will ensure that existing statutory and policy guidance is met along the journey, flagging up community care assessments, carer's assessments and CPA where appropriate, as well as being a hub for information and education around autism and ways to support people.

14.5 People with autism will be clearly identified within services to enable them to be offered the support they need within services.

"Co-operation between teams" - A protocol for deciding which teams should be responsible for the social care needs of a service user where people are not sure or where there should be shared responsibility will ensure that people with autism are not turned away from services they need to access based on their diagnosis and will be signposted to the most appropriate service at the point of access.

14.6 It is acknowledged that people with autism often do not access the services or support they need despite equality of access being a fundamental principle of all public services.

14.7 The Autism Partnership is committed to the delivery of autism awareness across public sector services as a first essential step in making a cultural shift across services. In addition to this, The Equality Act 2010 requirement for services to make reasonable adjustments for adults with autism will be monitored through contract compliance and a programme of service visits and reviews. The acute liaison nurse posts in both general hospitals and the anticipated appointment of health facilitators across Bedfordshire will be key in supporting services in understanding the adjustments that they will need to make.

14.8 Data will be collated on how people with autism are accessing services, what barriers are identified and how these are overcome. Commissioners will work across all providers to ensure that there are positive outcomes for people with autism.

14.9 In addition to the inadequate diagnostic arrangements, concerns have been made over the lack of local specialised service provision, resulting in people with autism needing to move away from their families and friends to live somewhere where their needs can be met.

The commissioners recognise the need to enable people to live within the communities they know, if they choose to do so and will develop local specialised services as part of its commissioning plan over the next three years.

- 14.10 The commissioners will review the Supporting People Strategy and work with housing providers to understand the needs of people with autism and how these can be supported.
- 14.11 To enable people to have fulfilling lives, there is a need to ensure that people are able to access public transport that is safe and provided by services that understand autism and are able to make reasonable adjustments that enable frequent use.

As part of the training programme being developed, training will be offered to public transport companies and a skills set will be provided for people with autism, to enable them to feel competent and able to use a range of public transport.

15. Transitions

- 15.1 Planning in relation to the provision of services to people with autism in transitions.

In consultation with parents in Bedfordshire, the need for planned transition in an acceptable time frame is essential. Too many families described instances where they were 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.

- 15.2 The needs of people with autism during the transition period is being addressed through work being undertaken within the transition groups across both councils and assurance against this will be sought by The Autism Partnership.

All existing policies will be scrutinised to establish whether they support young people with autism adequately.

- 15.3 It is important to establish effective exchange of information between children and adult services. This is not just in terms of information about individuals at the point of transition, but also reflects the need to share information about the needs and number of children with autism in a local area to help with longer-term planning.

- 15.4 All the professionals involved in transition planning must receive appropriate training so that they may adjust their behaviour to reflect the needs of the young person.

16. Development Of Services

- 16.1 There have been a series of workshops on autism within Bedfordshire, as well as consultation on an individual and group basis with people with autism and their carers.

- 16.2 The Autism Partnership has identified what things are working well locally and where gaps in services exist. These are being addressed within the local strategy and we are committed to continuing to work with our local community in taking this forward.
- 16.3 The Joint Strategic Needs Assessment (JSNA) will need to provide comprehensive data on the local autistic population.
- 16.4 Investment in services for assessment and diagnosis which are currently commissioned out of area will cease and the resources will be used to develop an Autism Service within Bedfordshire.
- 16.5 An outline of the key tasks has been developed into the strategic action plan and progress against this will be monitored through The Autism Partnership which will report into the Healthier Communities and Older People Board for Central Bedfordshire, Adult Health and Wellbeing Thematic Partnership Board for Bedford Borough and A Healthier Bedfordshire Programme Board for NHS Bedfordshire.
- 16.6 Each statutory organisation (Bedford Borough Council, Central Bedfordshire Council, and NHS Bedfordshire) will have a commissioner or senior manager responsible to ensure progress of this autism strategy.
- 16.7 Local Autism Partnership is in its infancy, however the group has been steering the implementation of autism strategy within Bedfordshire. It is important for the group to continue and expand. Governance of the group will be clearly identified within each statutory organisation.

17. Employment

- 17.1 Only 15% of adults with autism are in full-time employment, but most are willing and able to work.

It is estimated that there are about 332,600 people of working age in the UK with autism. But National Autistic Society research has shown that only 6% of all people with autism have full-time paid employment, and only 12% of those with high-functioning autism or Asperger's syndrome have full-time jobs. ²⁵

The problems in finding and keeping a job arise from the lack of available information, advice and practical support that is autism specific. .

- 17.2 People with autism and Asperger's syndrome often have numerous (and sometimes exceptional) skills which enable them to make excellent employees. As well as their individual abilities, some traits associated with autism can, when well channelled, be a considerable benefit in the work place. For example, many people with autism are good at paying close attention to detail and are meticulous about routines, rules and accuracy – meaning they are often

²⁵ National Autistic Society (2011) Employment. Available at: <http://www.autism.org.uk/employment> (Accessed on 08/07/2011).

extremely reliable, and can excel at jobs such as accounting, where consistent procedures and precision are vital. Other people with autism enjoy repetitive tasks (whether basic or complex) and perform very well in fields such as IT or administration.

- 17.3 The Autism Partnership proposes to single out employment as an additional priority. Many people with autism offer exceptional sets of skills, which with proper support are significant assets to any employer.

People with autism need to be supported to access employment and The Autism Partnership are committed to increasing the number of people with autism in work.

Development of supported employment programmes are being coordinated through the existing work groups in each local authority and feedback to assure that this is being achieved will be given to The Autism Partnership.

Additionally, The Autism Partnership proposes to work with Job Centre Plus to maximise chances of people with autism in Bedfordshire to get and maintain suitable employment.

18. Delivery

- 18.1 This strategy will be delivered through the three year action plan. During the life of the strategy we will continue to consult and invite feedback to ensure the annual action plans reflect any changes to local or national priorities.

- 18.2 Our challenge is to deliver on specific autism requirements and ensure autism is included in the delivery of mainstream health and social care services. This will require a joined-up approach across all agencies with a role in the health and wellbeing of Bedfordshire.

- 18.3 However, neither the Local Authorities nor NHS Bedfordshire can improve health outcomes and local quality of life alone. Individuals need to take responsibility for their own health and need support to access advice and information that will enable them to make informed lifestyle choices.

A range of public, private and voluntary organisations also need to work more effectively together in order to tackle the challenges facing Bedfordshire, joining-up services for the benefit of those that need them.

- 18.4 To this end, it is envisaged that a wide-range of stakeholders will come together as the Autism Partnership to identify what needs to be done and then take action to make sustainable improvements. It is this partnership which will be monitoring implementation of the strategy. – See Appendix I – Governance Structures.

Main stakeholders of the Autism Partnership are:

- Adults aged over 18 with an autistic spectrum disorder

- Young people aged 16 to 18 years with an autistic spectrum who are in transition process
- NHS Bedfordshire
- Central Bedfordshire Council
- Bedford Borough Council
- South Essex Partnership NHS Foundation Trust
- Advocacy services
- Autism Bedfordshire
- Family Carers and Carers Support services
- Providers of day time activities and education
- Supported Employment Providers
- Job Centre Plus
- Registered Social Landlords and other housing providers
- Police and Probation services

19. Glossary

Care Programme Approach (CPA)

Mental healthcare for people with severe mental health problems is coordinated under a Care Programme Approach.

Carers Assessments

Assessment by social services department of your local authority in order to find out what help you need with caring, if you are a carer.

Commissioning

Buying, monitoring and reviewing of social care and health services.

Community Care Assessments

The local authority uses the community care assessment to decide whether a person needs a community care service and, if they do, whether it can be provided by the local authority.

Health and Wellbeing Thematic Partnership

NHS and Local Authority working better together to deliver the necessary changes required to ensure that everyone in Hampshire are able to benefit from improvements in health and well-being.

Joint Strategic Needs Assessment

The purpose of JSNA is to pull together in a single, ongoing process all the information which is available on the needs of our local population ('hard' data i.e. statistics; and 'soft data' i.e. the views of local people), and to analyse them in detail.

Learning Disability Partnership Board

Brings together variety of people who buy, provide and use services to ensure that needs of people with learning disability are met.

Mental Health Partnership Board

Brings together variety of people who buy, provide and use services to ensure that needs of people with learning disability are met.

NHS Bedfordshire

Responsible for commissioning all health services for more than 420,000 people who live in the county.

Prevalence

Total number of cases of the disease in the population at a given time

South Essex Partnership Trust

Provides health and social care services for people with mental health problems and people with learning disabilities across Bedfordshire, Essex and Luton.

Sustainable Community Strategy

Set of goals and actions which local strategic partners, in representing the residential, business, statutory and voluntary interests of an area, wish to promote.

Supporting People

Supporting People provides housing related support to help vulnerable people to live as independently as possible in the community. This could be in their own homes or in hostels, sheltered housing or other specialised supported housing.

Stakeholder

Anyone who has an interest in or is affected by this strategy.

Transitions

Planned process that helps adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health and social care systems.

20. Appendices

Appendix I – Governance Structures

NHS Bedfordshire

NHS Bedfordshire is a key partner in the governance arrangements within both Bedford Borough Council and Central Bedfordshire Council. The commitment to this strategy and progress in its delivery will be reported through both structures through the Learning Disability Partnership Boards. Within NHS Bedfordshire, the Autism Strategy will be agreed by the Clinical Executive Committee.

Central Bedfordshire Council

The Healthier Communities and Older People Partnership Board is a Thematic Partnership of the Local Strategic Partnership, with members including our partners in Health, emergency services, voluntary sector organisations, etc. See below. It is supported by eight delivery partnerships.

The Delivery Partnerships are responsible for the detailed planning, implementation and monitoring of the priorities within each partnership stream. As well as cross cutting priorities, they will address issues more specific to their service area.

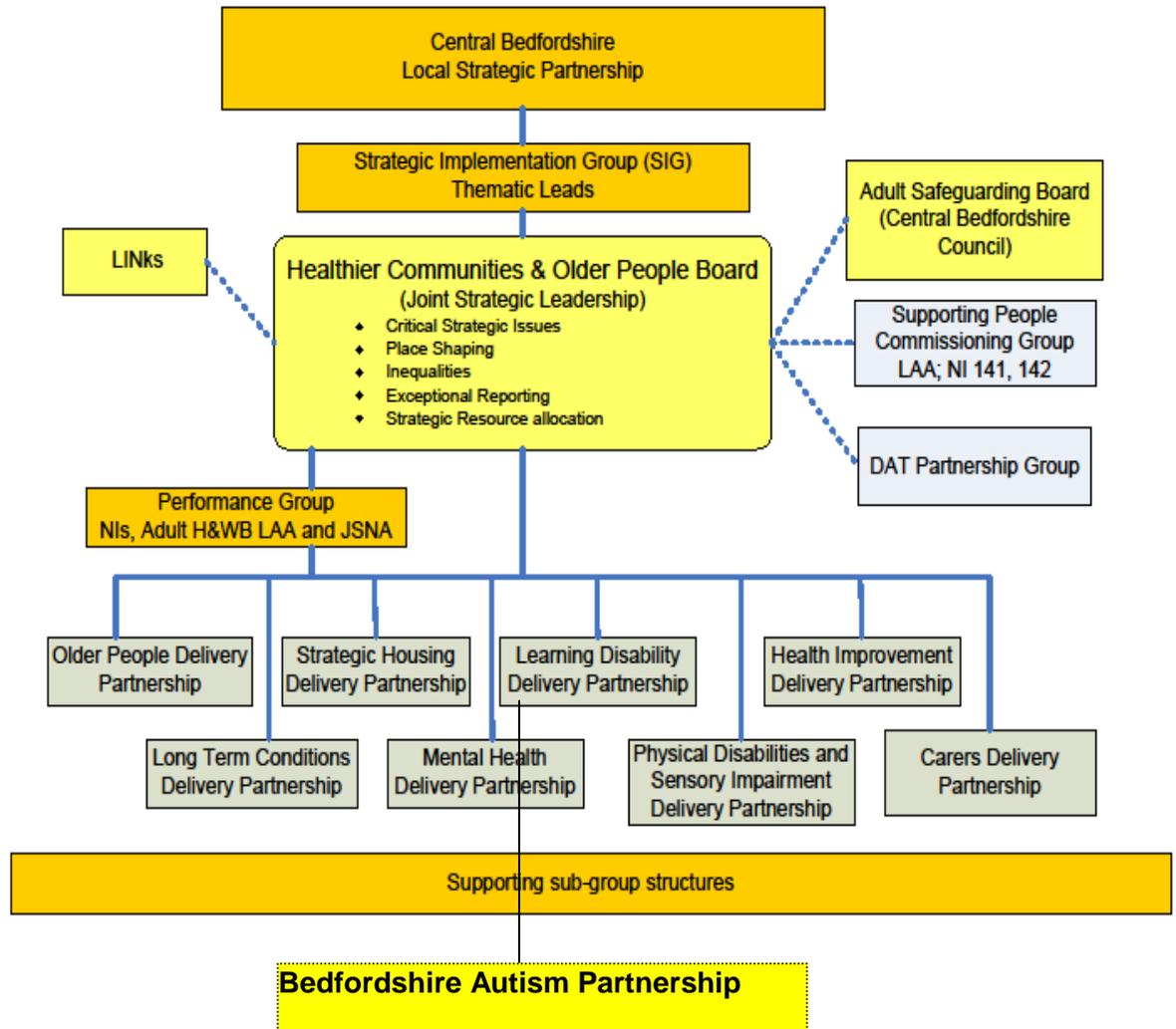
Each delivery partnership has set out its main aims and key priorities, for the next three years and will be responsible through an Outcomes Delivery Plan to the Partnership Board. Delivery Partnerships will:

- Be outcome focused
- Be responsible for Strategic commissioning
- Influence the wider agenda on cross-cutting issues
- Produce a strategic commissioning plan to deliver key outcomes
- Monitor performance including impact on outcomes of commissioned services
- Ensure participation and engagement with service users and carers.

Through these arrangements, a joint approach to service planning, commissioning and delivery will be at the heart of ensuring improved care and support services in Central Bedfordshire.

The delivery of autism services will be monitored and driven forward through the Learning Disability Delivery Partnership and will link directly with the County wide Autism Partnership.

Healthier Communities and Older People Partnership Board Structure



Bedford Borough Council

The Bedford Borough Partnership is the leadership of Borough Council, Health Service, Police, Fire, local businesses, parish councils, voluntary organisations and community groups - all wanting to make life better for everyone who lives, works and visits Bedford Borough.

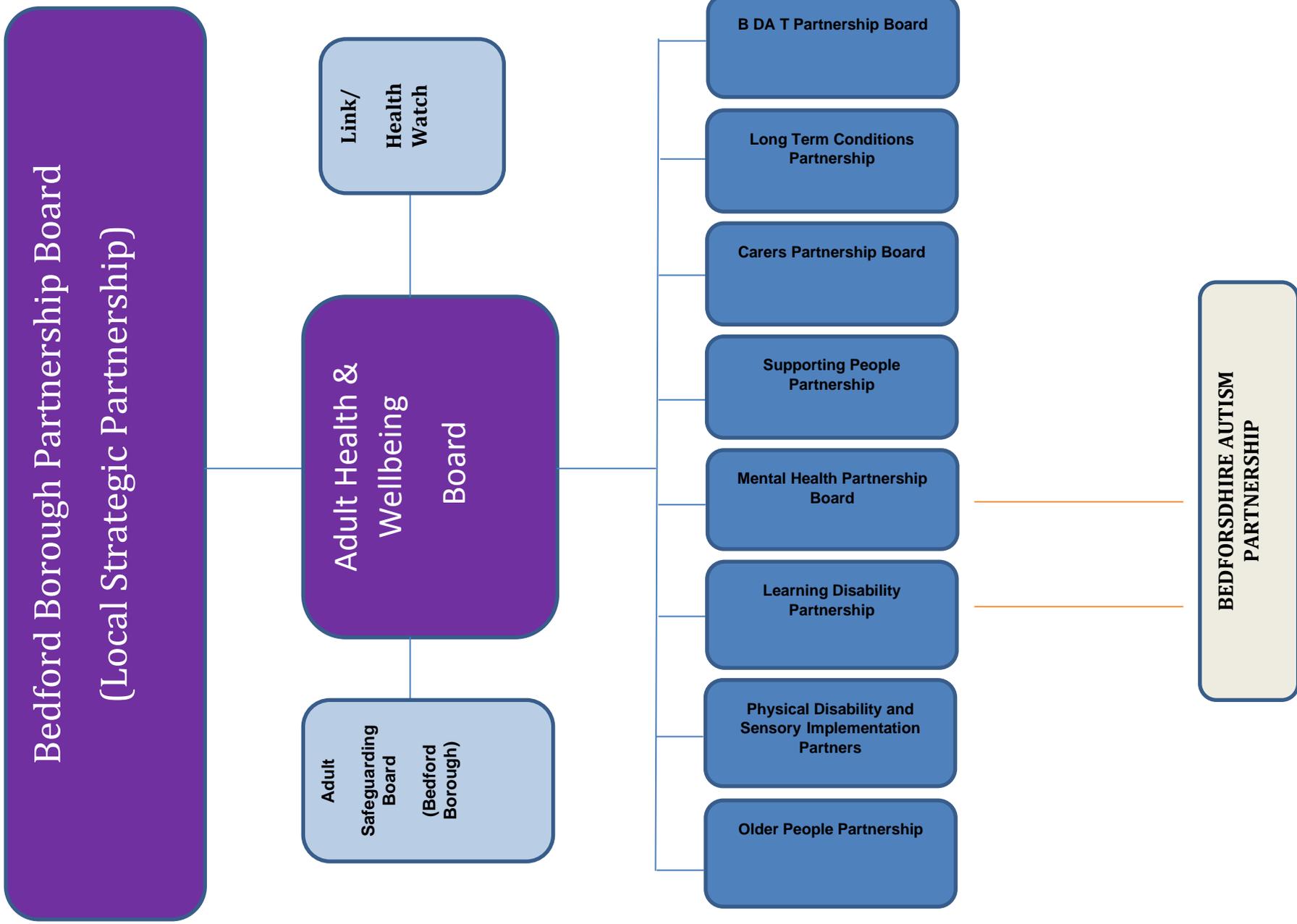
As well as providing services to the citizens of the Borough, the partnership work together to tackle variety of the issues that matter most to our residents and communities.

One of the issues is health and wellbeing – aspiration to be a healthy Borough, a Borough where everybody has access to high-quality health and social care services when they need them and the help they need to lead healthy and independent lives. Adult Health and Wellbeing Thematic Partnership is formed to deliver this aspiration.

It will be the role of The Autism Partnership to ensure that this strategy translates also into agenda of each of eight partnership boards.

Additionally, The Autism Partnership will be reporting the Adult Health and Wellbeing Thematic Partnership via the Learning Disability Partnership Board and Mental Health Partnership Board.

The delivery of this autism strategy will be monitored and driven forward by the responsible commissioning manager.



Appendix 2

Main Training categories as discussed at one of the workshops

Type of Training	Target Audience
<p>Brief interactive session, literature, information on services</p> <p>3 hours general awareness</p>	<p>Voluntary sector, police, job centre, library, front line public sector workers, reception staff in health services, probation, criminal justice system, ambulance staff, police, community health services</p>
<p>Service user involvement, formal lecture/interactive training, understanding of ASC, pre course practical work, experiential learning, how to make adjustments/practical strategies, information of services and signposting, information on pathway.</p> <p>1 day course and focus groups</p>	<p>GP, DEA's. Schools/colleges, Carers, Families, "Champions" in general services, Voluntary agencies, Mental health teams and Learning disability teams, Social workers, Day centres</p>
<p>Specialist training to be identified</p>	<p>Staff working within Specialist Autism Services</p>

BEDFORD HEALTH AND SOCIAL CARE DELIVERY ACTION PLAN for REWARDING AND FULFILLING LIVES IN BEDFORDSHIRE - AUTISM STRATEGY (2011-2014)

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.

Area for Improvement	Main Action Required	Bedford Health and / or Social Care Required Actions	Responsible Person + Target Date	Progress to date	Self Assessment Rating
Increasing Awareness	Include autism awareness training in general equality and diversity training across BBC and NHSB	<ol style="list-style-type: none"> 1. Review current provision within Corporate BBC and Adult Social Care training programmes 2. Discuss practicality of inclusion with Equality and Diversity Manager 3. Develop aims, objectives and learning outcomes for training 4. Commission training provider Deliver and evaluate training.	Jon Seth April 2012		
	Publish the Autism Training Strategy	<ol style="list-style-type: none"> 1. Work with Commissioning Group to develop and finalise approved strategy. 2. Distribute strategy for comment and approval 	Jon Seth April 2012		

		3. Publish strategy – link to awareness raising sessions.			
	Deliver the Autism Training Strategy	<ol style="list-style-type: none"> 1. Regularly monitor and revise strategy as necessary. 2. Maintain impetus of awareness raising through regular discussion with stakeholders. 3. Publicise updates to strategy as necessary to all relevant stakeholders 4. Implement strategy actions and continually monitor progress against actions and timescales. 	<p>Jon Seth/Marek Zamborsky</p> <p>April 2012 – April 2014</p>		
	Increase delivery of autism awareness training to staff in partner organisations	<ol style="list-style-type: none"> 1. Ensure that Job centre plus, Police, Probation Service, Criminal Justice Sector, Local Education institutions, and public transport companies are part of Autism Partnership 2. Seek evidence of autism awareness training action plans 	<p>Autism Partnership</p> <p>January 2012</p>		

		from the above organisations			
		3. Ensure reporting on delivery of the training to the Autism Partnership			

Area for Improvement	Actions required	Bedford Health and / or Social Care Required Actions	Responsible Person + Target Date	Progress to date	Self Assessment Rating
Pathway for Diagnosis and Needs Assessment	Include within contracts specific reference to people with autism	<ol style="list-style-type: none"> 1. Discuss with ADASS regional procurement coordinator autism specific reference in ADASS contracts (Equality Act, reasonable Adjustments). 2. Prepare specific contract schedule with requirements for support of people with autism. 	<p>Marek Zamborsky</p> <p>Michelle Bradley</p> <p>April 2012</p>		
	Appoint lead professional for autism diagnostic centre	1.To identify SEPT lead professional through Commissioning and Performance meetings	<p>Michelle Bradley</p> <p>April 2012</p>		
	"Develop diagnostic pathway for diagnosis, assessment, and support"	<ol style="list-style-type: none"> 1.To lead focus group on developing pathway 2. To develop a multi agency pathway of assessment and support using statutory organisations and 	<p>Michelle Bradley</p> <p>April 2012</p>		

		private/voluntary sector provision			
	Diagnosis leads to community assessment care	<p>1. Establish clear communication procedure between diagnostic services and local authority/SEPT.</p> <p>2 Establish procedure for allocation of assessment to the most appropriate team.</p> <p>3. Identify resources for staff to carry out LA assessment.</p>	<p>Marek Zamborsky/John Bruynseels</p> <p>April 2012</p>		
	All people providing social care assessment are appropriately trained	<p>1. Training Programme to be in place</p> <p>2. Identify staff to be trained</p> <p>3. Implement Training</p>	<p>John Bruynseels</p> <p>September 2012</p>	.	
	Signposting information and advice on alternative support available	1. Ensure that Autism friendly information is available (Autism Directory).	John Bruynseels/Mic		

		2. Ensure that all staff carrying assessment are aware of local universal and specialist services.	helle Bradley April 2012		
	Personal Budgets for People with autism available	1. Ensure internal business processes are fit to support people with autism. 2. Ensure staff are appropriately strained.	Jo Hawthorne April 2012		

Area for Improvement	Actions required	Bedford Health and / or Social Care Required Actions	Responsible Person + Target Date	Progress to date	Self Assessment Rating
Transitions	Transition protocol fit for people with autism	Recruit and train a permanent Transitions Co-ordinator for Children's Services	Abbey Woolgar April 2012		
	Exchange of Transition Information between adult services and children services to inform planning	<ol style="list-style-type: none"> 1. Ensure the data generated by the MAAT is exchanged with all relevant departments and that it is fit for purpose. 2. Ensure all Further Education provisions are fully engaged in the MAAT process. Transition Co-ordinator will ensure that all departments act upon the information provided. 	Abbey Woolgar/Marek Zamborsky April 2012		
	Transition Staff Training so they can adjust their practice to reflect the needs of young people with autism.	<ol style="list-style-type: none"> 1. Ensure that e-learning is available to all personnel and families who are involved in the transition planning process. 	Abbey Woolgar April 2012		

Area for Improvement	Actions required	Bedford Health and / or Social Care Required Actions	Responsible Person + Target Date	Progress to date	Self Assessment Rating
Local Planning and Delivery Arrangements	Autism Strategy to be launched	<ol style="list-style-type: none"> 1. Coordinate launch event with other organisations 2. Plan the launch event 3. Launch Event 	February 2012		
	Autism Agenda at relevant boards	<ol style="list-style-type: none"> 1. Autism to be recurring item on LD and MH partnership Board. 2. Regular updates provided on Autism Partnership at the boards. 3. A Chair on MH and LD board present at Autism Partnership meetings. 	Marek Zamborsky April 2012		
	Establish Autism Partnership	<ol style="list-style-type: none"> 1. Define annual delivery action plan linked to strategy acceptable 	Marek Zamborsky Michelle Bradley		

		<p>to all statutory stakeholders.</p> <p>2. Create terms of reference.</p> <p>3. To agree governance and reporting framework for autism pathway</p>	<p>April 2012</p>		
	<p>Review Local Autism provision and report recommendations</p>	<p>1. Conduct local service mapping: capacity and level of professional accreditation (residential services, community based services, day opportunities).</p> <p>2. Analyse the returns and data.</p> <p>3. Ensure the information informs JSNA and local commissioning intentions.</p>	<p>Marek Zamborsky/Michelle Bradley</p> <p>April 2012</p>		

	Local Housing Needs strategy will consider requirements of people with autism	<ol style="list-style-type: none"> 1. Include people with autism in the needs analysis. 2. Publish strategy. 3. Inform Autism Partnership and Commissioning on the recommendations of the strategy. 	<p>Andrew Kyle</p> <p>April 2013</p>		
	Data recording within BBC – data on people with autism recorded within BBC data management system	<ol style="list-style-type: none"> 1. Ensure that BBC data management system records autism as standalone category a) new referrals b) assessments completed c) exiting service users 2. Use the data to inform JSNA. 	<p>Marek Zamborsky</p> <p>Jenny McAteer</p> <p>April 2012</p>		
	JSNA chapter on autism	<ol style="list-style-type: none"> 1. Conduct research on local and national intelligence. 2. Ensure stakeholders consultation conclusions are part 	<p>Marek Zamborsky</p> <p>April 2012</p>		

		<p>of JSNA.</p> <p>3. Work in a partnership with public health.</p>			
	<p>Have a local commissioner with responsibility with autism</p>	<p>1.Appoint a commissioner with responsibilities for Autism</p>	<p>Frank Toner</p> <p>April 2011</p>	<p>NHSB commissioners in place.</p>	
	<p>Introduce data quality mark across health and social care</p>	<p>1. Engage with local providers on the idea of accreditation.</p> <p>2. Map national and best practice on autism quality marks.</p> <p>3. Define local answer to the quality mark.</p> <p>4. Ensure quality mark is part of a contracts of those service which provide specialist autism support</p>	<p>Marek Zamborsky</p> <p>Michelle Bradley</p> <p>December 2012</p>		

Area for Improvement	Actions required	Bedford Health and / or Social Care Required Actions	Responsible Person + Target Date	Progress to date	Self Assessment Rating
Employment	Review local supported employment for autism	<ol style="list-style-type: none"> 1. Liaise and Monitor Autism Bedfordshire's current BBC supported employment programme initiative. 2. Identify potential gaps in opportunity provision for Autistic people within BBC. 3. Plan and cost future service provision approaches 	Ian Mckenzie/Marek Zamborsky April 2012		
	Develop coordinated supported service for autism which will increase number of people with autism at work	<ol style="list-style-type: none"> 1. Determine and map who is providing SES for BBC autistic people 2. Determine number of BBC people with Autism who have been helped in the past 12 months and where they have been employed 3. Create awareness with employers about supported employment and employing people with autism 	Ian Mckenzie/Marek Zamborsky April 2012		

		<ol style="list-style-type: none"> 4. Comprehend how many BBC people with Autism are currently employed and where 5. Work with SES providers to gain work placements 6. Pull activity together in a 3 year plan 			
	<p>Increase the number of people with autism in employment by 10% per year for the life of strategy</p>	<ol style="list-style-type: none"> 1. Actively deliver and monitor the agreed 3 year plan. 2. Determine how many people in BBC have Autism and are of or coming up to working age an not in Education or Training. 3. Ensure the outcome is delivered, a year on year increase in employment for people with autism form an agreed starting point. 	<p>Ian McKenzie</p> <p>April 2012-April 2014</p>		

Area for Improvement	Actions required	Bedford Health and / or Social Care Required Actions	Responsible Person + Target Date	Progress to date	Self Assessment Rating
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Equality Analysis	Ensure the delivery of strategy is monitored and action taken to reach BME groups and females	<ol style="list-style-type: none"> 1. Ensure quality assurance process of all stakeholders captures data BME and females. 2. Collate annual monitoring report on quality data from NHS and BBC. 3. To identify champions for BME and females within the steering group and local services. 	Marek Zamborsky Michelle Bradley April 2013		
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Green – Completed or on time

Amber – In progress, delay possible

Red – Not completed, not on time.