

Adult Autism Strategy 2014-17

October 2013



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1. Introduction and Vision

Introduction – why do we need a plan?

A Strategy is a plan to make sure services from the Council, the Health Service and other agencies in Milton Keynes are right for the people who need them. From now on, instead of using the words Autism Strategy we will use the word "Plan".

The Plan is for individuals with Autistic Spectrum Conditions (ASC), for their families and for all the services that people with Autism need to use. We will ask people what they think of it. Although this is a Plan for adults with ASC, children and young people will be affected by this Plan as it will include transitions from schools and from Children's Social Services to Adult Social Services.

Adults with ASC have been identified in the Autism Act 2009 as being at risk of disadvantage through poor understanding of their needs and difficulties in getting a diagnosis. Lack of awareness in a wide range of agencies leads to problems with finding appropriate housing and support, reaching employment and addressing health needs. These deficits in support can lead to deterioration in the mental health and physical health of individuals and of their carers.

It is important however to remember that each autistic person is an individual, with unique needs and abilities. Because of this, he or she will experience issues in a unique way or may not experience them at all.

The Autism Act (2009) tells us what we should do to make services better along with other key national policies as listed in Appendix 1.

Locally the Health and Wellbeing Board is a partnership board designed to ensure an integrated approach across NHS, Social Care and Public Health services in Milton Keynes. The strategic priorities and key principles of the Health and Wellbeing Board are:

- To improve wellbeing
- To reduce early deaths and tackle major disease
- To reduce Health inequalities

These are based on the Joint Health and Wellbeing Strategy. This contains evidence from the Milton Keynes Joint Strategic Needs Assessment, which is a document that sets out the health and wellbeing needs of the population of Milton Keynes.

The Health and Wellbeing Board along with our Autism Partnership Board talked to lots of people about how they should work. This gives us the Strategic Priorities (what we need to do first) for Milton Keynes. This Plan starts from these Priorities and then thinks about what they mean for individuals with Autism.

This Plan will contribute to these priorities. Such a strategy cannot be developed in isolation and so it has been co-produced with individuals with Autism, their families, carers, staff and volunteers who work with people with Autism through their involvement in our Autism Partnership Board.

The Milton Keynes Autism Partnership Board (APB) makes sure the things in the Autism Act are done in Milton Keynes. A number of action groups are at different stages of working on smaller plans to do what the Autism Act says. MKC and MKCCG will keep working with the action groups and their plans to meet the changing needs of people living in Milton Keynes. We will also check what the Government says about how we should do things.

Please see Appendix 4 for the membership list and Appendix 5 for a list of 2013 work plans.

There are many strands to the work needed to improve services for adults with Autism in Milton Keynes and this cannot all be included in the strategic priorities for 2014-2017.

Further areas for future work have therefore been identified in Section 3.

1. Introduction and Vision - continued

The Vision - What the Autism act says

The National Autism Strategy 'Fulfilling and Rewarding Lives' focuses on five core areas of activity and clearly states that Milton Keynes Council and the NHS should be:

1. Increasing awareness and understanding of Autism among frontline professionals.
2. Developing a clear, consistent pathway for diagnosis of Autism in every area, which is followed by an offer of a personalised needs assessment.
3. Improving access for adults with Autism to the services and support they need to live independently within the community.
4. Focusing on helping adults with Autism into work, by improving access to information, advice and guidance, ensuring adults with Autism gain from wider programmes to ensure opportunities in the workforce, and providing effective support through the benefits system.
5. Enabling local partners to plan and develop relevant services for adults with Autism to meet identified needs and priorities, learning from what already works and involving adults with Autism in developing those services where possible.

When thinking about an individual with Autism we want to consider their changing needs at different life stages and ensuring services are flexible to meet these needs at the right time.

Birth – Primary School – Secondary School – College – First Job – Middle Age – Old Age

2. The Local Picture

Level of need in the population

The National Autistic Society website gives an estimated national prevalence rate of 1% (The National Autistic Society, 2008). However, a recent study by the Autism Research Centre, Department of Psychiatry, Cambridge University estimated the prevalence to be 157 in 10,000 (1.57%). They state that the increase in reported prevalence rates over time “is likely to reflect seven factors: improved recognition and detection; changes in study methodology; an increase in available diagnostic services; increased awareness among professionals and parents; growing acceptance that Autism can coexist with a range of other conditions; and a widening of the diagnostic criteria”. (Baron-Cohen et al, 2009).

The Autism prevalence rate is typically higher in men (1.8 per cent) than women (0.2 per cent). This fits with the gender profile found in childhood population studies. “(Brugha et al, 2009). However, local services tell us that they are supporting an increasing number of females with autistic spectrum conditions, as more are being diagnosed.

Population

The mid 2012 population estimate shows that Milton Keynes has a population of 252,400. (Mid-Year Population Estimates 2012) By 2021 it is estimated that the population of Milton Keynes will grow to 284,800. The age profile of Milton Keynes is younger than that of England as a whole; however Milton Keynes is facing an aging population. 26.1% of the population in 2011 were from black and minority ethnic groups. In 2011 there were 3,927 births and 1,552 deaths in Milton Keynes. Approximately 39 children born each year in Milton Keynes will have Autism.

The table below indicates the predicted number of people living in Milton Keynes with an Autism spectrum condition. The increase may be more than this as national and local strategies raise levels of diagnosis and awareness of how to access support.

| | 2012 | 2014 | 2016 |
|---|-------|-------|-------|
| People aged 18-24 predicted to have an autistic spectrum condition | 194 | 191 | 191 |
| People aged 25-34 predicted to have an autistic spectrum condition | 402 | 395 | 389 |
| People aged 35-44 predicted to have an autistic spectrum condition | 390 | 402 | 414 |
| People aged 45-54 predicted to have an autistic spectrum condition | 350 | 360 | 369 |
| People aged 55-64 predicted to have an autistic spectrum condition | 269 | 275 | 287 |
| Total population aged 18-64 predicted to have an Autistic spectrum condition | 1,605 | 1,624 | 1,649 |

Source: Milton Keynes Autism spectrum disorders - Projecting Adult Needs and Service Information Systems (PANSI).

2. The Local Picture - continued

Current Services in relation to need

Milton Keynes has made some progress in improving the experience of adults with Autism, including some developments that we are proud of. However it is important to acknowledge the difficulties in getting here and the difficulties we may face in the future.

We have an Autism lead, our senior joint commissioner for Learning Disabilities and Autism and a clinical lead in Milton Keynes.

Our achievements include:

- The establishment of the Autism Partnership Board set up with a variety of members, including people on the spectrum, their carers and professionals across services that are committed to ensuring that those with Autism in Milton Keynes live fulfilling and rewarding lives.
- The Partnership Board works through its action groups and where appropriate involves people with Autism and their carers in strategic planning. They are well represented on the Board and are supported by advocacy organisations to put over their views.
- The Autism Partnership Board sponsored a major conference in May 2013 aimed chiefly at GP's and other Health Professionals.
- Seven people with Asperger's Syndrome have been trained and are now being supported to train staff in how to work with individuals with autistic spectrum conditions. This group is known as the Autism Trainers and their presentations are highly regarded. They are currently paid as sessional workers by Milton Keynes Council and they are now exploring how to become a form of social enterprise.
- In response to the Autism Act we have improved the pathways for adults with Autism in the creation of an Autism Assessment and Diagnosis Service (AADS) a virtual team comprised from staff from Community Team for Adults with a Learning Disability, Mental Health Services and Adult Social Care. This team is making significant progress in addressing the need for diagnosis.
- We have also created three specialist Autism posts within the Adult Social Care Access Team made up of an Autism Social Worker and two Community Access Workers who carry out assessments of need and provide short term intervention work to those not eligible for social care services.
- An Autism Project Officer role has also been created within the Joint Commissioning Team to support the co-production of this Plan, co-ordination of data collection activity and the review of the current adult Autism care pathway.
- Autism is included in our current Joint Strategic Needs Assessment 2012/13 and our Adult Social Care Service Plan 2013/14.

See Appendix 6 for a full list of our current Autism services.

3. Strategic Priorities

On behalf of the Autism Partnership Board, the Strategy Group identified priorities in Milton Keynes based on work already started, what is working well and which areas need to be improved.

National Outcomes and Ambitions

The government has identified 7 quality outcomes and 3 service ambitions that will help evaluate progress towards the vision set out in Fulfilling and Rewarding Lives. These 10 outcomes should be achieved if the Autism strategy and statutory guidance can be judged as a success. These are:

- QO1.** Adults with Autism achieve better health outcomes.
- QO2.** Adults with Autism are included and economically active.
- QO3.** Adults with Autism are living in accommodation that meets their needs.
- QO4.** Adults with Autism are benefiting from personalisation agenda in health and social care, and can access personal budgets.
- QO5.** Adults with Autism are no longer managed inappropriately in the criminal justice system.
- QO6.** Adults with Autism, their families and carers are satisfied with local services.
- QO7.** Adults with Autism are involved in service planning.
- SA1.** Local authorities and partners know how many adults with Autism live in the area.
- SA2.** A clear and trusted diagnostic pathway is available locally.
- SA3.** Health and social care staff make reasonable adjustments to services to meet the needs of adults with Autism.

Local Priorities

The Strategy Group pulled together information gathered from the Adult Social Care Service Plan, the Joint Strategic Needs Assessment (JSNA), Autism Partnership Board work plans, NICE Adult Autism Guidelines, the Autism Act and Strategy and agreed the following priorities based on the subjects that would ensure we would achieve success in all of the ten adult outcomes.

The 5 priorities for 2014-2017 identified were:

Strategic Priority 1:

Diagnosis and Assessment

Strategic Priority 2:

Training, information and Awareness

Strategic Priority 3:

Life Transitions (Education, Employment, Adult Services and Health)

Strategic Priority 4:

Understanding Local Needs

Strategic Priority 5:

Explore, identify resources and support for those not eligible for social care services

3. Strategic Priorities - continued

Strategic Priority 1:

Diagnosis and Assessment

What we will do:

- Ensure people receive an appropriate diagnosis with appropriate signposting and information post diagnosis. This includes other conditions that often go along with Autism.
- Review against the NICE guidelines and improve the pathway for individuals with Autism through Health, Social Care and mainstream community services.
- Train non-specialist staff about referrals and the care pathway.
- Ensure those with ASC are aware they are entitled to a Community Care Assessment and are offered one.
- Ensure carers are offered a Carer's Assessment upon diagnosis of ASC.
- Engage with partners to explore a solution to the gap between children's diagnostic services ending at 16 years and adults' services beginning at 18 years.

Strategic Priority 2:

Training, information and Awareness

What we will do:

- Carry out an evaluation of the training and awareness raising already being delivered.
- Actively promote and provide Autism awareness training for all frontline staff to improve knowledge and promote a change in behaviour towards people with ASC.
- Provide specialist Autism training for key staff, such as GPs and community care assessors, to develop further knowledge and a change in attitudes towards people with ASC. These are the identified priority groups for training.
- Ensure that Autism awareness is included in the existing equality and diversity training of Milton Keynes Council and all NHS bodies and services.

- Ensure information is readily available and clear for individuals to understand about how to access specialist assessments and diagnosis.
- Ensure individuals and their families are provided with information about sources of support even if they are not eligible for social care services and that this information is presented appropriately for those on the autistic spectrum.
- Continue to liaise with the criminal justice system to raise awareness and understanding of individuals with ASC.
- Evaluate the usage of the Help Me, Help You Alert Card in Milton Keynes for those on the spectrum.

Strategic Priority 3:

Life Transitions (Education, Employment, Adult Services and Health)

What we will do:

- Ensure there is a clear transition pathway for young adults with Autism including those not eligible for social care services.
- Ensure that young people in need of mental health support who do not meet adult mental health services criteria are offered appropriate support and information.
- Ensure information relating to services at different life stages is clear and readily available to those on the spectrum and their families, carers in Milton Keynes.
- Liaise with further education and higher education establishments to identify education and training opportunities and to ensure that the establishments are making reasonable adjustments so that adults with Autism can progress.
- Identify best practice in removing barriers in recruitment and employment.
- Liaise with benefit agencies with regards to impact of welfare reform.

3. Strategic Priorities - continued

- As a follow up to the GP Conference, develop a clinical network to ensure reasonable adjustments are being made and barriers through health services are removed.

Strategic Priority 4:

Understanding Local Needs

What we will do:

- Ensure that accurate data is recorded by all relevant services in Milton Keynes about those with Autism. Data should be collected according to the recommendations made in "Implementing Fulfilling and Rewarding Lives".
- Ensure that information collected on adults with Autism in Milton Keynes is included in the Joint Strategic Needs Assessment and that it is used to inform the planning and commissioning of services.
- Undertake a local housing needs analysis of people with Autism including those not eligible for social care services.
- Continue to work with the criminal justice services to ensure there is data about the number and needs of people with Autism in contact with them.
- Develop systems to gain the views of the local population on what is and what should be offered.

Strategic Priority 5:

Explore, identify resources and support for those not eligible for social care services

What we will do:

- Ensure that early intervention is offered to those with Autism and their families.
- Continue to support individuals for short term interventions within the identified appropriate services whilst monitoring and recording unmet needs.
- Continue to work with colleagues in Housing to meet local need.
- Ensure that access to talking therapies is provided where appropriate through the Improving Access to Psychological Therapies (IAPT) programme.
- Ensure that all those on the spectrum have access to supported employment opportunities in Milton Keynes by identifying opportunities and co-ordinating efforts, in line with NICE guidelines.

The key principles of the Milton Keynes Health and Wellbeing Strategy will underpin all of these broad actions.

Future Priorities

Through our work we have identified other priorities that we would like to explore in Milton Keynes:

- Supporting older people with Autism affectively.
- Ensuring those from ethnic backgrounds are represented and engaged with Autism in Milton Keynes.
- Health Passports for those with Autism.
- Ensuring Autism is included in our local Housing Strategy.

4. How will we know and ensure we have made a difference?

The Autism Partnership Board has to make sure this will happen. The Partnership Board will finish this Plan and produce an action plan to implement it in Milton Keynes. It will report on progress with the Plan to the Health and Wellbeing Board.

Milton Keynes Council and Milton Keynes Clinical Commissioning Group will keep working with the Partnership Board action groups and their plans to meet the changing needs of people living in Milton Keynes.

When thinking about an individual with Autism we will be considering their changing needs at different life stages and ensuring services are flexible to meet these needs at the right time.

This 3 year Plan and its implementation will be reviewed on an annual basis by the Milton Keynes Health and Wellbeing Board and continuously reviewed by the Partnership Board to ensure that services for those with Autism in Milton Keynes are improved in line with the Government's 10 Adult Autism Outcomes.

5. References

The Autism Act (2009)

<http://www.legislation.gov.uk/ukpga/2009/15/contents>

Milton Keynes Health and Wellbeing Board (2012)

<http://www.milton-keynes.gov.uk/health-wellbeing/>

Joint Strategic Needs Assessment (JSNA) 2012/13

<http://www.mkiobservatory.org.uk/page.aspx?id=2203&siteID=1026>

Milton Keynes Health and Wellbeing Strategy 2012/15

<http://www.miltonkeynesccg.nhs.uk/health-and-wellbeing-board/>

Autism Partnership Board (APB)

<http://www.milton-keynes.gov.uk/autism/>

Milton Keynes Council (MKC)

<http://www.milton-keynes.gov.uk/>

Milton Keynes Clinical Commissioning Group (MKCCG)

<http://www.miltonkeynesccg.nhs.uk/>

The National Autism Strategy 'Fulfilling and rewarding lives' 2010

<http://www.gov.uk/government/publications/implementing-fulfilling-and-rewarding-lives>

National Health Service (NHS)

<http://www.nhs.uk/>

The National Autistic Society, 2008

<http://www.autism.org.uk>

Autism Research Centre, Department of Psychiatry, Cambridge University

- Baron-Cohen et al, 2009, Prevalence of Autism-spectrum conditions: UK school-based population study.
- Brugha et al, 2009, Autism spectrum disorders in adults living in households throughout England - Report from the Adult Psychiatric Morbidity Survey 2007.

<http://www.autismresearchcentre.com>

Milton Keynes Council Adult Social Care Service Plan, 2013/14

New National Institute for Clinical Excellence (NICE) Autism in Adults, 2012

<http://www.nice.org.uk/nicemedia/live/13774/59685/59685.pdf>

Appendix 1 - List of National Policy Drivers

The Autism Act, 2009

Department of Health (2010) A vision of adult social care: Capable communities and active citizens.

Department of Health (2010) Equity and Excellence: Liberating the NHS.

Department of Health (2010) Healthy Lives, Healthy People: Our strategy for public health in England.

Department of Health (2010) 'Fulfilling and Rewarding Lives': The strategy for adults with Autism in England.

Department of Health (2010) Implementing "Fulfilling and Rewarding Lives": Statutory guidance for local authorities and NHS organisations to support implementation of the Autism strategy.

Department of Health (2010) Towards fulfilling and rewarding lives: First year delivery plan for adults with Autism in England.

Equality Act (2010)

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

NICE (2012) Autism in Adults guidelines.

The Children's and Families Bill (2013)

Appendix 2 - Milton Keynes Health and Wellbeing Strategy Key Principles

The four key principles that underpin the Milton Keynes Health and Wellbeing Strategy 2012 – 15 are:

We will:

- Invest resources across all our communities in a way which achieves similar outcomes for each.

We want to do all that is possible to reduce the unacceptable level of health inequalities between different communities within Milton Keynes.

- Actively build on the strengths of communities (the “asset” approach) and engage people within those communities in taking action.

- Shift the budget allocation towards primary and secondary prevention and away from reactive, acute health and social care services.
- Identify and better respond to the needs of different groups within our population including, for example, the young, black and minority ethnic groups (BME) groups, the hearing and vision impaired, the lesbian, gay, bisexual and transsexual (LGBT) community, those with a learning disability, mental ill health, neurological conditions, long term conditions and older people.

Appendix 3 - Terms of reference and membership of the Strategy Group

| Terms of Reference Autism Strategy Group | |
|---|---|
| Structure | <ul style="list-style-type: none"> • The meeting will take place at Learning Disabilities Centre, Stantonbury. • The group will meet every month for up to two hours each time. |
| Reporting arrangements | <ul style="list-style-type: none"> • Minutes to be circulated to all members including virtual members for comments after each meeting. |
| Duties / responsibilities of the group | <ul style="list-style-type: none"> • To co-produce an Autism Strategy for Milton Keynes on behalf of the Autism Partnership Board. |
| Membership | <p>Group Members = Senior Joint Commissioner Learning Disabilities and Autism, Autism Project Officer, Learning Disabilities and Autism Partnership Officer, parent carer, Carers MK, Children's Assessment Services Co-ordinator, CNWL-MK, individual with autistic spectrum condition and Autism Trainer and a provider organisation.</p> <p>Virtual Members = Carers MK, information Officer, Head teacher, two parent carers, provider organisation, and three individuals with autistic spectrum conditions.</p> |
| Responsibilities of members | <ul style="list-style-type: none"> • To attend • To actively contribute to decision making • To work as a team • To respect other participant's opinions and values • To complete agreed actions within identified timescales • To report progress to the APB. • To consult as we go along with those with Autism and others. |
| Monitoring requirements | Should the above not be adhered to, the purpose of the meeting will be reviewed by MKC. |

Appendix 4 - Autism Partnership Board Membership List (2013)

The Autism Partnership Board is led by two co-chairs, one with an autistic spectrum condition, and has representatives from the following organisations and groups including individuals with Autism and parents, family members and carers:

MK College

The Walnuts School

MK Centre for Integrated Living

Carers MK

ECCO/Brokerage - Learning Disability Team

Equality Works - Learning Disability

Choice Support

MK SNAP

MKC Housing Team

Youth Offending Team

Connexions: MK

Community Team for Adults with a Learning Disability

MKC – Children and Young People’s Services

The Shaw Trust

Autism Care UK

ABI Homes

People’s Voices

Macintyre

PACA

MK Specialist CAMHS

Children’s Disability Team

Adult Mental Health Team

Children’s Specialist Health Services

Joint Commissioning Team

Talkback

MKC – SENDIS

Adult Social Care Access Team

Job Centre Plus, Department of Works and Pensions

National Autistic Society - Milton Keynes Branch

Brookdale Care

Appendix 5 - Autism Partnership Board work plans

A snapshot of work undertaken in 2013.

Training and information Action Group Work Plan

1. Keep a Training Database
2. ID Awareness Cards
3. Presentation of information
4. Conference for GP's and others
5. Collect data on people with Autism in Milton Keynes for service plans

Housing and Support Action Group Work Plan

1. Develop a house share matching system.
2. Information for people with Autism about Housing and Support
3. Get data on housing and support needs.
4. More access to housing and support.

Employment Action Group Work Plan

1. Raise awareness with employment agencies
2. Working with employers
3. Self Employment and Volunteering

Transitions Action Group Work Plan

1. Identify better pathways for young people who appear to fall below criteria of social care eligibility.
2. Transition through Education
3. Transition through Health
4. Information about Transition

Appendix 6 - Current Autism Services (September 2013)

Assessment and Diagnosis

Autism Assessment and Diagnosis Service (AADS)

The AADS is part of the Joint Health and Social Care Team, within Milton Keynes Council and CNWL-MK. The team's role is that of assessment and diagnosis of autistic spectrum conditions for people over the age of 18 and over.

Adult Social Care Assessment Team (ASCAT)

People call ASCAT if they think they need help from Adult Social Services. Even if they cannot help you, they may be able to point you in the right direction. ASCAT now has a three specialist Autism posts, an Autism Social Worker and two community support workers.

Community Team for Adults with a Learning Disability (CTALD)

The Learning Disability Team is a joint Health and Social Care team. Lots of different people work for the team and referrals can be made direct to the team or through Adult Social Care Access Team (ASCAT). If our services are not right for you, we will tell you about places and people that can help you.

Specialist Children's Health Services, Central North West London, NHS Foundation Trust-Milton Keynes (CNWL-MK)

Children requiring support are assessed and supported.

Advice and Support

Carers MK Carers Milton Keynes can help all carers with advice, information, emotional support and a range of training and social activities.

Connexions: MK Providing post 16 education and employment advice.

Providers

(for those eligible for social care services, including self-funders)

Autism Care provides community supported living solutions to people with a wide variety of needs in Milton Keynes.

Care Support MK Ltd is a company offering specialist supported living services to service users living in the Milton Keynes area.

ABI Homes provides specialist homes and development opportunities for people with autistic spectrum conditions if eligible for social care services.

Choice Support is a social care charity that supports people with learning disabilities.

Macintyre is a charity that provides learning and support to those with learning disabilities.

MKSNAP provides Education and Training for adults with learning difficulties.

Brookdale Care provides residential, supported living and hospital services for adults with Autistic Spectrum Disorder.

Walnuts Care Ltd provides educational support services.

Appendix 6 - Current Autism Services (September 2013) - continued

Social

Milton Keynes Autistic Spectrum Parent Support Group (MKASPS) a monthly support group for parents or carers.

MK Special Dons (Special Needs Football) this is a local special needs football team for under 25s a lot of members have Autism.

The National Autistic Society (NAS) local MK Branch invites everyone to monthly support meetings.

Walnuts Parents Friendship and Support Group a monthly meeting for parents, grandparents and carers.

AS Meet Up is for 18yrs and over. They meet every 3rd Wednesday in the month. People can meet up and discuss any issues they like and exchange information about social opportunities etc.

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October 2013