

D R A F T FOR CONSULTATION

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# AUTISM STRATEGY FOR ADULTS IN BIRMINGHAM

2013 – 2016

**HELPING PEOPLE WITH AUTISM TO ACHIEVE FULFILLING  
AND REWARDING LIVES**

RAISING AWARENESS TO INFORM, IMPLEMENT AND IMPROVE

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## CONTRIBUTORS

Dr Ashok Roy	Consultant Psychiatrist	Coventry and Warwickshire Partnership Trust
Mark Curran	Senior Strategic Commissioning Manager	Joint Commissioning Team
Emma Fitzgibbons	Commissioning Officer	Joint Commissioning Team
Daniella Gilligan-King	Commissioning Officer	Joint Commissioning Team
Jonathan Shephard	Chief Executive	Autism West Midlands
Jess Cook	Business Strategy Manager	Autism West Midlands
Robert Devlin	MH Commissioner	Joint Commissioning Team
Elizabeth Hurley	Research Officer	Autism West Midlands
Kalvinder Kohli	Senior Strategic Commissioning Manager	Birmingham City Council
Iris Fermin	Head of Information and Intelligence	Public Health
Amanda Skeate	Clinical Lead – Youth Space	Birmingham Solihull Mental Health Foundation Trust
Esther Young	Training and Conference Mangers	Autism West Midlands
Steve Farr	Employment Access Manager	Birmingham City Council
Gemma Higgins	Workforce Development Project Officer	Birmingham City Council
Ambrin Chauham	Workforce Development Manager	Birmingham City Council
Les Lawrence	Parent/Carer	
Sharon Banks	Equality Diversity and Human Rights Officer	West Midlands Police
Naila Suleman	Equality Diversity and Human Rights Officer	West Midlands Police
Fiona Washington	Equality Diversity and Human Rights Officer	West Midlands Police
Nicola Bonser	Equality Diversity and Human Rights Officer	West Midlands Police
John Simpson	Representative with Aspergers	
Lin Lloyd	Parent/Carer	
Bethan Welch	Senior Practitioner	Birmingham City Council
Shazia Hanif	Team Manager, Transitions	Birmingham City Council
Lesley Baker	Manager, Communication & Autism Team	Birmingham City Council
Dennis Wilkes	Public Health Consultant	Public Health
Satpal Hira	Equalities and Community Engagement Officer	Birmingham City Council
Dr Steve Hinder	Consultant Psychiatrist	Birmingham Community Healthcare
Chris Barber	Parent/Nurse/Aspergers	
Andrea Macleod	Lecturer in Autism Studies	University of Birmingham
Akib Qassim	Representative with Aspergers	
Lorna Gregory	Service Development Manager	Carefirst Ltd
Sharlene Davis	Area Development Officer – West Midlands	National Autistic Society
Laura White	Occupational Therapist	Birmingham Community Healthcare
Radha Bisnauth	Clinical Psychologist	Birmingham Community Healthcare

## INTRODUCTION



Welcome to Birmingham's first Autism Strategy for adults aged 18 and over. The strategy has been developed by the Birmingham Autism Partnership Board (BAPB). The Board is a partnership between health, social care, voluntary sector and people with autism and their families and carers.

Autism is a lifelong neurological disorder affecting the development of the brain, characterised by impairments in social interaction, communication (verbal and non verbal) and imagination. Autism is neither a Learning Disability nor a Mental Health condition in its pure sense. However, autism is known to be strongly associated with the presence of learning disabilities and mental health problems as well as other co-morbidities such as Attention Deficit Hyperactivity Disorder (ADHD).

Many people live with autism for their entire life without ever getting a formal diagnosis. Often this is simply because autism has not been widely recognised or understood when they were growing up. For adults, a diagnosis of autism can help to explain why they have always found certain things difficult. Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.

Up to now there has not been a clear system to support the management of autism within the City. I believe the Autism Act 2009 has produced a clear vision to address this. Therefore I am pleased to be able to deliver the City's first overarching strategy for meeting the needs and delivering better outcomes for those people with the condition and supporting their families living in Birmingham to care for them.

**Councillor Steve Bedser, Cabinet Member for Health & Well Being**

## EXECUTIVE SUMMARY OF THE STRATEGY

The Autism Act of 2009 was brought in by Government in response to an identified gap in provision for adults with autism. The Act specified that a national strategy be in place by 1<sup>st</sup> April 2010. ‘Fulfilling and rewarding lives: the strategy for adults with autism in England’ was published on 3 March 2010, the strategy sets a clear framework for all mainstream services across the public sector to work together for adults with autism.

### AUTISM IN BIRMINGHAM

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The Birmingham Joint Strategic Needs Assessment (JSNA) for Autism published in July 2012 stated that the ‘knowledge of people with autism is poor and evidence of their needs is less than satisfactory’. It also suggested a population of between 1-2% from a total population of 1.037million. This would suggest the Birmingham population with Autism to be between 10,000 and 20,000. The Birmingham Autism Partnership Board’s (BAPB) vision is that all people with Autism, whatever their age, should have the same opportunities as anyone else to live “rewarding and fulfilling lives”.

### STRATEGY AIMS

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The aim of this strategy is to improve the lives of all those with autism. For some, this means the development and delivery of more effective support that can address significant challenges in communication and health. For others, it means increasing acceptance, respect and support.

There are six main areas in which we intend to deliver progress:

#### **1. Raising Awareness and Improving Training**

We have set up a sub group to lead and co-ordinate training for stakeholder organisations and other agencies. This should ensure not only improved knowledge and understanding but also lead to a change in the behaviour and attitudes in health and social care staff.

## **2. Implement Pathways for Diagnosis**

We have agreed to develop an easily accessible pathway for assessment and diagnosis which will provide personalised management strategies and signposting for support for inclusion and integration into society. A centre known as the Specialist Adult Autism Assessment and Resource Centre (SPARC) will provide local specialist diagnosis and assessment for adults with autism, or suspected autism, with additional mental health problems.

## **3. Improve Opportunities for Employment and Education**

The Birmingham JSNA estimates that the number of people with autism in the working age group 16-64 who are unemployed range from 5,716 to 11,343 people. The Employment Sub-Group of the Birmingham Autism Partnership Board is coordinated by Birmingham City Council. Partners, including the Department of Work and Pensions (DWP), Autism West Midlands and Birmingham City Council's Disability Employment Service are working together to improve the opportunities for people with autism who are disadvantaged in the workplace.

## **4. Improve Access to Services**

The JSNA highlighted that adults with autism were under utilising services while recognising that service provision is limited. The overall vision is that adults with autism can depend on mainstream public services to treat them fairly as individuals. This covers services ranging from social care and health through to housing and leisure opportunities.

## **5. Improve Transitions from childhood**

Children with autism and their families/carers should have access to support that helps them to achieve their potential and promote inclusion. Without effective transition planning this support may not be available in an organised way once people with autism reach adulthood – leaving them isolated at a critical point in their lives. In Birmingham we are working to improve the transition support offered to young people including those with autism.

There is a Transition Development Board, which is addressing the issues related to the transfer of social care for young people with disabilities from Children, Young People and Families to the Adults and Communities Directorate.

## **6. Improve interactions with the Criminal Justice System**

In December 2012 a report was provided to the Health and Social Care Overview & Scrutiny Committee, Birmingham City Council entitled: Adults with Autism and the Criminal Justice System. It concluded that:

- Finding routines and activities that can be easily accessed could reduce interaction with crime and criminals thereby reducing impact on the criminal justice system;
- Reducing the circumstances where stress levels in the adult with autism produce abnormal behaviours will reduce contact with the police;
- Providing better support to the adult with autism could mean fewer compulsive interests taken to excess;
- Better training and awareness for the police will be likely to reduce the numbers of inappropriate arrests of people with autism.

## **NEXT STEPS**

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A consultation on the strategy for people with autism living in Birmingham will be launched in April 2013 and the comments received will be considered by the Partnership Board in July, after which a comprehensive action plan will be drawn up to ensure timely progress to achieve the aims of our strategy. **Dr Ashok Roy, Chair, Birmingham Autism Partnership Board**



## THE VISION

Birmingham Autism Partnership Board's vision is that all people with autism, whatever their age, have the same opportunities as anyone else to live rewarding and fulfilling lives.

There are six main areas in which we intend to deliver progress:

- 1. Implement Training and Raise Awareness**
- 2. Implement Pathways for Diagnosis**
- 3. Improve Opportunities for Employment and Education**
- 4. Improve Access to Services**
- 5. Improve Transitions from Childhood**
- 6. Improve Interactions with the Criminal Justice System**

In addressing these areas it is anticipated that there will be more positive experiences and outcomes for people with autism from statutory organisations (such as the NHS, Social Care, Education, Police and the Criminal Justice System) as well as from many other organisations as awareness and understanding of autism improves and ignorance and stigma reduce.

We want to ensure we are drawing upon resources and skills from local people and communities to create a more inclusive City for people with autism.

The aim of this strategy is to improve the lives of all those with autism. For some, this means the development and delivery of more effective support that can address significant challenges in communication and physical health. For others, it means increasing acceptance, respect and support.

## BACKGROUND

The Autism Act 2009 was brought in by Government in response to an identified gap in provision for adults with autism. The Act specified that a national strategy be in place by 1<sup>st</sup> April 2010.



‘Fulfilling and rewarding lives: the strategy for adults with autism in England’ was published on 3<sup>rd</sup> March 2010, the strategy sets a clear framework for all mainstream services across the public sector to work together for adults with autism. The national strategy ‘Fulfilling and Rewarding Lives’ “represents a shared approach towards a common goal; a society that not only accepts and understands Autism, but also provides real opportunities for adults with Autism to live fulfilling and rewarding lives”.

One of the many requirements of this strategy was for local authorities to develop their own strategy for autism.

The Birmingham Autism Partnership Board (BAPB) was set up in 2011 in response to this requirement for a local strategy. The Birmingham strategy for adults with autism responds to the central government guidance and legislation and to other priorities that have been agreed locally.

The BAPB has developed this strategy through consultation with people with autism, parents and carers and a broad range of professionals in the public sector and beyond.

This strategy has utilised two major reports which were commissioned in 2012 ‘The Joint Strategic Needs Assessment Autism Spectrum’ (JSNA) from August 2012 and the ‘Adults with Autism and the Criminal Justice System’ from December 2012. Both reports have provided valuable insight, data and recommendations many of which have been referred to or included within this strategy.

Please see Appendix A for structure and terms of reference of the BAPB.

## WHAT IS AUTISM?

Autism is a complex condition perplexing and fascinating in equal measure. A relatively newly identified disorder, autism presents differently in each individual but taken together these presentations can be grouped within a broad spectrum of presentations.

The word autism comes originally from ‘autos’, the Greek word for ‘self’ and means, literally, being absorbed in oneself. In 1943, the psychiatrist

Leo Kanner adopted the term to describe some of his child patients. They appeared isolated from the world, withdrawn from social contact, and most had severe intellectual difficulties (Kanner, 1943). Kanner became convinced that these and other features of the children's behaviour reflected a syndrome, a specific disorder with a characteristic set of symptoms. Increasingly in recent years the idea of an autistic syndrome has been elaborated to allow for a spectrum – a range or constellation of disorders reflecting slightly different patterns of symptoms, and collectively known as autism spectrum disorders (ASD).

Despite individual variation in symptoms, ASDs are usually considered to involve a three-way pattern of impairment originally described by the psychiatrist Lorna Wing (Wing and Gould, 1979). This so-called triad consists of impairments in:

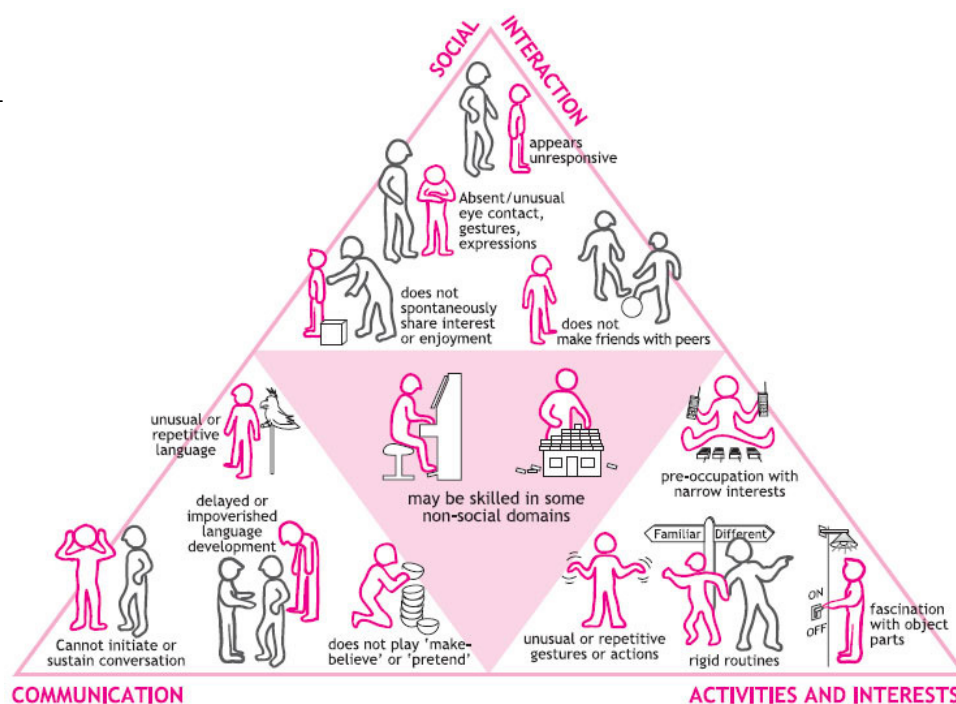
- social interaction;
- communication;
- flexibility of thought

Figure 1 illustrates key symptoms in the three areas of the triad. The central triangle gives examples of non-triad skills that may accompany the impairments.

A consistent finding is that males are more likely to be diagnosed with ASDs than females: the ratio ranges from 4:1 for classic autism to as much as 10:1 for 'milder' conditions within the spectrum such as Asperger Syndrome. It has also been noted that there is a similar male/female difference for dyslexia, and this is a typical feature of developmental disorders where communication is a central component.

However, how and to what extent each person is affected is unique and has resulted in the saying "once you have met one person with autism – you have met one person with autism".

FIGURE 1



© National Autistic Society

## DEFINITION OF AUTISM

The extract below is taken from 'Autism: recognition, referral, diagnosis and management of adults on the autism spectrum'.

Issued: June 2012; **NICE clinical guideline 142**;  
<http://guidance.nice.org.uk/cg142>

*Autism is a lifelong neurodevelopmental condition, the core features of which are persistent difficulties in social interaction and communication and the presence of stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests. The way that autism is expressed in individual people differs at different stages of life, in response to interventions, and with the presence of coexisting conditions such as learning disabilities (also called 'intellectual disabilities'). People with autism also commonly experience difficulty with cognitive and behavioural flexibility, altered sensory sensitivity, sensory processing difficulties and emotional regulation difficulties. The features of autism may range from mild to severe and may fluctuate over time or in response to changes in circumstances.*

*A significant proportion of adults with autism across the whole autistic spectrum experience social and economic exclusion. Their condition is often overlooked by healthcare, education and social care professionals, which creates barriers to accessing the support and services they need to live independently. In addition, people with autism are more likely to have coexisting mental and physical disorders, and other developmental disorders. Some may have contact with the criminal justice system, as either victims of crime or offenders, and it is important that their needs are recognised.*

There are two standard sets of criteria used to classify all behavioural and psychological disorders - the Diagnostic and Statistical Manual for Mental Disorders (DSM) and the International Classification of Diseases (ICD).

## **DIAGNOSTICS & STATISTICS MANUAL**

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The Diagnostic and Statistical Manual (DSM) was created by the American Psychiatric Association and is currently in its fourth version. DSM-5 is due for publication in May 2013.

The DSM contains criteria for the diagnosis of nearly 300 different disorders from schizophrenia, personality disorders and depression to acute medical conditions such as brain injury. The earlier versions were used to collect data for the census and hospitals, which is why it's called a statistical manual.

The current DSM (DSM-IV-TR) identifies autism (Autistic Disorder) and Asperger Syndrome as separate categories within the Pervasive Development Disorders. DSM-5 will group the pervasive developmental disorders under one umbrella diagnosis: Autism Spectrum Disorders.

## **INTERNATIONAL CLASSIFICATION OF DISEASES**

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The International Classification of Diseases (ICD) was created by the World Health Organisation and is currently in its tenth revision.

While the DSM focuses on mental health classification, the ICD has a much wider scope and covers all diseases and health-related conditions. It was developed from systems used to classify causes of death, and its

use extends beyond diagnosis to recording the incidence of disease and mortality statistics.

Both the DSM and ICD contain criteria for diagnosing autism. The two sets of criteria are very similar, with identical wording in parts, although the number and groupings of behaviours are different. Neither set is considered to be more correct or valid than the other. The ICD is used internationally and the DSM is favoured in the United States and Australia.

## **WHAT CAUSES AUTISM?**

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Research suggests that autism is likely to be caused by predominantly genetic effects but there are also environmental factors that play a role.

The environmental factors that play a role in autism are equally challenging to reliably identify. It is also unclear how these environmental factors may interact with a person's genetic risk for developing autism. It is widely thought that most cases of autism require a genetic predisposition plus some environmental factor or factors. This is because there are cases of identical twins where one has autism and the other does not.

There are currently no biological tests to confirm a diagnosis of autism. Identification of the condition is at present based solely on observed behaviours. Many parents and adults struggle to get a diagnosis and there is often a delay of years between the time of first concerns and finally receiving a diagnosis.

## **THE IMPACT OF AUTISM**

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Autism brings with it many challenges for the individuals themselves, their families, for the services which try to support them and society which often just does not understand them.

While many people with autism and their families will cope well with the additional challenges autism brings, the emotional and financial impact of autism is often difficult and sometimes devastating for people with autism and their families. For the families, it can be compared to a

grieving process for the 'loss' of the life that their family member could have had but for autism.

Research by the National Autistic Society

has found that:

- 90% of parents of children with autism report their child has been a target of bullying;
- 1 in 5 children with autism have been excluded from school;
- Only 15% of adults with autism are in full time paid employment;
- Half of adults with autism still live with their parents;
- Two third of people with autism presenting to services do so with symptoms of psychiatric disorder (depression, anxiety , psychoses).

(<http://www.autism.org.uk/about-autism/myths-facts-and-statistics/some-facts-and-statistics.aspx>)

## THE ECONOMIC COST OF AUTISM

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(*M.knapp, 2009*)

Each year, autism costs families and public services some £28 billion in the UK. Of this:

- £15 billion provides services for adults;
- £9.2 billion is the cost of lost employment;
- £2.7 billion is the cost of supporting children with autism in their education.

The remaining costs, £1.1 billion, are the additional family expenses. This should be considered an underestimate as there are considerable difficulties in modelling these figures.

## HOW PREVALENT IS AUTISM?

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Rates of diagnoses of autism have been rising for decades. Leo Kanner himself estimated rates of 1 in 10,000 for autism. However, more recent studies globally have suggested something more akin to 1 in 100. In the

United States, rates of autism diagnoses are rising rapidly from 1 in 110 in 2008 to 1 in 88 in 2012.

In the United Kingdom, studies have been incomplete and not a matter of routine. Current estimates suggest 1 in 100 prevalence of autism. In Birmingham, the estimated prevalence is between 1% and 2% of the population.

Part of this perceived increase in autism is due to the increased awareness and better identification and diagnosis. As awareness is raised, so will the number of diagnoses thereby increasing the apparent rates of autism.

There are three types of population with autism:

- Those with a diagnosis of autism;
- Those with a misdiagnosis of another condition;
- Those without a diagnosis of autism.

Work is in underway in Birmingham to identify those with a diagnosis, but the numbers of misdiagnoses or no diagnosis are not known.

The JSNA suggested a population with autism of between 1-2% from a total population of 1.037m. This would suggest the Birmingham population with autism to be between 10-20,000 patients in the diagnosed population. The population without diagnosis living in Birmingham is not known.

See Appendix C for more detail.


## **ADULTS WITH AUTISM IN BIRMINGHAM**

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The Birmingham JSNA identified that the ‘knowledge of people with autism is poor and evidence of their needs is less than satisfactory’.

Where data does exist the outcomes for adults with autism is less than ideal:

- 7 times more likely to come into contact with police either as victims, witnesses or alleged criminals;

- Lower than average likelihood of entering higher education;
  - While some can live in independent accommodation, the majority will remain at home with parents.
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## 1. RAISING AWARENESS AND IMPROVING TRAINING

A lack of understanding of autism can lead to inappropriate or stereotypical views being held by staff who support people with autism and this can have a negative impact.


‘Fulfilling and rewarding lives’ makes it clear that the most fundamental step towards improving services for adults with autism is to increase awareness and understanding of autism across all public services. Increased awareness and understanding of autism will provide the foundations for the broader changes sought to the way services are provided, planned and delivered.

In Birmingham a training sub group has been set up to lead and co-ordinate training for stakeholder organisations and other agencies. This should ensure not only improved knowledge and understanding but also lead to a change in the behaviour and attitudes in health and social care.

An autism awareness package is being developed with the core aim that staff are able to identify potential signs of autism. Also, it is hoped that the package will help staff to understand how to make reasonable adjustments in their behaviour, communication and service provision for people with a diagnosis of autism or who display autistic characteristics.

To improve general awareness of autism we will seek to:

- Ensure that the e-learning programme for autism awareness training is made widely available to as many agencies as possible through a specific training strategy with identified targets;
- Provide general autism awareness raising training for staff working in health, social care, community based organisations, housing officers/support staff and retail staff. Measuring the success so that its impact can be evaluated;
- Provide specialist training for staff working in key roles such as GPs, social workers, health professionals and those in leadership roles. Ensuring recognition and signposting to the diagnostic pathway;

- Ensure expert level of training (2013/2014) for all those who carry out diagnostic assessments;
  - Actively involve people with autism, parents and carers in the development of the learning programme and in the delivery of the training programme;
  - Ensure that autism training and learning opportunities are publicised to health and social care staff and other stakeholders;
  - Consider all staff when identifying those that need training, not just front-line staff;
  - Develop a network of autism co-ordinators/advisors.
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## 2. IMPLEMENT PATHWAYS FOR DIAGNOSIS

One of the aims of our strategy is to ensure everybody suspected of having autism has access to the local identification and assessment pathway. It is widely accepted that people with autism have been poorly served in this respect in the past. This has led to people being misdiagnosed and ending up in services that are not appropriate and worse still being given treatment that in fact harms them and leads to challenging behaviour resulting in stays in restrictive environments.

It is crucial that we have an easily accessible pathway for assessment and diagnosis which will lead to accurate formulations and signposting for useful support mechanisms leading to inclusion and integration into society. While the majority of diagnosis and support will be provided by local trusts, this will be complemented by a high quality service to be known as the Specialist Adult Autism Assessment and Resource Centre (SPARC). The centre will assess complex cases and provide a diagnostic and support service. This development is being led by a multi-professional clinical team with special expertise in autism, a leading academic from the University of Birmingham and Autism West Midlands. Pilot referrals to this facility began in February 2013.

The centre will provide specialist assessments and diagnosis for adults with autism or suspected autism and a link to advice and signposting to support services also being developed currently.

Our focus will be on the existing population and all of those within transitions to ensure we reach them at the earliest opportunity. We aim to ensure that those individuals have a care plan in place, and are supported to realise their ambitions within education, training, employment, housing and leisure and good social networks as well as being aware of health inputs that are required by them.

The current pathway as we envisage it is detailed below :-

Step 1 – Contact with public sector organisations such as NHS including GPs, social services, and police. Awareness raising at this level should lead to provision of support for people with autism and referral for people whose diagnosis is in doubt;

Step 2 – Referral to Mental Health and Learning Disability teams (including psychiatrists and psychologists). This should lead to a further assessment which should help arrive at a diagnosis with advice and support in a majority of cases. There would be diagnosis and treatment of any co-existing mental illnesses.

Step 3 – A small proportion of people may still face uncertainties with the diagnosis. Referral to SPARC will lead to 3 sessions provided by SPARC as part of the specialist diagnosis and assessment and commencement of a coordinated management plan if necessary.

The proposed diagnostic pathway is set out below:

### **Proposed Diagnostic Pathway**



A person centred needs assessment (examining individual, social and environmental factors) will be required to determine the level of support required by an individual. Individual factors may include mental illnesses, social and communication problems and sensory difficulties and other agreed priority areas such as relationships, occupation and leisure.

We will measure and monitor success in the following ways:

- The number of people referred at each stage;
- Increase in numbers over a 3 year period;
- Clinical Commissioning Groups know within their own patch, how many people there are with autism and how they plan for them;
- Diagnosis and assessment pathway is well known.

### 3. IMPROVE OPPORTUNITIES FOR EMPLOYMENT AND EDUCATION

The aim is to ensure Birmingham citizens with autism who want to work or receive training are able to access the same employment, education and training opportunities as 'neurotypical' citizens.

We recognise the need for awareness raising and training for frontline staff and are committed to raising Birmingham employer organisations' knowledge and understanding of autism through an online e-learning resource.

Birmingham City Council co-ordinates the Employment Sub-Group of the BAPB where partners, including the Department of Work and Pensions (DWP), Autism West Midlands and Birmingham City Council's Disability Employment Service are working together to improve the opportunities for people with autism, who are disadvantaged in the workplace.

The JSNA estimates that the number of people with autism in the working age group 16-64 that are unemployed range from 5,716 to 11,343 people. However, we know that not all people with autism are able to work.

With support, including individual advice, training and practical assistance, estimation shows that at least 2,500 unemployed people with autism in Birmingham could both get and retain a job. Many would be able to work full or part-time if supported to do so, enabling them to be financially more independent, to be socially included and more fulfilled.

Investing in further education (FE) and skills training for learners with learning difficulties or disabilities (LLDD learners) is an important part of the support that the Government provides to disabled people. This means making sure the right level of support is available to make sure barriers to education and training are removed and learners can make the most of their potential. The Skills Funding Agency will fund LLDD learners as set out in the Apprenticeships, Skills, Children and Learning Act. That is, it is responsible for funding provision for adults who are:

- 19 to 24 who do not have a Learning Difficulty Assessment or Education, Health and Care Plan (The Education Funding Agency is responsible for funding provision for students aged 19 to 24 who have a Learning Difficulty Assessment or Education, Health and Care Plan); or
- 25 and over and who self-declare they have a learning difficulty or disability.

Apprenticeship vacancies are advertised by employers on a free, national website. Individuals can search and apply at [www.apprenticeships.org.uk](http://www.apprenticeships.org.uk)

Access to Work is a programme to support disabled people or those with a long-term health condition to overcome barriers when moving into or retaining their employment.

The programme provides advice, can sometimes provide an assessment of a persons disability needs in the workplace and if required can provide a financial grant towards the cost of any necessary support. There grants are subject to eligibility criteria not set out in this document. A grant is usually only provided where the employee requires support or adaptations beyond those “Reasonable Adjustments” which an employer is legally obliged to provide under the Equality Act 2010.

Table 1

Unemployment estimation among expected population with autism in the general population in Birmingham

<b>Autism Prevalence</b>	<b>1%</b>	<b>2%</b>
<b>Estimated population with Autism</b>	6,725	13,450
<b>Expected number unemployed or unable to work</b>	5,716	11,343

**Reference Source: Birmingham JSNA Autism Spectrum August 2012**

The three main areas of difficulty experienced by people with autism are:

- Communicating socially, particularly using and understanding facial expressions, tone of voice and abstract language;
- Recognising or understanding other peoples' emotions and feelings and expressing their own which makes it more difficult to fit in socially;
- Understanding and predicting others' behaviour, making sense of abstract ideas and imagining situations outside their immediate daily routine.


These difficulties put a person with autism at a disadvantage in a standard recruitment interview. Employers have a duty to avoid discrimination and we are committed to supporting employers to review their recruitment processes to ensure they are accessible to someone with autism. As interviews rely heavily on social and communication skills we are encouraging employers to adopt alternative recruitment methods including work trials (which have proved to be very successful), use of closed questions and the promotion of peer support at face to face interviews.

Adults with autism are at greater risk of suffering stress and anxiety from pressures at work. Many workplace adjustments are cost free or do not require particularly expensive equipment. These include clear and concise communication, timetables and cue cards, flexible working arrangements and mentor support systems.

*“Interviewers and employers need real knowledge of autism (the positives and the negatives, the assets and problems) in order to provide individualised support to that person; they need to know how autism affects the individual”.*

**Person who has benefited from specialist employment support with Autism West Midlands**

To improve education and employment opportunities for people with autism in Birmingham we will seek to:

- Encourage employers to have autism-friendly recruitment and retention strategies being aware of the impact poor employment can have on the individual;
  - Raise the profile of employment for people with autism and help to increase their opportunities into paid employment/voluntary work placements;
  - Develop an effective pathway, information, advice and signposting service to citizens, their families and carers;
  - Establish Autism Champions in organisations which employ people with autism, to ensure there is on the job support from a trained co-worker to support with managing work routines, social interactions, job performance and career development to ensure job retention;
  - Work to develop knowledge of good local employers. Identifying job roles where people with autism excel, what the person can offer to the employer and vice versa;
  - Roll out the E Learning training package to employers and their employees to help with understanding and awareness raising.
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## 4. IMPROVE ACCESS TO SERVICES

Improving access to services and support is a long-term goal and will require a cultural change within public services, ensuring they are reflective and more personalised for adults with autism.

The Birmingham JSNA highlighted that adults with autism were under utilising services. This means that just over 3% of the identified adult population (8,091) with autism are receiving services in the community.

The overall vision is that:

“They (adults with autism) can depend on mainstream public services to treat them fairly as individuals”.

To improve access for people with autism we will seek to:-

- Encourage/promote reasonable adjustments for adults with autism in areas such as GP surgeries, dentists, hospitals etc. This is also a requirement under the Equality Act for all public sector organisations. Potential areas to consider include: premises, processes, communication, planning and preparation;
- Ensure that service specifications for Mental Health and Learning Disabilities demonstrate how reasonable adjustments for adults with autism are made by developing a network of professionals with expertise in autism and mental health who can work seamlessly around the individual;
- Influence housing service specifications to be more inclusive of people with autism;
- Deliver housing related support to help those that are eligible to maintain their tenancy or supported accommodation;
- Give adults with autism more say in their care and support;
- Enable adults with autism to benefit from personalisation of social care. Ensure that they are able to access personal budgets and direct payments, in line with the assessment of their needs;

- Improve information about employment support and benefits for adults with autism;
- Develop links with the Third Sector including indirect access through voluntary sector organisation, access to advocacy services and autism co-ordinators;
- Involve GPs further in the role they can play in high level screening by providing information, training and support;
- Support travel training to help build confidence in using public transport;

**Improve access to health services:**

- Improve access to health and wellbeing initiatives such as lifestyle advice, diet advice and fitness opportunities;
- Improve access to primary care services to receive timely support and good quality signposting for diagnosis and support as well as access to primary care based Mental Health services such as IAPT (Improving Access to Psychological Therapies);
- Improve access to mainstream Mental Health services and Learning Disability services for the treatment of commonly occurring conditions such as depression, anxiety and brief psychotic illnesses;
- Improve access to specialist services such as inpatient beds and forensic services.

## 5. IMPROVE TRANSITIONS FROM CHILDHOOD

Children with autism and their families/carers should have access to support that helps them to achieve their potential and promote inclusion. Without effective transition planning this support will not be available to people with autism when they reach adulthood – leaving them isolated at a critical point in their lives.

In Birmingham we are working to improve the transition support offered to all young people including those with autism. There is a Transition Development Board, which is addressing the issues related to the transfer of social care for young people with disabilities from ‘Children, Young People and Families’ and ‘Adults and Communities Directorate’. Procedures and protocols are in place.

Currently social care transition in Birmingham includes 17 – 25 year olds with the intention to cover 14 – 25 year olds by 2016. Referrals to Adults and Communities Directorate are received from a diverse range of sources with around half coming from the Children With Disabilities Service (these are received in the month before the individual’s 17<sup>th</sup> birthday).

We want to ensure that effective transition planning is in place for people with autism. Current figures indicate that some autistic service users are now being identified with autism as their primary need. It is anticipated that diagnosis will have been made prior to those reaching transitions age. Early Intervention teams are dealing with some young people with autism and mental health needs who may need to be moved on to appropriate service for longer-term support.

Transitions should not be seen as a single point of switch over. The most effective transitions are carefully planned and managed over a number of years. A Connexions Personal Assistant will attend the Year 9 Transition Planning meeting for all young people who have a statement of educational need. They will also complete a Learner Support Plan (LSP) in that person’s last year at school if they are expected to go onto full time education or training. Connexions will also work with young people who are at school and identified as being in one of a number of vulnerable groups and will also work with people who are

Not in Education, Employment or Training ('NEET') and aged 16-19. This might be extended up to 25 if they previously received a statement of educational need.

Transition pathway plans are currently being embedded in all special schools in Birmingham and it is expected that the individual's aspirations are included. The plans are reviewed and updated yearly by Special Education Needs, Assessment and Review team within the Children, Young People and Families Directorate. These plans are owned by the young person. It is important that all young people who have autism and a statement of need but are in mainstream schools also have a robust transition plan.

The Birmingham Autism Partnership Board and Learning Disabilities Partnership Board are working in partnership and have a Transition to Adult Life Group and a newly formed consultation group made up of young people.

To improve transitions for young people with autism we will seek to:

- Map day opportunities for young people with social care needs;
- Ensure where appropriate, that young people are offered the assistance of an advocate to speak on their behalf and to ensure their views are heard. Where possible specialist trained autism advocates will be engaged;
- Ensure an effective transitions process by sharing information between children's and adult services. Not just in terms of information about individuals at the point of transition, but also about the needs and numbers of children with autism in Birmingham to help with service planning;
- Ensure that all professionals within the local authority and NHS bodies who are involved in transitions for young people with autism have received appropriate autism training;

- Ensure that young people with co-existing mental health needs that are already receiving services (Paediatric services and CAMHS - Child and Adolescent Mental Health Services) move seamlessly to adult services provided by Birmingham Community Health Care and Birmingham and Solihull Mental Health Foundation Trust;
- Continue to strengthen and develop the work of the Transitions Project Board which includes representation from adult and children's services;
- Ensure that young people with autism and their families and carers are involved in transition planning;
- Begin working with children from the age of 14 by 2016;
- Ensure adequate information and signposting such as advising individuals about their ability to request a community care assessment/carer's assessment if they have a need for social care;
- Develop a health pathway – if the severity of autism is such that Health has to be involved the impact on the service user is substantial, therefore a pathway through health services for mental health needs, GP care and acute health care needs to be in place. A GP will determine if someone has a need for a health assessment;
- Ensure that strategic arrangements are in place, including a clear multi-agency agreed protocol, to help organisations to meet their statutory duties and to follow existing guidance effectively.

## 6. IMPROVE INTERACTIONS WITH THE CRIMINAL JUSTICE SYSTEM

In December 2012, a report was provided to the Health and Social Care, Overview & Scrutiny Committee, Birmingham City Council entitled: Adults with Autism and the Criminal Justice System.

The report highlights a number of key areas of concern which emerge as children with autism reach adulthood:

- Time gap – full-time school provides a regular routine which is lost once school has ceased;
- Financial gap – after full-time school, one parent from a family may have to forego employment in order to support the adult with autism;
- Support gap – there is a broad range of support for children up to 16, at which point support services are limited for adults with autism.

Neither the police, courts, prison nor the Mental Health Trust have reliable, accessible data on the number of autistic people with whom their organisations interact.

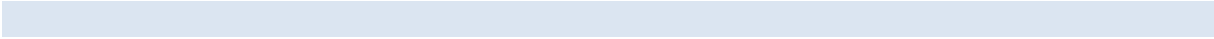
There appears to be little by way of provision for the adult with autism in law and in the way they are managed through the court process, putting the adult with autism in a very difficult situation. Specialist support may reduce the burden on the courts and save on the public purse as a consequence.

Finally the report draws the following conclusions:

- For the adult with autism, finding routines and activities that can be easily accessed could reduce interaction with crime and criminals thereby reducing impact on the criminal justice system;
- Reducing the circumstances where stress levels in the adult with autism produce abnormal behaviours will reduce contact with the police;
- Providing better support to the adult with autism could mean fewer compulsive interests taken to excess;

- Better training and awareness for the police will be likely to reduce the numbers of inappropriate arrests of people with autism.

The action plan that supports this overall strategy has been taken from the December 2012 report. The action plan requests a number of actions of statutory organisations to raise awareness of autism.



## APPENDIX A: BIRMINGHAM AUTISM PARTNERSHIP BOARD

### TERMS OF REFERENCE

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#### 1. What is the Birmingham Autism Partnership board (BAPB)?

The BAPB is made up of a group of people who are committed to improving the lives of people with autism.

#### 2. Aims

- To move forward with development of local services using the guidance provided in *Implementing Fulfilling and Rewarding Lives* and development of the strategy and local services.
- To support and monitor progress of the development of services for people with autism.
- To share information about service development with networks involved with people with autism.

#### 3. Membership

- People with autism
- Family carers
- Birmingham City Council
- Birmingham Community Health Care
- Birmingham Solihull Mental Health Foundation Trust
- Voluntary organisations
- Connexions
- Others e.g. advocacy groups (TBC).

#### 4. Chair

4.1 Dr Ashok Roy, Consultant Psychiatrist.

#### 5. Meetings

##### 5.1 Timing of meetings

The meetings will be held at least every quarter (4 meetings a year)



## 5.2 Format

The agenda will be sent out 7 days prior to the meeting. The meeting will review the actions from the last meeting, share items of information, promote discussion on a specified topic and promote discussion and feedback.

## 5.3 Papers and presentations

Papers and presentations will be in easy to read format. To enable people to prepare for meetings these papers should be sent to the administrator 10 days prior to the meeting so that they can be sent with the agenda.

## 5.4 Requests to attend BAPB

Requests to attend the meeting will be made to the Chair at least 5 working days before the meeting.

## 5.5 Quorum

There must be at least 8 members present for a meeting to take place.

## **6. Minutes**

Notes of the meeting will be taken and made available. These minutes will be a public document and will be available on the Health and Wellbeing website.

## **7. Responsibilities of Board members**

- 7.1 Each member represents a stakeholder group and will therefore have a responsibility to communicate information between the Board and the group or organisation they represent.
- 7.2 Members must attend at least 3 meetings a year. Apologies must be given to the Chair. A member unable to attend may send a representative as a deputy.

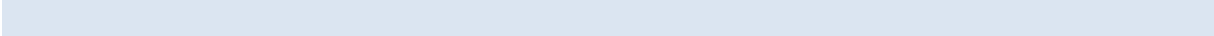
## **8. Support for people with Autism**

Support will be provided in helping prepare for meetings, having supporters at meetings, keeping language simple and free of jargon,

have support to inform others about the meeting and to use electronic communication more effectively.

## **9. Links with other groups**

BAPB will have links with Partnership Boards for Mental Health and Learning Disability as well as other Autism Partnership Boards. It will have links with other regional and national groups which help in fulfilling its aims. It will report to the Joint Commissioning Team.



## APPENDIX B: CONTEXT AND POLICY FRAMEWORK

### NATIONAL DRIVERS

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- The Autism Act 2009 placed a duty upon the Government to produce a strategy by April 2010.
- Fulfilling and rewarding lives: the strategy for adults with autism in England (March 2010);
- Towards 'Fulfilling and rewarding lives': the first year delivery plan for adults with autism in England (April 2010);
- Implementing 'Fulfilling and rewarding lives': Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy (December 2010).
- Autism: recognition, referral, diagnosis and management of adults on the autism spectrum - NICE Clinical guideline 142 (issued June 2012);
- Supporting people with autism through adulthood – National Audit Office.(2009);
- The economic consequences of autism in the UK Foundation for People with Learning Difficulties (2007);

### LOCAL DRIVERS

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- Birmingham Joint Strategic Needs Assessment Autism Spectrum (July 2012);
- Birmingham Joint Strategic Needs Assessment Autism Spectrum: Key Findings (August 2012);
- Overview & Scrutiny Report: Adults with Autism and the Criminal Justice System (December 2012).

### SUPPORTING ORGANISATIONS

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Birmingham City Council

Birmingham Cross City Clinical Commissioning Group

Birmingham South & Central Clinical Commissioning Group

Sandwell & West Birmingham Clinical Commissioning Group

Birmingham Community Healthcare NHS Trust

Birmingham & Solihull Mental Health Foundation Trust

West Midlands Police

Autism West Midlands

National Autistic Society

Voluntary Organisations



## APPENDIX C: THE LEVEL OF NEED IN BIRMINGHAM

**SUMMARY OF THE JOINT STRATEGIC NEEDS ASSESSMENT, JULY 2012**

- The population of people with autism is steadily increasing as general population increases, even though prevalence is around 1% of the population. There is evidence that in some areas this could reach up to 2%.
- Adult population (18-64) is estimated at 6,482 and by 2025 it will increase to 6,965.
- Adult population (16+) is estimated 8,091 and 9,080 by 2025.
- The national ratio male: female for people with autism is 4:1 however, in Birmingham the data is showing at 2:1
- Birmingham's prevalence of autism in SEN pupils is 26.2% higher than England 19.6% (2011).
- Social services currently deal with only 1:3 of the population that is already known to services.

The population of Birmingham is diverse and presents many challenges due to its ethnicity and age structure. The total resident population estimation (ONS Mid-Year estimation 2010) is 1,036,878 inhabitants, which is shown in Table 1. The population of people with autism is estimated to be 1 in 100 people (1%).

**Table 2 Population estimation**

Age Range	AUTISM	General Population
Age 0-15	2,278	227,763
Age 16 +	8,091	809,115
Total	10,369	1,036,878

**Table 3 Autism population trends applying 1 % prevalence**

Birmingham Local Authority	2011	2015	2020	2025	2030
Birmingham: Total males aged 18-64 predicted to have autistic spectrum disorders	5828	5976	6122	6271	6446
Birmingham: Total females aged 18-64 predicted to have autistic spectrum disorders	654	669	681	694	710
Birmingham Total 18-64	6482	6645	6803	6965	7156

From this estimated population there is only a small proportion that is known or registered in services across the city, generating a challenge at the moment of understanding the needs of this specific population.

### Unknown need

The needs are largely projected from school figures, one priority for future will be identifying and mapping adults with autism across the City. We can then begin to look at actual need. We will only be able to talk about people that are known to us.

This paucity of data presents the first major challenge for Birmingham to overcome. Our first achievement needs to be to develop a Citywide system that will capture all people with autism regardless of need.

The autism self assessment framework highlighted data capture as a consistent area of concern nationally with fewer than half being able to provider numeric data about people with autism known to local authorities, and their living and work circumstances.

**Figure 1 – Autism Prevalence by Ward, 2011**

