

**SHROPSHIRE**

**ADULTS  
AUTISM  
STRATEGY**

**2012 - 2015**

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## 1. EXECUTIVE SUMMARY

### a. Context

This strategy covers Shropshire local authority area and has been written in response to the Autism Act 2009 and the national adult autism strategy 'Fulfilling and Rewarding Lives' which was published in March 2010.

The national strategy focuses on five core areas of activity:

- ✓ Increasing awareness and understanding of autism among frontline professionals
- ✓ Developing a clear, consistent pathway for diagnosis in every area
- ✓ Improved access to the services and support which adults with autism need to live independently within the community
- ✓ Helping adults with autism into work
- ✓ Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities

The Shropshire Strategy has been prepared with the aim of addressing these objectives.

### b. The Shropshire Goals and Action Plan

Five priority areas have been identified:

- ✓ Training of staff who provide services to people with autism
- ✓ Data collection and identification of adults with autism and assessment of needs for relevant services
- ✓ Development of a care pathway for Shropshire
- ✓ Transition planning in relation to people with autism moving from children's services to adults
- ✓ Local planning and leadership in relation to the provision of services for adults with autism (including transition)

The actions needed to achieve these goals are set out in the action plan at the end of the document in section 11.

c. Staffordshire, Stoke-on-Trent, Shropshire and Telford and Wrekin Adult Autism Partnership Board

This Adult Autism Partnership Board has been established to develop and produce the local overarching autism strategy and lead the planning and implementation of the local delivery plan.

The Board is responsible for overseeing the commissioning, planning and provision of autism services across the County which also includes low level preventative services.

Stoke-on-Trent, Staffordshire and Telford and Wrekin are part of the Board as we commission services from some of the same providers: Shropshire commission mental health and learning disabilities services along with Staffordshire through South Staffordshire and Shropshire Healthcare NHS Foundation Trust. Having a joint Board provides a basis for partnership working, sharing of ideas and information and an excellent model for joint commissioning.

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## 2. INTRODUCTION

This strategy has been developed by Shropshire, Staffordshire, Stoke-on-Trent and Telford and Wrekin Partnership Board. Its purpose is to provide the strategic direction for statutory health and social care organisations in Shropshire with regards to supporting adults and young people with an Autistic Spectrum Condition.

*(NB: This strategy replaces the draft Shropshire Adult Autism Strategy 2010 – 2013, in order to respond to the significant changes that have taken place in financial and structural context across health and social care, both in statutory and voluntary sector services.)*

The document sets out:

- ✓ The objectives and outcomes for the Autism services in Shropshire in line with the National Autism Strategy published in April 2010, national guidance published in December 2010 and the Essential Outcomes Framework published in April 2011.
- ✓ Includes an action plan of how the work programme will be taken forward over the next three years.
- ✓ Considers the national and local drivers, prevalence statistics and stakeholders who need to be involved in the development work.
- ✓ Provides a framework of how we want to monitor and evidence service quality to ensure that it will support the achievement of national and key local targets and performance indicators.

### a. What is Autism?

In this strategy we recognise that there are a number of terms that different individuals and groups prefer to use for recognising autism. In this strategy we use the term 'autism' as an umbrella term for all the terms listed below:

- Autistic Spectrum Disorder (ASD)
- Autistic Spectrum Conditions (ASC)
- Asperger Syndrome
- Autistic Spectrum Difference
- Neuro-diversity

Autism is a lifelong condition that affects how a person communicates with and relates to other people. It also affects how a person makes sense of the world around them. The word "spectrum" is used because the characteristics of the condition vary from one person to another.

Autism is a lifelong developmental disability which affects social interaction, communication, social relationships and making sense of the world.

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

- ✓ Social communication, which includes understanding facial expressions and body language, tone of voice and giving and receiving verbal and non verbal communication
- ✓ Social interaction – recognising or understanding other people's emotions and feelings and expressing their own
- ✓ Social imagination – understanding and predicting other people's behaviour, making sense of abstract ideas and imagining solutions outside of their own routines

However people struggle in different ways depending on how autism affects them.

Many people with autism may also experience some form of sensory sensitivity or under-sensitivity to sounds, touch, taste, light or colours and often prefer to have a fixed routine.

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### **3. WHY DO WE NEED A STRATEGY?**

#### **a. National Context**

During the last few years there has been a strong message from Central Government and people within the autism communities that there is a need for local services to meet the needs of adults and young people with autism. There is now a requirement that local commissioners will commission and local providers will provide such services in readiness to comply with the law.

#### **Key events and dates:**

- ✓ November 2006 – ‘Better services for people with an autistic spectrum disorder’
- ✓ 2009 – Valuing People Now
- ✓ June 2009 – Supporting People with Autism through Adulthood, National Audit Office
- ✓ 12<sup>th</sup> November 2009 – Autism Act
- ✓ 3<sup>rd</sup> March 2010 – Department of Health publish Adult Autism Strategy ‘Fulfilling and Rewarding Lives’
- ✓ July 2010 – National Institute Clinical Excellence (NICE) begin to work to develop a clinical guide for Autism in Adults
- ✓ December 2010 – Statutory guidance published for Local Authorities and NHS organisations to support the implementation of the Autism Strategy
- ✓ The Standard Contract for Mental Health and Learning Disabilities for 2010/2011 explicitly requires service providers to explain how reasonable adjustments for people with autism are made
- ✓ April 2011 – ‘Fulfilling and Rewarding Lives’ Evaluating Progress Essential Outcomes Framework published
- ✓ By 2013 there will be a pathway to diagnosis in every local area

#### **A Summary of Key Themes from the Autism Strategy**

##### The ‘must do’s’

- ✓ Improve access for adults with autism to the services and support they need to live and work as independently as possible within their community
- ✓ By 2013 – a clear commissioned multi-agency pathway to diagnosis in every area
- ✓ Local appointment of a senior professional lead on the development of pathway and to develop a local diagnostic and assessment service
- ✓ Standard contract for Mental Health and Learning Disabilities for 2010/2011 explicitly requires explanation of how ‘reasonable adjustments’ will be made

- ✓ Local partners to develop a local commissioning plan for services for adults with autism
- ✓ Consider the establishment of local autism partnership boards
- ✓ Carers to be involved in the planning

The document makes reference to best practice, particularly the need to:

- ✓ Increase awareness and understanding of autism
- ✓ Develop a clear, consistent pathway of diagnosis of autism
- ✓ Help adults with autism to gain a sustainable lifestyle which includes maintaining work and suitable accommodation
- ✓ Enabling local partners to develop and maintain relevant services for adults with autism to meet identified needs and priorities
- ✓ Greater involvement of clients, parents, carers and partners of, personal assistants and interpreters

National Indicators:

- ✓ Carers to be seen as expert partners
- ✓ NICE developing guidelines on model care pathways – published 2012
- ✓ Lead professional to ‘get on with’ examining existing services, to change to be in good position to act on NICE guidelines

#### b. The Local Context

While national drivers have set the scene for how organisations should progress, all local statutory organisations are operating in a fluid local environment, which is beginning to offer opportunities to review our service delivery systems.

Historically, services have developed disparately and unevenly across the local health economy, which has led to inconsistencies in the services that users might expect and physical surroundings which are not fit for purpose. All the factors above provided possibilities to re-look and redesign how services might be delivered in the future. We would wish to see a range of outcomes from re-designed service models:

- ✓ A truly user and carer led service
- ✓ Locally rooted services with care closer to home



- ✓ Services that offer early recognition and intervention, that encourage and maintain independence
- ✓ A review of the workforce skill base
- ✓ Development of training programmes for staff to enable them to deliver high quality, effective services

Shropshire, Staffordshire, Stoke-on-Trent and Telford and Wrekin statutory organisations are committed to working together to improve services for people with autism and their carers. The care pathway will be drawn up to include provision of support and prevention for all people with autism, and recognise the greatest area of unmet need which is support for autistic people without learning disabilities.

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#### **4. KEY PRIORITIES**

The strategy document includes key priorities for action to address service gaps. It is about adults who fit the definitions of autism and young people over the age of 14.

It includes specific services commissioned and mainstream services such as leisure, housing and education. The strategy and action plan reflects the four key themes of the national autism document 'Fulfilling and Rewarding Lives'.

- ✓ Training of staff who provide services for people with autism
- ✓ Identification and diagnosis of autism in adults
- ✓ Planning in relation to the provision of services to people with autism as they move from children to adults
- ✓ Local planning and leadership in relation to the provision of services for adults with autism.

The strategy sets out specific key actions to improve these services and promote choice and inclusion for people with autism.

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## 5. AIMS OF THE STRATEGY

The aims of the autism strategy are to:

- ✓ Ensure a planned and open approach to commissioning of services for people with autism making use of information about demand, unmet needs/service gaps, resources and the voluntary sector.
- ✓ Ensure that services are centred on people's needs and family carers.
- ✓ Ensure a transparent relationship with stakeholders in the commissioning and provision of services.
- ✓ Provide direction and structure for both Health and Social Care provision within Shropshire and for other mainstream services such as Housing, Leisure, Education, Training and Employment.
- ✓ Continue to review service requirements identified through the Joint Strategic Needs Assessment with due regard to available resources and the need to work within existing budgets for the main Stakeholder organisations.

## 6. STAKEHOLDERS

The Stakeholders in this strategy are:

- ✓ Any adults of 18 years of age and over with autism living in Shropshire
- ✓ Carers and family members of adults with autism
- ✓ Shropshire Social Care and Health
- ✓ Shropshire Primary Care Trust & Clinical Commissioning Group
- ✓ South Staffordshire and Shropshire Healthcare NHS Foundation Trust
- ✓ Advocacy services
- ✓ Providers of day time activities and education
  - Local Authority
  - 3<sup>rd</sup> sector services
  - Voluntary Services
  - Supported employment providers
- ✓ Police, Probation, Prison Service and Criminal Justice System
- ✓ Housing Providers
- ✓ Leisure services
- ✓ Carers Support Services
- ✓ Prison Service
- ✓ Criminal Justice
- ✓ Disability Employment Advisors (DEA's), Employment Support Providers and Employers

## 7. PREVALENCE DATA

It is estimated that autism affects 1 in every 100 adults. The estimated numbers have been worked out from the population of the UK as given in the 2011 census 58,789,194 of whom 13,354,297 were under 18.

Literature on the provision of services for people with autism repeatedly states that statutory organisations do not collect data on many people they are providing for or how many live in the catchment area.

Estimates of the proportion of people with autism who have a learning disability (IQ less than 70) vary considerably and it is not possible to give an accurate figure. It is likely that over 70% of those with autism have an IQ in the average to high range and a proportion of these will be very able intellectually.

### Prevalence in Shropshire

The Joint Strategic Needs Assessment document, February 2009 quotes the following prevalence data for autism:

**Table 8.3: People aged 18-64 years old projected to have autistic spectrum disorders in Shropshire**

	<b>2008</b>	<b>2010</b>	<b>2015</b>	<b>2020</b>	<b>2025</b>
18-24	220	229	225	210	207
25-34	267	269	304	323	313
35-44	419	399	338	326	366
45-54	410	429	462	436	376
55-64	422	420	411	454	490
Total	1,738	1,746	1,740	1,749	1,752

*Source: Based on the report 'Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)', Baird, G. et al, The Lancet, 368 (9531), pp. 210-215, 2006, National Statistics population projections 2006, projections produced by Projecting Adult Needs and Service Information System (PANSI) www.pansi.org.uk Crown Copyright, 2007.*

The Shropshire Children & Young People Autism Steering group identified that there were approximately 120 children from 0 – 18 being supported by the CAMHS-LD team, with an Autism diagnosis and the Consultant Paediatrician supporting between 400 – 500 children and young people with a diagnosis or autistic traits.

The Shropshire Joint Strategic Needs Assessment is currently being refreshed. It will become a more interactive and evolving tool, with a much broader scope so that qualitative data from a wider range of sources, including local stakeholders and services can be captured, as well as hard quantitative data. A first stage version is due to go live in the next month. It is recognised that more work needs to be carried out locally to improve the collection of data around people with autism which can then be fed in to the JSNA to gain a more complete picture. Improved information about the numbers of adults in the area will enable better local service planning within health and social care

## **8. OBJECTIVES FROM THE NATIONAL STRATEGY**

In no particular order:

### **Objective 1 - Make sure people can get a diagnosis if they want one**

Currently there is no defined diagnostic pathway in Shropshire once an individual reaches 16 or leaves school. A referral for a diagnosis, usually at the request of the individual or their parents, will depend on where you live, how knowledgeable a GP is about autism, the determination of the individual, parents or carer to pursue a diagnosis or their means to pay for private consultation.

For some people with an undiagnosed condition of autism, the desire to have a formal diagnosis is very important. It can begin to answer many questions and assist them in beginning to understand why they behave, react and respond to situations in the way that they do and to develop coping strategies.

Without a formal diagnosis, individuals have difficulty in accessing welfare benefits or support.

### **Objective 2 - The identification of adults with autism**

Key staff working across stakeholder groups receive basic training to more accurately identify potential signs of autism in adults and are able to adapt their behaviour and communication as appropriate.

### **Objective 3 - The assessment of the needs of adults with autism for relevant services**

Diagnosis or identification of autism is not enough; the most important outcome is that, where appropriate for the individual and carer, a diagnosis leads to an assessment for care and support and/or signposting to other relevant services or support. Diagnosis of autism should also be recognised as a catalyst for a carer's assessment.

### **Objective 4 - Planning in relation to the provision of relevant services to people with autism as they move from being children to adults**

Effective transition planning will ensure that support remains in place once people with autism reach adulthood as appropriate to the individual.

Effective transition planning should include career preparation up to age 16 and plans for education, employment, training, transport, housing and leisure from 16 to 19 and beyond. Crucially transition plans should be individually tailored to the needs and wishes of the individual young person and reviewed and updated each year. If an individual has a Special Educational Needs statement then we will work with them up until they are 24 years of age.

**Objective 5 - Other planning in relation to the provision of services to adults with autism**

This objective ensures appropriate planning of services for adults with autism ranging from locally based community services through to the provision of specialist or dedicated autism services, and including access to universal services.

**Objective 6 - The training of staff who provide services to people with autism**

Our objective is to ensure that training around autism is provided to all public service staff. This includes not only general autism awareness training, but also refresher and highly specialised training for staff and carers in a range of roles that wish to develop their knowledge of autism. This will also be available for staff to continue their professional development.

**Objective 7 - Local arrangements for leadership in relation to the provision of services to adults with autism**

Our objective is to ensure there is effective leadership that ensures that the needs of adults with autism in Shropshire are met.

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## 9. CURRENT SERVICE PROVISION

At the present time some people with autism are receiving a range of services in various settings. However, it is difficult to come to an accurate picture of exactly how many people with autism are using which service. To date there has been no statutory or performance indicator requirement to keep this data.

Currently in Shropshire there are no statutory services specifically for people with autism.

To identify current services we are reliant on the use of prevalence rates applied to overall service provision.

As detailed in Section 7 of this strategy, applying national prevalence rates to the population indicates that we would be expecting there to be around 1,746 adults with some form of autism in Shropshire. However, we would not necessarily expect all of these people to be accessing statutory services for a variety of reasons, for example some will not meet criteria for services.

Given that there is not a specific statutory service catering for people with autism, we can expect that this client group will be present in a number of mainstream services:

- ✓ Caseloads of learning disability social workers
- ✓ Caseloads of mental health social workers
- ✓ People within services provided by the two specialist Mental Health and Learning Disability Provider Trusts
- ✓ Caseloads of Consultant Psychologists/Psychiatrists
- ✓ Attending learning disability day services
- ✓ Attending mental health day services
- ✓ Short break and respite services
- ✓ Living in independent sector residential and nursing homes
- ✓ Living in supported tenancy schemes
- ✓ Third sector provision

This is not an exhaustive list and does not take into account the accessing of housing, supporting people, leisure or educational/training services by people with autism. It is also recognised that some people will not be known to any service.



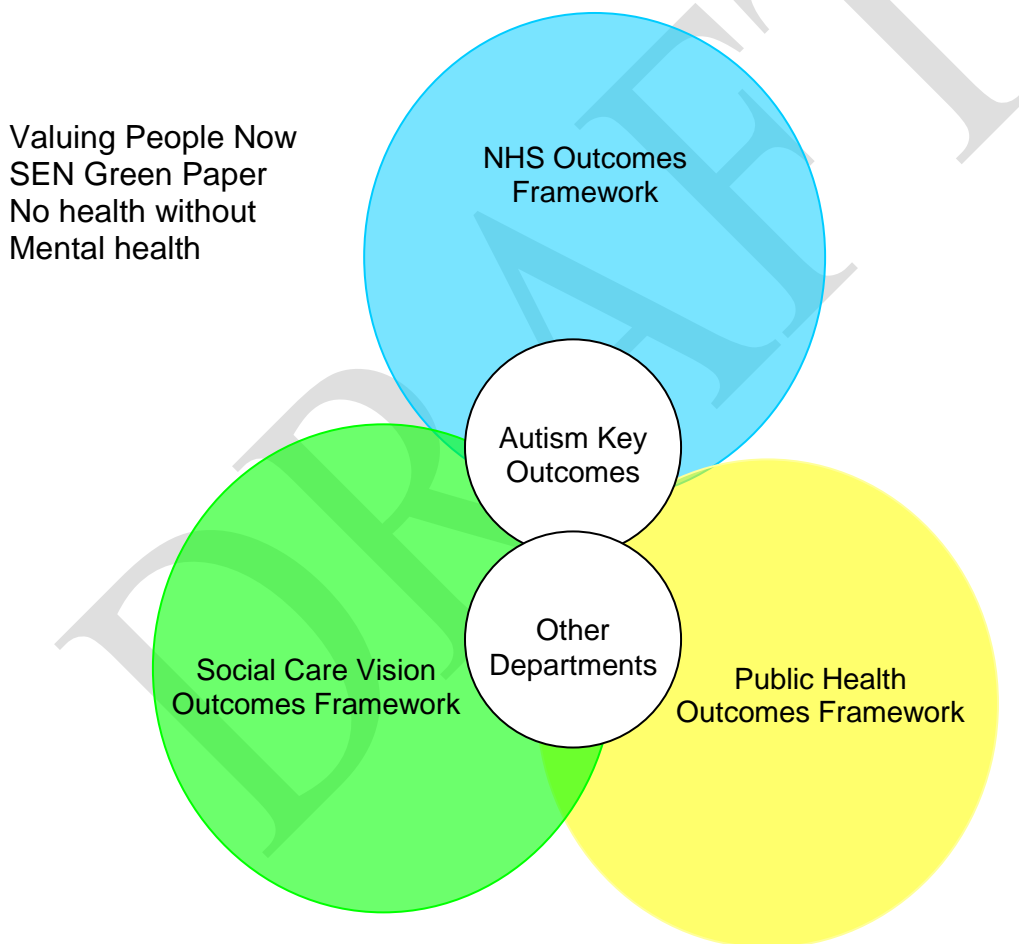
## 10. MONITORING AND REVIEW

The Adult Autism Partnership Board will have overall responsibility for monitoring and reviewing the strategy on an annual basis and will update the rolling action plan accordingly. The Board will have meaning, be productive and worthwhile. It will have objectives and outcomes which need to be achieved.

In line with the document launched in April 2011, 'Evaluating Progress'; we are committed to a clear focus on and transparent approach to outcomes.

The diagram below highlights how the outcomes frameworks align with each other and other national policies/initiatives.

From targets to outcomes – aligning the outcomes frameworks:



In the 'Fulfilling and Rewarding Lives' Evaluating Progress released on 1<sup>st</sup> April 2011 provides guidance on measuring progress towards implementation after one year for the following seven areas:

- ✓ Adults with autism achieve better health outcomes
- ✓ Adults with autism are included and economically active
- ✓ Adults with autism are living in accommodation that meets their needs
- ✓ Adults with autism are benefiting from the personalisation agenda in health and social care, and can access personal budgets
- ✓ Adults with autism are no longer managed inappropriately in the criminal justice system
- ✓ Adults with autism, their families and carers are satisfied with local services
- ✓ Adults with autism are involved in service planning

Shropshire will work towards these outcomes listed above to make a difference to the lives of adults with autism, their families and carers. We will also embrace the following three key ambitions:

- ✓ Local authorities and partners know how many adults with autism live in the area
- ✓ A clear and trusted diagnostic pathway is available locally
- ✓ Health and social care staff make adequate adjustments to services to meet the needs of adults with autism

Monitoring of progress will be in line with the Self assessment framework 'Essential Quality Outcomes for local self assessment'.

## **11. AUTISM STRATEGY IMPLEMENTATION PLAN**

The plan is included at Section 12 and progress will be regularly tracked through monitoring. There is a need to focus on building capacity and capability at local level to enable local partners to develop relevant services for adults with autism to meet identified needs and priorities and the local area therefore also needs to develop its own commissioning plan for services for adults with autism.

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## 12. AUTISM STRATEGY ACTION PLAN

### Section 1 – Training of staff who provide services to adults autism

	<b>Action</b>	<b>Lead</b>	<b>Target Date</b>
1.1	Establish Autism Training Sub Group with reps from Social Care and Health to agree work programme	Autism Lead & Training Leads from Joint Training	March 2012
1.2	Review Department of Health on line materials and local programmes to identify best practice	Autism Training Sub Group	July 2012
1.3	Undertake mapping exercise across organisations about training carried out	Autism Training Sub Group	July 2012
1.4	Develop a training plan for implementing dependent on care pathway development, agreement and rollout	Autism Training Sub Group	September 2012
1.5	Agree content of Autism awareness training	Autism Training Sub Group	March 2013
1.6	Identify key priority groups for training	Autism Training Sub Group	March 2013
1.8	Agree content of specialist training and who should receive it	Autism Training Sub Group	April 2013

## Section 2 – Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services

	<b>Action</b>	<b>Lead</b>	<b>Target Date</b>
2.1	Organise a countywide workshop to map out a model care pathway for Shropshire	Autism Partnership Board	May 2012
2.2	Review existing best practice and other models across the country.	Autism Partnership Board	July 2012
2.3	Each LA should appoint a lead professional to develop diagnostic and assessment services for adults with autism in their area. Agree where this responsibility should rest. Consider interface with the proposed West Midlands diagnostic and Support Centre (SPAAARC).	Autism Partnership Board	November 2012
2.4	Await NICE guidance and review local model against this.	Autism Partnership Board	July 2013
2.5	Work with NHS and LA partners to ensure sign up to local Care Pathway across organisations and consider the effects of potential care cut-backs and reorganisation.	Autism Partnership Board	July 2013
2.6	Inform statutory organisations about the pathway – Social Care & Health, Health, 3 <sup>rd</sup> Sector	Autism Partnership Board	September 2013

**Section 3 – Planning in relation to the provision of services to people with autism as they move from children to adults**

	<b>Action</b>	<b>Lead</b>	<b>Target Date</b>
3.1	Work with Shropshire 0 – 25 group to ensure that revised Transition Protocol reflects the needs of people on the autistic spectrum	Autism Lead Officer	November 2012
3.2	Work with Autistic Spectrum Disorder Children’s groups to ensure feedback mechanisms in place around transition planning	Autism Lead Officer	November 2012
3.3	Work and share information with Shropshire 0 – 25 group.	Autism Lead Officer	November 2012
3.4	Collect data of young people in transition and provide an annual update		November 2012

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#### Section 4 – Local planning and leadership in relation to the provision of services for adults with autism

	<b>Action</b>	<b>Lead</b>	<b>Target Date</b>
4.1	Identify autism Commissioner leads in Staffordshire, Shropshire, Stoke On Trent and Telford and Wrekin.	Autism Partnership Board lead	May 2011 - Completed
4.2	Develop revised autism strategy and action plan	Autism Partnership Board	March 2012
4.3	Consult family carers, service users and local interest groups in autism planning as part of the strategy work	Autism Partnership Board	March – April 2012
4.4	Collect data on total numbers of people with autism through the Joint Strategic Needs refresh	Public Health and the CareFirst data collection system	May 2012
4.5	Continue to raise wider public awareness and profile of autism across Shropshire	Autism Partnership Board	June 2013
4.6	Work with wider partners including Employment and Housing to raise awareness about support, advice and services available.	Autism Partnership Board	June 2013
4.7	All stakeholders make explicit their ability to make reasonable adjustments to support adults with autism	Autism Partnership Board	March 2013
4.8	Develop a local integrated commissioning plan for autism	Commissioners/ Director for Adult Social Care	September 2012
4.9	Consider the benefits and need for establishment of a specialist team / Hub for provision of low cost low level intervention, support and prevention	Autism Partnership Board	July 2012
4.10	Autism Lead to consider the work of the Shropshire and T&W Asperger	Autism Partnership	June 2012

	Housing /Hub steering group and explore and identify elements that are considered achievable within current resources	Board	
4.11	Make links with the Staffordshire Learning Disability Partnership Board Employment Sub Group.	Autism Partnership Board	January 2012 – completed

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### 13. GLOSSARY

NICE	National Institute of Clinical Excellence
SSSHFT	South Staffordshire and Shropshire NHS Healthcare Foundation Trust
LA	Local Authority

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