

# Swindon Adult Autism Strategy 2015-2018

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Swindon Adult Autism Partnership Boards' joint strategy to improve the health and wellbeing of adults with autism living in Swindon.

Draft July 2015

## **Swindon Adult Autism Strategy – Draft v2**

### **Contents**

Foreword .....	2
1. About autism .....	3
2. Why do we need an Autism Strategy for Swindon? .....	4
3. Purpose and aims of the strategy .....	7
4. Priorities for Action .....	8
1. Evidence led planning, commissioning and service provision .....	8
2. Training and awareness raising to improve understanding of autism amongst professionals and the public. ....	9
3. Ensuring that the right support for people with autism in Swindon is available at the right time during their life time .....	10
4. Transition planning and support for young people with autism as they prepare for adulthood. ....	11
5. Employment and learning opportunities for adults with autism .....	12
6. Working with the criminal justice system .....	13
7. Housing and support to live independently .....	14
8. Governance and Monitoring of the Strategy .....	14
9. Summary of Intent .....	14

## Foreword

Autism occurs early in a person's development. It affects the way a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. Autism is a relatively 'modern' diagnosis; whilst most diagnosis now occurs in childhood many adults remain undiagnosed.

It is estimated that around 1% of the population in England have autism. This is equivalent to approximately 2,300 adults and children in Swindon. Autism is neither a learning disability nor a mental health problem although mental health problems are more common among people with autism and it is estimated that one in three of adults with a learning disability also have autism.

Autism affects people in different ways; some can live independently without any additional support, while others require a lifetime of specialist care. The needs of adults with autism thus vary widely. A significant proportion of adults with autism across the whole autistic spectrum experience social and economic exclusion. Improving access to local support and services is important to develop the skills and independence of adults with autism in Swindon and prevent, delay or reduce the care needs of them and their carers.

People with autism need to have access to a clear pathway to diagnosis and know that this pathway is aligned with care and support assessments, and that there is post-diagnostic support available even if the person does not meet social care support criteria. Commissioning decisions need to be based on knowledge and awareness of autism, the needs of the local population, and informed by people with autism and their families.

This strategy has been developed by the Swindon Adult Autism Partnership Board which is a multi-agency group which includes Swindon Borough Council, Swindon Clinical Commissioning Group, SEQOL, representatives from the voluntary sector and local community and people from across the autism spectrum and their carers.

The Adult Autism Strategy for Swindon sets out local actions to achieve the 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 makes the most of their talents."*

The strategy aims to provide co-ordination for the excellent work that is already in place in Swindon, and maximise the opportunities for joint working between member organisations of the Autism Partnership Board. It is based on priorities outlined in national policy and statutory guidance and local needs identified in the Swindon Adult Autism JSNA Bulletin. By working together, we hope that the implementation of this strategy will help make Swindon a better place for everyone and enable those affected by autism to live healthier, safer and more fulfilling lives.

Swindon Adult Autism Partnership Board  
July 2015

## 1. About autism

Autism is known as a spectrum condition, both because of the range of difficulties that affect adults with autism, and the way that these present in different people. Throughout this strategy, unless otherwise specified, the term 'autism' is used to refer to all diagnoses on the autism spectrum, including Asperger syndrome, high functioning autism, Kanner or classic autism.

Autism occurs early in a person's development. Autism is neither a learning disability nor a mental health problem, although mental health problems can be more common among people with autism and it is estimated that one in three of adults with a learning disability also have autism<sup>1</sup>. Autism affects the way a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It affects people in different ways; some can live independently without any additional support, while others require a lifetime of specialist care.

Gathering data on the numbers and needs of people with autism at a local level is challenging as historically services have not collected comprehensive data about this population. Health and adult social care services are likely to know only a small number of all local people with autism because many people are undiagnosed and not all people with autism will come into contact with health and social care services.

The latest prevalence studies of autism indicate that 1.1% of the population in the UK may have autism. When applied to Swindon Borough Council's current estimated population (214,000) this equates to just over 2,300 people (adults and children) in Swindon.

A local needs assessment<sup>2</sup> was undertaken to inform this strategy. The resulting Swindon Adult Autism JSNA Bulletin provides more information about the number of people with autism in Swindon<sup>2</sup>. Information about autism in Swindon is also included in both the Learning Disabilities and Adult Mental Health and Wellbeing Joint Strategic Needs Assessments<sup>3</sup>.

Autism is a relatively 'modern' diagnosis; the term 'autism' only came into common clinical use in the 1960s and whilst most diagnosis now occurs in childhood many adults remain undiagnosed. Getting a diagnosis can be a crucial milestone for people with autism; many have felt different and unable to "fit in" for all of their lives. Those with the condition share three main areas of difficulty, which are sometimes called the triad of impairments.

- **Difficulty with social communication**

People with autism have difficulty using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice. Some might not speak, or have fairly limited speech. Some are very articulate and enjoy talking but may nevertheless find it difficult to engage in two-way conversations. Some people become selectively mute under certain circumstances. They may understand what people say to them but prefer to use alternative forms of communication, such as sign language.

- **Difficulty with social interaction**

Those with the condition have difficulty recognising and understanding people's feelings and managing their own. This can make it hard for those with the condition to make friends and can lead to social isolation and into conflict with other people.

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<sup>1</sup> Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey, The NHS Health and Social Care Information Centre (2012)  
<http://www.hscic.gov.uk/article/1733/New-study-estimates-autism-prevalence-among-adults-with-learning-disability>

<sup>2</sup> Swindon Adult Autism JSNA Bulletin 2015. <http://www.swindonjsna.co.uk/dna/Autism-needs-assessment>

<sup>3</sup> Swindon Joint Strategic Needs Assessment <http://www.swindon.gov.uk/sc/sc-healthmedicaladvice/jsna/Pages/sc-jsna.aspx>

- **Difficulty with social imagination**

People with autism have difficulty understanding and predicting other people's intentions and behaviour, and imagining situations that are outside their own routine. Difficulty processing information, reflected as cognitive inflexibility or rigid thinking – is very common and one of the biggest difficulties to overcome. A lack of social imagination should not be confused with lack of imagination. Many people with autism are very creative.

People with autism may also experience some form of sensory hypersensitivity or lack of sensitivity. For example to sound, touch, taste, smell, lights or colours can have an impact on how people experience, and cope with, different environments.

A significant proportion of adults with autism across the whole autistic spectrum experience social and economic exclusion. Their condition can be overlooked or missed 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.

Autism is a lifelong condition and people may need support and to use services at any time in their life. However, every day we hear stories of people with autism who are living successful and rewarding lives: achieving at college, working in fulfilling jobs, and contributing to their local community.

## **2. Why do we need an Autism Strategy for Swindon?**

### **National Policy Context**

Autism is a national priority. In 2009 the Autism Act<sup>4</sup> to make provision about meeting the needs of adults with autistic spectrum conditions was published, and the publication of a national autism strategy *Fulfilling and rewarding lives: the strategy for adults with autism in England*<sup>5</sup> followed in 2010 together with statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy<sup>6</sup>.

An update to the strategy, *Think Autism Fulfilling and Rewarding Lives, the strategy for adults with autism in England*<sup>7</sup> was published in April 2014 and is supported by new statutory guidance published in March 2015<sup>8</sup>. These updates build on rather than replace the themes of the 2010 strategy. The clear vision is that:

*“All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support 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.”*

The building blocks of the Autism Strategy 2010 are crucial foundations to future work and are expected to be in place in every local area. They are:

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<sup>4</sup> Autism Act 2009 <http://www.legislation.gov.uk/ukpga/2009/15/contents>

<sup>5</sup> Fulfilling and rewarding lives: the strategy for adults with autism in England

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113369](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369)

<sup>6</sup> Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy 2010. <https://www.gov.uk/government/publications/implementing-fulfilling-and-rewarding-lives>

<sup>7</sup> 'Think Autism': an update to the government adult autism strategy

<https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>

<sup>8</sup> Adult autism strategy: statutory guidance 2015 <https://www.gov.uk/government/publications/adult-autism-strategy-statutory-guidance>

- **Increasing awareness and understanding of autism among frontline professionals**  
Autism awareness training should be available to all staff working in health and social care and local areas should develop or provide specialist training for those in key roles in order to increase the recognition of autism and enable staff to be better equipped to meet people's needs.
- **Developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment**  
There should be a clear pathway to diagnosis in every area from initial referral through to assessment of needs. Diagnosis should lead to a person centred assessment of need and should be recognised as a catalyst for a carer's assessment.
- **Improving access for adults with autism to the services and support they need to live independently within the community and helping adults with autism into work.**  
Ensure that a range of services and support can be accessed by people with autism and that most importantly; opportunities for employment and housing are expanded, challenging the current high levels of social exclusion.  
  
Local areas must follow statutory duties around transition for children with SEN, which will include most young people with autism. Protocols should be in place in every area for the transition of clinical mental health care for children with autism in receipt of CAMHS.
- **Improving information about the population of adults with autism and enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.**

There is NICE Guidance<sup>9</sup> and a NICE Quality Standard<sup>10</sup> for the recognition, referral, diagnosis and management of adults on the autism spectrum which covers the care provided by primary, community, secondary, tertiary and other health and social care professionals who have direct contact with, and make decisions concerning the care of, adults with autism.

There are also strong links between autism and The Care Act 2014<sup>11</sup>. The Act puts in place requirements for local authorities to meet a person's eligible care and support needs, and to help and protect people with care and support needs who may be at risk of abuse or neglect as a result of those needs. The areas of the Care Act most relevant to local authorities' approach to autism are prevention, integration and co-operation (in terms of health and social care provision), information and advice, duty and powers to meet needs, safeguarding adults at risk of abuse or neglect, transition for children, and advocacy.

Although the focus of this strategy is on adults with autism it has also been informed by The Children and Families Act 2014<sup>12</sup>, particularly with regard to duties relating to transition and preparing for adulthood. The reforms have a particular focus on children and young people with special educational needs and disability (SEND). Together with The Care Act 2014 the reforms create a system from birth to 25 through the development of coordinated assessment and single Education, Health And Care Plans; improving cooperation between all services responsible for providing education, health or social care.

<sup>9</sup> NICE guidelines CG142. Autism: recognition, referral, diagnosis and management of adults on the autism spectrum <https://www.nice.org.uk/guidance/cg142>

<sup>10</sup> NICE Quality Standard QS51. Autism. <https://www.nice.org.uk/guidance/qs51>

<sup>11</sup> The Care Act 2014. <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

<sup>12</sup> The Children and Families Act 2014 <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

The national strategy 2014 review highlights fifteen priority challenges for action which have been identified by people with autism, carers, professionals and others who work with people with autism.

## **The 15 Priority Challenges for Action – *Think Autism* National Strategy**

### **An equal part of my local community**

1. I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism.
2. I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others.
3. I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low level support.
4. I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism.
5. I want to be safe in my community and free from the risk of discrimination, hate crime and abuse.
6. I want to be seen as me and for my gender, sexual orientation and race to be taken into account.

### **The right support at the right time during my lifetime**

7. I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.
8. I want autism to be included in local strategic needs assessments so that person centred local health, care and support services, based on good information about local needs, is available for people with autism.
9. I want staff in health and social care services to understand that I have autism and how this affects me.
10. I want to know that my family can get help and support when they need it.
11. I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies.
12. I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging.
13. If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.

### **Developing my skills and independence and working to the best of my ability**

14. I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible.
15. I want support to get a job and support from my employer to help me keep it.

### **Local Policy Context**

Swindon has an Autism Partnership Board as recommended by the national strategy but no local autism strategy until now. The Department of Health led self-assessment exercise<sup>13</sup> and the Swindon Adult Autism JSNA have highlighted some excellent local services and areas of good practice for supporting adults with autism, but also some gaps and opportunities for improved communication between agencies and more joint working and information sharing. This will best be achieved through a strengthened Autism Partnership Board and local autism strategy.

A local autism strategy will contribute to wider strategic objectives in Swindon. The five strategic priorities of Swindon Borough Council set-out below. All are relevant to the *Think Autism* vision.

- Work with residents to create well cared for neighbourhoods
- Right skills, right jobs, in the right places
- Together, find new ways to reduce vulnerability and improve health for all
- Work with people and families to help them fulfil their potential
- Make best use of Swindon's resources inside and outside the Council

The Joint Health and Wellbeing Strategy<sup>14</sup> focusses more specifically on health and wellbeing outcomes. Its priorities are also very relevant to the *Think Autism* vision.

They are:

- Every child and young person in Swindon has a healthy start in life
- Adults and older people in Swindon are living healthier and more independent lives
- Improved health outcomes for disadvantaged and vulnerable communities (including adults with long term conditions, learning disabilities, physical disabilities or mental health problems, offenders)
- Improved mental health, wellbeing and resilience for all
- Creation of sustainable environments in which communities can flourish

### **3. Purpose and aims of the strategy**

The purpose of this strategy is to set out Swindon Adult Autism Partnership Boards' joint strategy to improve the health and wellbeing of adults with autism living in Swindon, and local actions to achieve the national 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 makes the most of their talents."*

It is based on priorities outlined in national policy and statutory guidance, and local needs identified in the Adult Autism JSNA Bulletin.

These are:

1. Evidence led planning, commissioning and service provision
2. Training and awareness raising to improve understanding of autism amongst professionals and the public.
3. Ensuring that the right support for people with autism in Swindon is available at the right time during their life time.

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<sup>13</sup> Autism self-assessment framework 2013 <https://www.improvinghealthandlives.org.uk/projects/autism2013>

<sup>14</sup> Swindon Health and Wellbeing Strategy <http://www.swindon.gov.uk/healthandwellbeingstrategy>



4. Transition planning and support for young people with autism as they prepare for adulthood.
5. Employment and learning opportunities for adults with autism
6. Working with the criminal justice system
7. Housing and support to live independently

The following sections describe the priorities for in more detail. Each section provides further context to the priority, the outcomes we are aiming to achieve and some proposed actions identified in the JSNA and consultation undertaken to inform the development of this strategy. The Autism Partnership Board will work together to develop and monitor an annual action plan to support the delivery of this strategy which will outline intended actions and outcome measures in more detail.

## **4. Priorities for Action**

### ***1. Evidence led planning, commissioning and service provision***

#### **CONTEXT**

In-line with Statutory Guidance Local Authorities and NHS bodies with commissioning responsibility should jointly develop and update local joint commissioning plans for services for adults with autism based on effective joint strategic needs assessment, and review them annually, for example with the local Health and Wellbeing Board. Services should be commissioned and delivered in-line with national guidance and best practice including NICE Guidelines.

NICE Guidance states that autism strategy groups should be responsible for developing, managing and evaluating local care pathways. Nationally Autism Partnership Boards have proved to be a highly effective means for stakeholders to shape and monitor local commissioning and service delivery and it is clear that all members of the Autism Partnership Board have a role to play in providing data and insight to inform local needs assessment and commissioning plans.

Data collection and analysis is integral to the success of local planning, as is user involvement. The first Swindon Adult Autism JSNA was presented to the Health and Wellbeing Board in March 2015. This identified significant gaps in the data available to inform commissioning plans and recommended that all services work to develop and improve methods of data collection to ensure that the numbers of people with autism in their area of responsibility are appropriately recorded and analysed, and information about need (health, social care, education, employment, housing) is captured.

#### **OUTCOMES**

- There are clear local commissioning plans in place which have been informed by recommendations from the Swindon Adult Autism JSNA and local intelligence about need.
- Plans are in place for local services to (as a minimum) gather information locally about:
  - The number of adults known to have autism
  - The range of need for support to live independently
  - The age profile of people with autism in the area – to enable local partners to predict how need and numbers will change over time
- Autism Partnership Board has agreed clear governance structures in place and reporting mechanisms through to the Joint Commissioning Group and Health and Wellbeing Board to monitor progress against agreed actions and to ensure senior level sign off for responses to the national autism self-assessment exercises and other appropriate developments around the delivery of the local autism strategy.
- The Autism Partnership Board has strong service-user representation and the views and aspirations of adults with autism and their carers are taken into account when decisions are made about service in Swindon.

## **PROPOSED ACTIONS**

- Autism Partnership Board to develop and monitor an annual action plan based on local and national strategy and Swindon Adult Autism JSNA led by a named joint commissioner/senior manager who leads commissioning of care and support services for adults with autism in the area, known as the autism lead.
- Autism Partnership Board members to work together to develop and improve methods of data collection to ensure that the numbers of people with autism in their area of responsibility are appropriately recorded and analysed, and information about need (health, social care, education, employment, housing) is captured.
- Autism Partnership Board members to work together to ensure information sharing protocols are in place and that all necessary information for service planning is available.

## **2. *Training and awareness raising to improve understanding of autism amongst professionals and the public.***

### **CONTEXT**

People with autism and their carers report that when professionals understand autism the impact on their experience of services and the care they receive can be immense. NICE Guidelines state that all staff working with adults with autism should have an understanding of the nature, development and course of autism and its impact and how to make necessary adjustments or adaptations.

A survey undertaken for the Swindon Adult Autism JSNA found that adults with autism felt that increased awareness and acceptance of autism in their community and in local services was the factor that would most help develop their skills and independence.

In line with the statutory guidance, local authorities should be providing general autism awareness to all frontline staff in contact with adults with autism, so that staff are able to identify potential signs of autism and understand how to make reasonable adjustments in their behaviour and communication. In addition to this, local authorities are expected to have made good progress on developing and providing specialist training for those in roles that have a direct impact on and make decisions about the lives of adults with autism, including those conducting needs assessments.

There are a number of autism training opportunities available in Swindon and some innovative programmes and projects delivered by Autism Partnership Board member agencies such as the Wiltshire Autism Alert Card scheme and training programmes delivered by DASH and SEQOL for the Criminal Justice System, but no overall strategic approach to training or for raising public awareness and understanding.

### **OUTCOMES**

- People and organisations in Swindon have opportunities to raise their awareness and acceptance of autism.
- Autism awareness is included in equality and diversity training of all health and social care services in Swindon.
- Front-line staff have access to training which enables them to recognise autism and make reasonable adjustments and adapt the support they give to adults with autism, particularly if they have additional needs such as a mental health problem, a learning disability or challenging behaviours.
- GPs, as the gatekeepers to diagnostic services, have adequate training and information available to so that they have a good understanding of the whole autistic spectrum and the local diagnostic pathway and how to refer.
- People with autism feel accepted within their local community.

## PROPOSED ACTIONS

- Undertake a training needs assessment to identify training needs for those who would benefit from general autism awareness training and more specialist training.
- Map and review autism training currently available in Swindon with a view to promoting a multi-agency programme of training led by the Autism Partnership Board.
- Autism Partnership Board to work together to develop a communications plan and strategy to raise wider awareness of autism and promote existing schemes such as the Wiltshire Autism Alert Card.

### ***3. Ensuring that the right support for people with autism in Swindon is available at the right time during their life time.***

## CONTEXT

Statutory Guidance states that CCGs are expected to take the lead responsibility for commissioning of diagnostic services to identify people with autism, and work with local authorities to provide post-diagnostic support. There should be a clear pathway to diagnosis and post-diagnosis in every local area. There is NICE Guidance<sup>15</sup> and a NICE Quality Standard<sup>16</sup> for the recognition, referral, diagnosis and management of adults on the autism spectrum. Autism strategy groups should be responsible for developing, managing and evaluating local care pathways

People with autism say that they want services and commissioners to understand how autism affects them through their life and that that this can be different at different times. They want to be supported through big life changes such as transition from school, getting older or when a person close to them dies. Commissioners need to plan appropriate services for all those with autism including men and women, those from black and ethnic minority communities and older people, and ensure that mainstream services are appropriate for people with autism.

Psychosocial and preventative support is important for people with autism. Preventative support can be provided in many different ways; Autism Partnership Board members have a critical role to play. User-led and voluntary support groups help adults with autism build relationships with peers, friends, partners and colleagues and also support independent living and being part of the community.

There is a range of services and sources of support available in Swindon to people with autism and their carers. Whilst some of these are health and social care services, the community and voluntary sector play an important role. A local adult autism diagnostic service has been provided in Swindon since 2010 in line with the Autism Act (2010). The SEQOL Autism Team has been highlighted as an example of national good practice by the Department of Health and National Autistic Society and their diagnostic process has recently won the National Autism Award for Clinical Excellence. However, waiting times for a diagnostic assessment can be up to a year.

## OUTCOMES

- Clear pathways of care are in place in Swindon for diagnosis, post-diagnosis and care assessments.
- Information about support services in Swindon available to people with autism is up-to-date and accessible in a way that is appropriate and identifiable.
- Local preventative support and activities that enable people with autism to be connected with peers and other local community groups is available across Swindon.

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<sup>15</sup> NICE guidelines CG142. Autism: recognition, referral, diagnosis and management of adults on the autism spectrum <https://www.nice.org.uk/guidance/cg142>

<sup>16</sup> NICE Quality Standard QS51. Autism. <https://www.nice.org.uk/guidance/qs51>

## PROPOSED ACTIONS

- Ensure up-to-date protocols are in place for the provision of relevant information to adults with autism and their family or carers at the point of diagnosis and signposting/referral to other appropriate services including a community care assessment. Commissioners to ensure that Swindon Advice and Support Centre has staff trained to offer appropriate advice and signposting.
- Ensure the Autism Directory of Services is incorporated into the Swindon My Care, My Support website.
- Autism Partnership Board members to work together to map existing voluntary and community information and advice and work with Commissioners across health and social care to scope with service users and carers the way their needs can be addressed to ensure that they continue to have access to information and advice, and peer networks which help them to feel in control of their lives and to maintain their independence and wellbeing.

## ***4. Transition planning and support for young people with autism as they prepare for adulthood.***

### CONTEXT

Transition to adulthood is a crucial stage in the lives of all young people, and a time when those with autism may face particular challenges as many find change difficult. Good transition support for children and young people with autism can have a profound impact on their ability to reach their potential, through access to further learning or training, employment and independent living.

The Children and Families Act 2014 provides for a new special educational needs and disability (SEND) support system, covering education, health and social care. Under the provisions of that Act, a young person (someone over compulsory school age and under 25) can ask the local authority to assess their Education, Health and Care (EHC) needs. Others, including schools and colleges, can also make such a request. This is with a view to an EHC plan being drawn up for the young person that sets out the special EHC provision required.

Most young people with autism are likely to have an education, health and care plan or an early help plan if they had additional needs and received support. However it is also important to consider those young people who are not receiving children's services and are likely to have care and support needs as an adult can be identified. Where individuals do not fulfil referral criteria for adult services, there should be clear signposting to other sources of support and information.

Swindon has a Transition Protocol and Local Offer in place which outlines services available for children and young people with special educational needs and disabilities (SEND) who are aged from 0 to 25 years. Findings from the Autism JSNA Bulletin and consultation with stakeholders highlighted the need to ensure that specific information and guidance is available for young people with autism and their parents, particularly those with Asperger Syndrome and high functioning autism. This should include help with facing and planning for adult life; specialist, and on-going employment support; peer support and opportunities to spend time with other with the same diagnosis; voluntary work placements in settings where autism was understood and accommodated.

### OUTCOMES

- All young people with autism are supported to think about, prepare, understand and plan what and where they want to be in the future.
- Young people with autism approaching transition are offered appropriate assessments through education and adult social care (based on national eligibility criteria) and carers are offered a carer's assessment.
- Sources of information and support are easily accessible to young people with autism who are preparing for adulthood and to everyone including those not eligible for adult social care. This should be part of the Local Offer on the Swindon My Care, My Support website.

## **PROPOSED ACTIONS**

- Autism Partnership Board members to work together to ensure information and support for young people with autism approaching adulthood is in place and that transition planning covers all relevant areas of service provision, including housing and employment support.
- Develop a transition pathway for all young people with autism preparing for adulthood including those not receiving children's services or with special educational needs and disability to support good transitions to adulthood.
- Ensure information about transition is easily accessible on the Swindon My Care, My Support website.

## **5. *Employment and learning opportunities for adults with autism***

### **CONTEXT**

Access to learning and appropriate employment opportunities can be highly beneficial for people's health and wellbeing. Many people with autism, like anyone else, want to work and have a variety of skills and talents that would be valued in a range of different workplaces yet nationally adults with autism are currently significantly under-represented in the labour market. The Swindon Adult Autism JSNA found that many people with autism experience difficulties in finding and maintaining sustainable employment and there was significant unmet need for employment support identified in the needs assessment.

It is important that employment is promoted as a positive outcome for those with autism including children and young people as part of transition planning. NICE Guidelines state that for adults with autism without a learning disability or with a mild learning disability, who are having difficulty obtaining or maintaining employment an individual supported employment programme should be considered. It is therefore essential that this kind of support is available locally.

Qualifications don't always match aptitude and skills levels therefore vocational assessment is an important tool to use with people with autism. It is also important to acknowledge that for those individuals with a more severe learning disability and those with complex needs paid employment may not be the most appropriate outcome and alternative approaches to support them to be meaningfully occupied throughout the day are needed.

The Autism Partnership Board includes membership from Job Centre Plus and the local charity DASH which currently delivers an employment support project funded by a South West Community Foundation Grant. DASH as well as other community and voluntary organisations provide support to achieve outcomes related to meaningful occupation and reducing social isolation. There are opportunities for member agencies to work together both as employers and advocates to support adults with autism to find and maintain work or explore other ways to develop their interests in a way that enables them to be meaningfully occupied in something which they are interested in and enjoy.

### **OUTCOMES**

- Transition and the assessment and care planning process for adult needs for care and support considers participation in employment as a key outcome, if appropriate, and looks at the ways that any such needs may be met in a way which could support adults with autism to become 'work ready'.
- There is a wide range of employment opportunities for people with autism in Swindon and a range of employment services and support in Swindon that can be accessed by people with autism. Those for whom paid employment is not appropriate have support to identify alternative opportunities for meaningful occupation.
- Employers and employment agencies in Swindon have an awareness and understanding of autism and are able to make reasonable adjustments for people with autism in recruitment processes and employment arrangements.

## **PROPOSED ACTIONS**

- Work with local employers, colleges and support services to ensure that there are employment opportunities for people with autism in Swindon and that appropriate support is available to help people with autism to find and keep a job.
- Autism Partnership Board member agencies to identify ways in which they as employers lead the way in recognising the value of employing people with autism and by actively recruiting and employing more people with autism
- Promote access to guidance and training for employers and employment support services about autism and employing people with autism.

## **6. *Working with the criminal justice system***

### **CONTEXT**

People with autism need access to support whether they are a victim, or witness, or are suspected of committing a crime. There is no evidence of a higher rate of offending amongst people with autism; however, there may be under-diagnosis of autism amongst people in the criminal justice system, and the social difficulties of people with autism may make them both vulnerable to becoming victims of crime and, sometimes, perpetrators.

Local authorities, NHS bodies and voluntary organisations can play a key role in supporting adults with autism who come into contact with the criminal justice system. Police, probation services, courts and prisons should be supported so that they are aware of the communication challenges experienced by people with autism. There is a need for the criminal justice system to refer people with autism for appropriate health and care support to divert them from offending, where appropriate, and prevent re-offending.

Members of the Autism Partnership Board should work with the Community Safety Partnership and the criminal justice system to achieve this. Both Wiltshire Police and the probation service are represented on the Swindon Adult Autism Partnership Board. There has been support from the Police and Crime Commissioner for Swindon & Wiltshire, to support individuals with autism at risk of anti-social and offending behaviour and/or in contact with the Criminal Justice System (CJS) through funding of training and awareness raising. The Wiltshire Autism Alert Card has also proved useful to some people with autism in contact with the criminal justice system.

### **OUTCOMES**

- Swindon's Community Safety Partnership recognises autism as a priority and there are established relationships between the Autism Partnership Board and the Swindon Community Safety Partnership which support the Autism Strategy.
- Those working in the criminal justice system who come into contact with adults with autism are aware of autism and know how to recognise it.
- Those working in the criminal justice system make reasonable adjustments for autism and when appropriate refer people with autism to health and care support to divert them from offending, where appropriate, and prevent re-offending

### **PROPOSED ACTIONS**

- Ensure appropriate representation from the criminal justice system on the Swindon Adult Autism Partnership Board.
- Establish relationships with the Swindon Community Safety Partnerships in order to bring agencies together to develop plans to support the Autism Strategy.
- Consider training needs of local police and criminal justice agencies as part of wider training needs assessment and consider undertaking some joint training with police forces and criminal justice services working with people with autism.

## **7. Housing and support to live independently**

Good housing can play a vital role in supporting people with autism to maintain good health, independence and improve quality of life. The Swindon JSNA process highlighted a gap in knowledge about the housing needs of people with autism. Experience of those working with this group is that many have on-going problems with finding suitable accommodation and that those currently living with their parents may have housing needs in the future when parents are no longer able to manage.

There is a need to ensure that all adults with autism are supported to live as independently as they are able and have choice and control over where they live and with whom. Housing needs should be considered as part of the transition process and in all assessments, and insight and data collected in a way that can be used to inform housing strategy and planning.

### **OUTCOMES**

- The housing needs of adults with autism in Swindon are well understood and housing strategy and planning is informed by local evidence of need.
- All adults with autism in Swindon are supported to live as independently as they are able and have choice and control over where they live and with whom
- Those undertaking assessment for young people and adults with autism have the training to support assessment of housing needs and are able to offer appropriate advice and support.

### **PROPOSED ACTIONS**

- Develop work to assess and understand better the housing needs of people with autism in Swindon.
- Identify ways of working with Swindon housing teams to inform plans for housing that supports people with autism to live independently.

Develop staff training and pathways to support people with autism to access information and support about housing.

## **8. Governance and Monitoring of the Strategy**

This is the strategy of the Swindon Adult Autism Partnership Board and is thus a multi-agency strategy to which all member agencies have contributed. The Autism Partnership Board will be responsible for ensuring that the priorities identified in the Strategy are implemented through an Action Plan.

The Swindon Adult Autism Partnership Board was established to bring together key organisations and representatives of people with autism and their carers. The terms of reference for the Board set-out appropriate governance arrangements to take this strategy forward. Since the Adult Autism Partnership Board spans adult health and social care services it will report to the Joint Commissioning Board for Swindon Borough Council and Swindon Clinical Commissioning Group and then to the Health and Wellbeing Board

The Swindon Adult Autism Partnership Board will meet every three months. Sub-groups will be formed as required to work on specific work areas in-line with the strategy and action plan. They will report to the full Partnership Board as necessary.

## **9. Summary of Intent**

The Swindon Adult Autism Strategy is intended to focus on local needs whilst incorporating best practice and national strategy and guidelines. This includes raising awareness and improving understanding of autism amongst professionals and the public; ensuring that the right support for people with autism in Swindon is available at the right time during their life time including in the transition from childhood to

adulthood; and that all adults with autism in Swindon have the opportunities for education and employment and housing they need to enable them to live as independently as they can.

Together the priorities and proposed actions outlined will help all adults with autism in Swindon to live fulfilling and rewarding lives within a society that accepts and understands them.

Once the strategy is approved an action plan outlining actions to achieve these goals will be set out by the Autism Partnership Board. This plan will include key milestones and outcome measures, and will outline any necessary business cases for consideration to deliver the actions.

DRAFT



# **Swindon Adult Autism Partnership Board**

## **Terms of Reference**

### **1. Background**

The National Autism Strategy and statutory guidance published in 2010 set out that every local area is expected to have an Autism Partnership Board (APB) in place or a similar mechanism to ensure that all relevant stakeholders, including people with autism and their families and senior commissioners of health and care services help identify local need and plan appropriate services and support.

The need for strong local partnership working with people with autism and their families was reiterated in *Think Autism*, an update to the strategy for adults with autism in England published in April 2014 and in the updated statutory guidance.

### **2. Purpose of the Group**

The purpose of the Swindon Adult Autism Partnership Board is to provide a forum for all stakeholders with an interest in autism in Swindon, including people with autism and their families, commissioners and providers of health and care services, and community and voluntary sector organisations to come together to help identify local need and work together to in the planning and delivery of appropriate services and support for people with autism in Swindon.

### **3. Objectives**

The objectives of the Swindon Adult Autism Partnership Board are to:

- Contribute to the development and endorse an Autism Strategy for Swindon in-line with the National Autism Strategy.
- Work with commissioning leads to develop and implement an annual action plan with clear objectives and milestones for delivery in-line with the Autism Strategy for Swindon and the National Autism Strategy.
- Support and advise all stakeholders on the implementation of the Autism Strategy for Swindon and the National Autism Strategy and regularly review progress towards the annual action plan.
- Promote joint working and service improvement through sharing resources and expertise and local and national examples of good practice.
- Raise awareness and understanding of issues affecting people on the autistic spectrum.
- Encourage new and innovative ways to support all adults in Swindon with autism to live fulfilling and rewarding lives within a society that accepts and understands them.

### **4. Accountability/ Governance**

The Swindon Adult Autism Partnership Board will span adult health and social care services and will therefore report to the Joint Commissioning Board for Swindon Borough Council and Swindon Clinical Commissioning Group.

## **5. Membership**

Membership of the Autism Partnership Board will include:

- Local people with autism from across the spectrum (up to 3 members)
- Local people who have experience of caring for someone on the autism spectrum (up to 3 members)
- Elected member with an interest in autism
- Lead Commissioner for adult autism for Swindon (SCB/CCG)
- Professional Lead for Autism, SEQOL
- Local GP with interest in autism
- Healthwatch Swindon
- Representatives from commissioned service providers including:
  - Autism Diagnostic Service
  - LIFT Psychology
  - Social Care
- Representatives from the community and voluntary sector including:
  - National Autistic Society, Swindon Branch
  - DASH (Discovering Autistic Spectrum Happiness)
  - SAM (Swindon Advocacy Movement)
- Representatives from Criminal Justice Service (when required)
- Representatives from employment services e.g. Job Centre Plus (when required)
- Representatives from education e.g. New College, Swindon

## **6. Meeting arrangements**

The Swindon Adult Autism Partnership Board will meet every three months. Additional meetings will be held if necessary. Sub-groups may be formed as required to work on specific projects. They will report to the full Partnership Board as necessary. Subgroup meetings will be held at appropriate intervals.

Meeting Chair to be agreed by the Autism Partnership Board and reviewed annually.

The Swindon Adult Autism Strategy and annual implementation plan will form the basis of the agenda for meetings. Standing agenda items will include:

- Welcome, introductions and apologies
- Notes from the last meeting
- Review of progress against implementation plan
- Member agency updates

Additionally, the Autism Partnership Board may invite subject experts to provide updates and presentations on specialist subject areas.

## **7. Review Arrangements**

These terms of reference will be reviewed annually by the Autism Partnership Board.

Draft v1 27 August 2014

Draft v2 29<sup>th</sup> January 2015

Draft v3 8<sup>th</sup> June 2015

Approved: July 2015

Next review: July 2016