

**Fulfilling and Rewarding Lives In
Central Bedfordshire**

**Autism Strategy
For Central Bedfordshire**

(2011 – 2014)

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1. Executive Summary

- 1.1 This strategy links with the joint commissioning strategy to improve outcomes for people with Autism in Bedfordshire and 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.

Central Bedfordshire Council has worked in partnership with Bedford Borough Council and NHS Bedfordshire to produce a local 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.

Central Bedfordshire Council

- 4.5 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

- 4.6 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 – Central Bedfordshire

- 5.1 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.
- 5.2 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.
- 5.3 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.
- 5.4 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.
- 5.5 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.
- 5.6 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.

6. Autism In Central Bedfordshire

6.1 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 Bedfordshire	All Ages	252,900	2529	910	885
	16-64	165,200	1652	595	578

6.2 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

6.3 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

6.4 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.

- 6.5 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.

7. Local Services For People With Autism In Central Bedfordshire

7.1 Universal Services

Putting People First⁹ 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.

7.2 Higher Education

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.

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.

Central Bedfordshire College

⁹ Putting people first: a shared vision and commitment to the transformation of adult social care, DH, 2007

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.

Autism Bedfordshire are developing a Directory of universal services to provide information on all services which are accessible to people with autism across Bedfordshire and Luton.

7.3 Employment

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.

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.

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.

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.

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.¹⁰

7.4 Leisure

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”.

7.5 Directory of Local Services

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.

7.6 Information and Advice on Various Local Services

Central Bedfordshire Council hosts a website which provides guidance on social care, health and housing services, making it easier to access information and advice: <http://www.centralbedfordshire.gov.uk/health-and-social-care/Adult-Social-Care>

7.7 Health Needs ¹¹

7.7.1 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, and NES respectively).

7.7.2 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.

7.7.3 Hospital Trusts

There are two hospitals in the Bedfordshire area: Bedford Hospital NHS Trust and Luton & Dunstable Hospital NHS Trust They provide accident and emergency departments, outpatient and inpatient services at Bedford. Other hospital trusts in

¹⁰ Information provided by Louise Peck-Cooper, Integrated Partnership Manager, Jobcentre Plus, Jobcentre Directorate, St Albans (July 2011)

neighbouring areas are also commissioned to provide services for patients from Bedfordshire.

7.7.4 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.

7.7.5 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.
Learning Disabilities Community Forensic	Delivering treatment programmes to people living in the community, Wood Lea Clinic, and supporting people who have committed	

Name	Description	Location
Team	offences.	

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.

7.7.6 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.

7.7.7 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, and Velo-Cardio Facial Syndrome.

Referrals to SLAM are made by a consultant psychiatrist.

7.8 Justice and Probation System

7.8.1 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.¹²

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.

7.8.2 Probation Service¹³

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

¹² Information provided by Theresa Peltier, Head of Diversity and Inclusion, Bedfordshire Police. (July 2011)

¹³ Information approved by Bedfordshire Probation Trust. (July 2011)

7.8.3 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.

7.9 Specialist Services Examples

7.9.1 Supported Employment

Central Bedfordshire Council’s supported Employment Team is a specialist service and is committed to providing supported employment opportunities for those people with a learning disability who need support the most. For this reason, the service predominantly supports people who meet the local authority service eligibility criteria. The service aims to empower the individual to reach their full potential through a person centred approach ensuring that support is tailored to individual need. The service works in partnership with other employment support agencies in order to achieve a collaborative approach and to ensure that the person being supported has access to the right opportunities for personal development, training and career progression.

7.9.2 Autism Bedfordshire¹⁴

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

¹⁴ 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.

7.10 Day services in Central Bedfordshire

Central Bedfordshire Council currently provides day services for people with learning disabilities in Biggleswade and Houghton Regis but these are under review as part of the wider modernisation of day opportunities. They support people with autism.

The Independent Lifestyles Team is a recent service development offering an enablement service to people with a learning disability. The aim of the service is to provide assessment and training to people with a learning disability to maximise their opportunity and ability to live the life they want to. This will include the right to live in their own home, with support if appropriate and to be in paid employment. The service will seek to support people with a learning disability who have autism by ensuring that the Independent Lifestyle Officers are fully conversant in the specific needs of people with autism, through specialist training, so are best placed to support them appropriately during assessment and training.

Working with the person and their family, the service will proactively contribute to breaking down of barriers by encouraging and engaging with universal services to ensure that the person is receiving the right type of support in a timely manner. The service will work collaboratively with all agencies, including working with Children's Services so that as young people work through their transition, the service is already aware and in contact with them and their family. This seamless approach will be further developed as a result of the current disability review that is being undertaken in response to the "Support & Aspiration: A New Approach to Special Educational Needs and Disability" consultation document (March 2011). The service also has a lead practitioner who will champion the needs of people with autism and a learning disability across the scope of the work of the adult learning disability team and the agencies that the team will be engaged with, to ensure better outcomes are delivered in a holistic way.

8. 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.

9 Autism Workshops

- 9.1 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.

- 9.2 Two autism workshops were held in October 2009 and January 2010 involving individual consultation meetings with service users, carers, interest groups and service providers.
- 9.3 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

10. Local Strategy

10.1 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.

10.2 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.

11. Awareness And Training

11.1 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.

11.2 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.

12. Diagnosis, Assessment And Community Services

- 12.1 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.

- 12.2 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 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.

- 12.3 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.

- 12.4 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.

- 12.5 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.

- 12.6 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.

- 12.7 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.

12.8 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.

12.9 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.

12.10 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.

12.11 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.

13. Transitions

13.1 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.

13.2 Central Bedfordshire Council is currently undertaking a disability review in response to "Support & Aspiration: A New Approach to Special Educational Needs and Disability" consultation document (March 2011) This review includes children and young people from the age of 0-24. Adult Services are contributing to this review on the basis that people going through transition will be identified at the age of 14 and therefore allowing preparation and planning for transitions to commence at a much earlier point. Young people and their families will be able to contribute to the transitions process through the introduction of a single education, health and social care plan. The Independent Lifestyles Team will play a key role in this collaborative approach.

13.3 The needs of people with autism during the transition period are 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.

- 13.4 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.
- 13.5 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.

14. Development Of Services

- 14.1 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.
- 14.2 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.
- 14.3 The Joint Strategic Needs Assessment (JSNA) will need to provide comprehensive data on the local population of people with autism.
- 14.4 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.
- 14.5 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 and A Healthier Bedfordshire Programme Board for NHS Bedfordshire.
- 14.6 Each statutory organisation (Central Bedfordshire Council and NHS Bedfordshire) will have a commissioner or senior manager responsible to ensure progress of this autism strategy.
- 14.7 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.

15. Employment

- 15.1 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. ¹⁵

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

- 15.2 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 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.
- 15.3 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.

16. Delivery

- 16.1 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.

¹⁵ National Autistic Society (2011) Employment. Available at: <http://www.autism.org.uk/employment> (Accessed on 08/07/2011).

16.2 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.

16.3 However, neither Central Bedfordshire Council 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.

16.4 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

17. 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 Delivery Partnership

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.

18. 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.

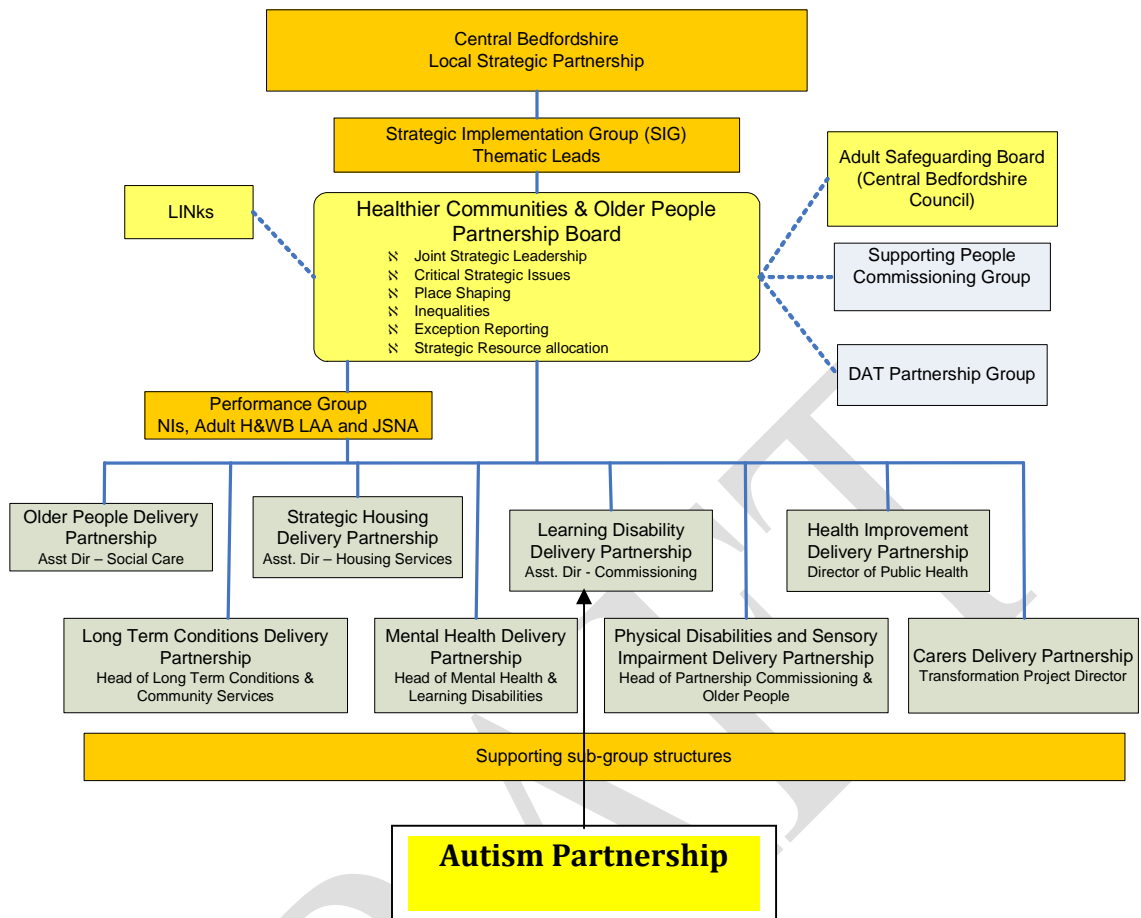
Each delivery partnership has set out its main aims and key priorities, for the next three years and will be responsible through an Outcomes Delivery Plan to the Partnership Board. Delivery Partnerships will:

- 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



Appendix 2

Main Training categories as discussed at one of the workshops

Type of Training	Target Audience
Brief interactive session, literature, information on services 3 hours general awareness	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
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. 1 day course and focus groups	GP, DEA's. Schools/colleges, Carers, Families, "Champions" in general services, Voluntary agencies, Mental health teams and Learning disability teams, Social workers, Day centres
Specialist training to be identified	Staff working within Specialist Autism Services

Fulfilling and rewarding lives
The strategy for adults with autism in England (2010)
Work Plan

NHS Bedfordshire and Central Bedfordshire Council

	Identified Action	Key Task	Responsible Body / Named Lead	Timescale
1	<p><u>To increase awareness and understanding of autism among frontline staff across the whole community.</u></p> <ul style="list-style-type: none"> • Autism awareness to be included in general equality and diversity training across the public sector. • To develop specialist training for staff in health and social care • Autism awareness training to be an essential part of training provided for staff carrying out community care assessments • There should be advanced training for staff wishing to pursue careers focusing on working with adults with autism 	<p>To develop a training plan with tiered training packages.</p>	<p>Central Bedfordshire Council/NHS Bedfordshire</p>	<p>December 2011</p>
2	<p><u>To 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</u></p>			

	<ul style="list-style-type: none"> • To develop a clear and consistent local pathway for diagnosis • To ensure diagnosis of autism is recognised as a reason for assessment of individual who may be in need of community care services. • Assessments can be offered to adults with suspected autism without the need of a formal diagnosis • To ensure involvement of individuals in assessing their care needs with the outcome of personalised social care aims • To a lead professional to develop diagnostic and assessment services for adults with autism who will work closely with the specialised commissioning group 	<p>To complete local pathway for diagnosis.</p> <p>To deliver training to all social workers</p> <p>To audit effectiveness of signposting into services</p> <p>To ensure adults with ASC have access to self-directed support and personal budgets</p>	<p>NHS Bedfordshire / Central Bedfordshire Council</p> <p>Central Bedfordshire Council</p> <p>NHS Bedfordshire/ Central Bedfordshire</p> <p>Central Bedfordshire Council</p>	<p>December 2011</p> <p>December 2011</p> <p>April 2011 onwards</p> <p>December 2011</p>
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	<ul style="list-style-type: none"> • Trained practitioners will complete the person centred assessment of need taking into account the communication needs of adults with autism, provide a robust and comprehensive view of the person's condition, a clear description of needs and how it affects them. The assessment can be referred to as required to inform care decisions or to support applications for additional services • To enable adults with autism to access personal budgets and direct payments in line with their assessment of needs • To establish a local autism partnership board 	<p>To develop Team</p> <p>To develop operational framework for ASC</p> <p>As above</p> <p>To agree governance arrangements with HCOP</p>	<p>Central Bedfordshire Council</p> <p>Central Bedfordshire Council</p> <p>Central Bedfordshire Council</p>	<p>March 2012</p> <p>March 2011 onwards</p> <p>March 2011 onwards</p>
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			Central Bedfordshire Council	March 2012
3	<p><u>To plan in relation to the provision of services to people with autism in transitions</u></p> <ul style="list-style-type: none"> To improve the transition experience for young people from age 14 to enable the young person to access services they need at the start of their adult life To undertake an audit on implementation of joint assessment tool 	To review transition services for young people with ASC	Central Bedfordshire Council	September 2011 March 2012
4	<p><u>To enable local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities</u></p> <ul style="list-style-type: none"> To ensure autism awareness training is available to all staff in the criminal justice sector To ensure that authorities should adequately signpost people who do not meet the eligibility threshold to alternative sources of 	To deliver training to staff in criminal justice sector To develop a local	Central Bedfordshire Council	March 2012

	<p>support</p> <ul style="list-style-type: none"> To provide information regarding autism and for resources to be available from the point of diagnosis To explore how to support volunteer and third sector groups in planning and commissioning services locally Travel training (Valuing People Now) to be made available for all adults with autism 	<p>directory of services</p> <p>As above</p> <p>To engage with third sector groups in the development of local service</p> <p>To deliver transport training</p>	<p>Autism in Bedfordshire</p> <p>NHS Bedfordshire/ Central Bedfordshire Council</p> <p>Central Bedfordshire Council</p> <p>Central Bedfordshire Council</p>	<p>December 2011</p> <p>October 2011</p> <p>October 2011</p> <p>March 2012</p>
5	<p><u>To help adults with autism into work</u></p> <ul style="list-style-type: none"> Develop co-ordinated supported employment service which will be able to support people with autism Map local training, vocational and voluntary opportunities which support adults with autism into paid work 	<p>Link to review of supported employment service</p>	<p>Central Bedfordshire Council</p>	<p>September 2011</p>

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