

# SHROPSHIRE ADULT AUTISM STRATEGY

2016 - 2020



### **CONTENTS**

VISION	3
INTRODUCTION	3
WHAT IS AUTISM?	4
BACKGROUND	5
STAKEHOLDERS	9
PREVALENCE DATA AND EVIDENCE	10
2012 – 2015 STRATEGY - WHAT HAVE WE ACHIEVED ALREADY?	13
MONITORING AND REVIEW	20
SHROPSHIRE AUTISM STRATEGY IMPLEMENTATION PLAN	21
GLOSSARY	31
APPENDICES	32

### VISION

In Shropshire we support the Government's vision that:

'All adults with Autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat then fairly as individuals, helping them make the most of their talents'

(Department of health, 2010, Fulfilling and rewarding lives; the strategy for adults with autism in England and Think Autism 2014.)

### INTRODUCTION

This strategy has been developed by Shropshire Autism 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.

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

(NB: This strategy replaces the draft Shropshire Adult Autism Strategy 2012 – 2015, in order to respond to the work that has already been carried out and to the updates in strategy and guidance since that was written.)

### The document sets out:

- The objectives and outcomes for the Autism services in Shropshire in line with Think Autism and the statutory guidance issued by the DoH in March 2015.
- Considers the national and local drivers, prevalence statistics and stakeholders who need to be involved in this work.
- The achievements in Shropshire from the previous 3year strategy.
- Includes an action plan of how the work programme will be taken forward over the next four years.
- 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.

### 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 was first recognised as a distinct condition in the 1940's. Since then research has improved our understanding of the condition and numerous theories have been put forward as to its causation, including theories about genetic links, but as yet no definitive cause has been found and there is no cure. The national autism strategy for adults **Fulfilling and Rewarding Lives 2010 1** defined autism as:

"...a lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them".

Autism is known as a spectrum condition because of both the range of difficulties that affect people with autism and the way it presents in different people. In the 1970's the symptoms were described as a triad of impairments (Wing 1976):
□ Social communication, e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice
<ul> <li>Social interaction, e.g. problems in recognising and understanding other people's feelings and managing their own</li> </ul>
<ul> <li>Social imagination, e.g. problems in understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine.</li> </ul>
In the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychological Association), the triad was reduced to two core dimensions:
□ Social communication difficulties, which incorporates both communication and social interaction as these are intertwined.
☐ Strongly repetitive behaviour (e.g. difficulties in adapting to change and unusually narrow interest).

In addition, people with autism may experience some form of sensory sensitivity or under-sensitivity to sounds, touch, tastes, smells, light or colours; they often prefer to have a fixed routine and can find change difficult to cope with. However every person's experience of autism is unique to each individual who will have a range of strengths as well as needs.

Asperger's Syndrome is also a form of autistic spectrum disorder affecting people of average or above-average intelligence, who typically have fewer problems with speaking than others on the autistic spectrum; but do still have significant needs that can be masked by their ability to speak fluently. People with autism are often stigmatized and this can cause barriers in accessing services.

### **BACKGROUND**

In **2010** the government published a national strategy for autism entitled **Fulfilling** and **Rewarding Lives**. A draft strategy was developed for Shropshire which outlined the key priorities for achieving the changes locally that were needed, so that people with an autistic spectrum condition have access to the opportunities, support and services to enable them to live a full and rewarding life. The Shropshire strategy was also available as a summary in Easy Read version.

In **April 2014** the government published **Think Autism**, an update to the National Strategy published in 2010. This update was produced as a result of major changes to many parts of the system since the 2009 Autism Act and the 2010 Autism Strategy as part of the programme right across Government to reform public services.

In **March 2015** the department of Health issued Statutory guidance for Local Authorities and NHS organisations to support implementation of the adult autism strategy.

This updated local strategy covers the Shropshire Council / Shropshire CCG (Clinical commissioning group) local authority area and has been written in response to these updates and developments.

Think Autism focuses on 15 Priority challenges for action and these challenges form the basis of the Shropshire strategy for 2016 – 2020.

These action points have been determined by individuals with autism, their families and professionals. They formulate the key areas to be worked upon moving forward.

The priorities are:

### 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.

The actions needed to continue and to work towards fully achieving all these goals are set out in the action plan at the end of the document.

Running in tandem with this strategy will be the **Transforming Care Plan for Shropshire.** This is the local response to 'Building the Right Support' (October 2015, a service model for commissioners of health and social services, DOH).

'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'

The Transforming Care Partnership (TCP) is for people with a learning disability and/or autism who may present with behaviours which can challenge and may include mental health issues. The TCP Programme is endorsed by NHS England, ADASS and LGA. It runs from July 2016 – 31st March 2019

### Building the right support -

A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition" was published on 30 October 2015 and requires local authorities and NHS bodies to deliver against Transforming Care Partnership implementation plans from 1 April 2016.

In summary, the TCP is progressing work from the original 'Winterbourne View' situation, where people with learning disability and/or autism and behaviours which may challenge were neglected and abused. NHS England acknowledged that individuals should not live in hospital environments. Thus, at a national level TCP is intended to reduce the number of beds provided across the country overall and ensure that when placements occur, the average length of stay is reduced to 85 days.

Each area of the country is required to devise and implement a plan to reduce the numbers of people with learning disability and/or Autism, including those with a mental health condition placed in out of area inpatient facilities due to displaying behaviour that challenges by putting in place the right support in local communities.

The Shropshire Transforming Care Partnership brings together Shropshire Council, Telford and Wrekin Council, Shropshire CCG and Telford and Wrekin CCG.

Work-streams include: Strategic communication, engagement with stakeholders; particularly families and carers, workforce development, housing/accommodation and the system service model.

### **STAKEHOLDERS**

'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'

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 Council Adult Social Care
- Shropshire CCG (Clinical Commissioning Group)
- SSSFT (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
- employers

The Shropshire Autism Partnership board is held on a quarterly basis and is attended by representatives from the Local authority, Shropshire CCG, SSSFT, Individuals with lived experience of Autism and Asperger's, Autonomy, NAS (National Autistic Society), AWM (Autism West Midlands), STACS (Shropshire and Telford Asperger Carer's Support) Adelphi, Bromford housing and the West Mercia Police equalities and diversity officer.

### PREVALENCE DATA AND EVIDENCE

'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'

The latest prevalence studies of autism indicate that 1.1% of the population in the UK may have autism. This means that over 695,000 people in the UK may have autism, an estimate derived from the 1.1% prevalence rate applied to the 2011 UK census figures.

Estimates of the proportion of people with autism who have a learning disability (IQ less than 70) vary considerably but It is estimated that between 31% and 35.4% of people with a learning disability (IQ less than 70) also have autism.

Applying national prevalence rates to the population indicates that we would be expecting there to be around 1,816 adults (18-65) 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.

This client group will be present in a number of mainstream services:

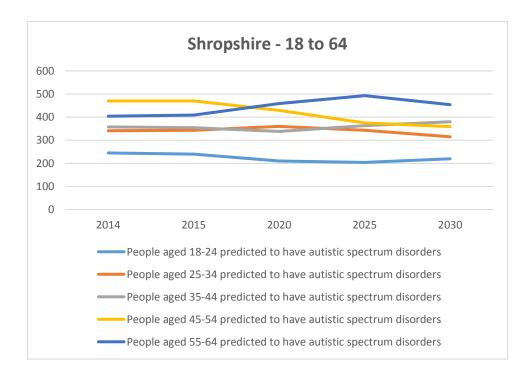
- ✓ Caseloads of learning disability social workers
- ✓ Caseloads of mental health social workers
- ✓ People within services provided by the two specialist Mental Health and Learning Disability Provider Trusts
- ✓ Caseloads of Consultant Psychologists/Psychiatrists
- ✓ Attending learning disability day 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 it is recognised that some people will not be known to any service.

### **Prevalence in Shropshire**

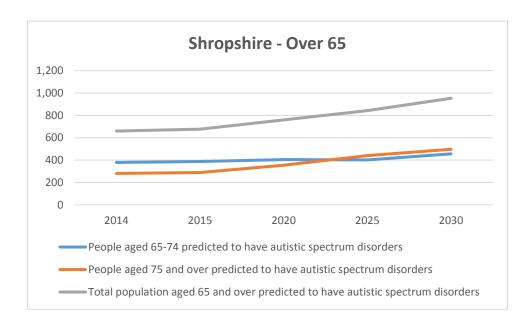
Shropshire: Autistic spectrum disorders - all people	2014	2015	2020	2025	2030
People aged 18-24 predicted to have autistic spectrum					
disorders	245	240	210	204	220
People aged 25-34 predicted to have autistic spectrum					
disorders	341	343	360	343	315
People aged 35-44 predicted to have autistic spectrum					
disorders	358	354	338	363	380
People aged 45-54 predicted to have autistic spectrum					
disorders	470	470	429	375	359
People aged 55-64 predicted to have autistic spectrum					
disorders	404	409	459	493	454
Total population aged 18-64 predicted to have autistic					
spectrum disorders	1,818	1,816	1,796	1,777	1,728

Shropshire: Autistic spectrum disorders - all people	2014	2015	2020	2025	2030
People aged 65-74 predicted to have autistic spectrum disorders	379	387	405	402	456
People aged 75 and over predicted to have autistic spectrum disorders	281	289	355	440	497
Total population aged 65 and over predicted to have autistic spectrum disorders	660	676	760	843	953



The percentage of adults (18-64) with ASD in Shropshire will fall by 2.1% by 2030 compared to 2014 whilst the England figure is predicted to rise to 3.9% by 2030.

For those people aged 55-64 ASD in Shropshire is predicted to rise by 3.1% in 2030 compared to England at 1.7% and the gap between Shropshire and England has increased from 4.5% in 2014 to 5.9% 2030.



There are 324 adults with autism classified as receiving a long term service funded by Adult social care in Shropshire as of April 2016. The Carefirst client information system now specifically identifies people with Autism receiving long term support.

The Shropshire Autism Needs assessment for Children and Young People aged 0 -25 identified that there were approximately 275 children with autistic traits from 0 - 18 being supported by the CAMHS (Child and Adolescent mental health services) team in autumn 2014.

See appendix 5 for the full report.

### 2012 - 2015 STRATEGY - WHAT HAVE WE ACHIEVED ALREADY?

In line with the updates and guidance from the National strategy we have undertaken a review of the Shropshire strategy to reflect what we have heard from people with autism, their families and other services.

Much work has been undertaken to deliver on Shropshire's strategy and the 15 priorities; we now need to take stock and move forward.

Many things have changed in key services over the last few years. Shropshire is increasingly becoming a commissioning authority and many new organisations make up the care and support marketplace.

### **Diagnostic Pathway**

'I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process'

We had a joint diagnostic and care pathway set up in 2014 by the SSSFT with support from the CCG and Shropshire Council which involved service user groups and other organisations in its development. Diagnosis was primarily accessed through GP referral but referrals were considered for assessment wherever Autism was a consideration. There were 2 strands to the diagnostic pathway and where it was clear that the individual also has a LD (learning disability), they will be referred through the Community Learning Disability Service Shropshire, Telford and Wrekin for assessment, diagnosis and on-going case management. For the majority where no significant Learning disability presents, referral was directed to the MH (Mental Health) arm of the pathway irrespective of the presence of co-morbid MH conditions. From here, there was an automatic option of referral into the autism hub.

The plan was that pre and post diagnostic support would be made available at the hub by SSSFT champions.

Before the recent inception of this diagnostic pathway everyone was diagnosed on the LD pathway.

Since the end of 2015 this pathway is no longer being commissioned by Shropshire CCG.

There have been complications to the locally delivered pathway and as such, there needs to be a redesign. Currently access is via spot purchase but is part of a temporary pathway. A working group, led by the CCG, including experts by experience, is being convened to ensure the new pathway best meets the needs of adults with suspected autism. Diagnosis is primarily accessed through GP referral but referrals will be considered for assessment wherever Autism is a consideration. Where it is clear that the individual also has a learning disability, they will be referred through the Community Learning Disability Service Shropshire, Telford and Wrekin for assessment, diagnosis and on-going case management.

### **Carers**

### 'I want to know that my family can get help and support when they need it'

STACs hold a carers support group each week which runs concurrently with the Hub.

Under the Care Act 2014 every carer is eligible for a carers assessment; these are carried out in Shropshire by workers from Shropshire Adult Social Care.

Carers Trust for all provide Carers support services, short carer breaks, Carer emergency response service and Young carers support.

The NAS, AWM and Autonomy support carers through their networks of advice and support.

### **Training and Development**

### 'I want staff in health and social care services to understand that I have autism and how this affects me'

We would expect that all Shropshire Council workers carrying out assessments under the Care Act will have received appropriate training.

Extensive training has taken place following a pathway developed for Adult Social Care workers – social workers, assistants and occupational Therapists and CMHT social workers by Shropshire Council Joint Training.

Currently SC Joint Training now offer a progressive range of courses. Experts by experience co-deliver all of these face to face. The training framework can be found in Appendix 1.

The Joint Training Unit is currently designing a further training package of increased specialist training to staff each frontline teams to enable them to be identified as the Autism Specialist within those teams. These will include any staff involved in running the Autism hub.

Some Autism Hub members have commenced a specific training package for individuals who want to move on in life entitled 'Tools to Make a Difference' provided by Joint training and Adult Community Education at the Gateway, Shrewsbury.

SSSFT have also held 2 development days for staff who will be ASC champions within their teams co-facilitated by lived experience experts and self-advocates, SSSFT have identified two champions per locality who support the work in this area with leads in place now against Primary Care IAPT also.

Autism West Midlands have delivered awareness sessions at the Autism hub co facilitated by a member of their staff who is on the autistic spectrum.

The West Mercia Police provide Autism awareness training for all front line staff (officers, call takers, custody, front counter staff.) In addition their Equality and

Diversity Advisor has created an aide memoire for officers for use when dealing with an individual on the Autism Spectrum. (see appendix 2)

There are a variety of awareness courses available from Autonomy, AWM, NAS and Adelphi care.

### Hub

'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'

The Shropshire Autism hub has been running since 29th January 2015. This is a weekly service for individuals both pre and post diagnosis where trained staff offer information and advice tailored to meet their specific requirements. There is 1:1 and group support on offer and weekly information sessions largely as suggested by the service users who attend. People can self- refer or obtain information on how to access the hub through Shropshire Choices, primary care and voluntary care sector as well as many other avenues including AWM, STACS, A4U, Autonomy, the chamber of commerce and SPIC (Shropshire Partners in Care)

The core number of attendees averages between 20 and 25 per week and is increasing.

Up to 5 professionals and 5 volunteers each week.

Up to 5 carers each week.

4 Hub users have become volunteers for A4U

The hub has delivered a number of different courses and sessions including; life skills; confidence building and assertiveness; money management; cookery and bespoke personal support planning.

A recent grant from the Arts Council resulted in a drama project culminating with a performance by the group members.

18.5k capital from the DoH (Department of Health) has been spent on supporting the hub including improving IT facilities and equipment and improving the environment to become more Autism friendly.

Hub staff and volunteers have received training from SC joint training.

The hub runs its own website and Twitter account.

Bromford Housing and Autism West Midlands support hub users and there is input from Enable, Shropshire Adult Social Care and Autonomy.

Support planning sessions by Shropshire Adult Social Care, Lets talk local staff have been held at the Hub.

Local employers have visited the hub to discuss the support they can offer.

A4U, Bromford Housing and AWM meet monthly to discuss concerns and help progress Hub users to towards achieving their goal

Healthy Cooking – 4 Hub users went home having made quiche for supper and other cooking sessions proved very successful.



### **Physical Activity**

'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'

Links have been made with the Inclusively fit project which aims to increase participation in sport by disabled people.

There have been taster sessions in sports and games and indoor exercise. Two Hub users were inspired by a talk from 'Sailability' and then went off to take part in a session on their own in Telford

Shropshire Cycling for Health has inspired some of the Hub users to cycle to the Hub, and one member set up a free service check for Hub users before embarking on a cycle ride.



### Housing

'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'

Through contracts with Sustain and Shropshire Housing Support, floating support is provided by coordinating workers to people with Autism. This contract prioritises people who are vulnerable in all types of accommodation including privately rented and owned.

Support focuses on benefits, getting about, neighbour issues and will signpost to experts when appropriate.

Bromford Housing have provided regular support in the Hub and a recent pilot project has meant that a worker from Shrewsbury homes 4 All is attending the Hub for 6 months to support people with housing issues beyond the service level agreement that we have with housing providers.

Shropshire Council has commissioned a number of new properties for supported living including some purpose built units in Market Drayton in North Shropshire for people with LD and /or Autism with complex behaviours that challenge. Some individuals have returned from out of county placements.

### Safe Places scheme

'I want to be safe in my community and free from the risk of discrimination, hate crime and abuse'

Shropshire has a network of over 300 **safe places** (see appendix 3) in all the major towns and a number of hate crime reporting centres.

A Session on Hate crime has been delivered to hub users.

A card for people with autism to carry and use if they are involved with the police has been developed by the West Mercia Police Equality and Diversity officer with hub members and carries the WMP logo. (see appendix 4)

### **Employment**

'I want support to get a job and support from my employer to help me keep it'



Shropshire Council's disability employment service is Enable which provides a supported employment pathway for people with autism through a number of routes, including those from social care and those from Jobcentre Plus. These are:

- a. Social workers can refer service users to Enable directly and information is provided to social work teams to promote that route. This information takes the form of leaflets, posters and electronic newsletters.
- b. Shropshire Council's First Point of Contact (FPOC) social care contact centre can make referrals to Enable for people with autism enquiring about support into employment. These referrals are often for people who may not be eligible for a full social care / social work service.
- c. Shropshire Council social care has a number of social care hubs around the County all of which can send referrals to Enable. In particular, the Council also runs a county wide Autism Hub for people with autism and their carer's. Enable staff run employment surgeries at these Hubs, including that for people with autism, so that people (or their carers / families) can get information about the types of support available and refer themselves directly.
- d. Enable also sub contracts the governments specialist disability employment programme, Work Choice. Referrals can be made from the jobcentre or other sources e.g. education, to help the person with autism into employment of 16 + hours a week.
  - Enable initially carries out vocational assessments for people with autism who have been referred. This is followed by CV creation and job seeking i.e. looking for possible job opportunities for people in line with their skills, interests and experience. The latter involves both "normal" advertised job application routes and also "cold calling" employers to investigate new job roles. Extensive work is carried out with employers directly and through local Chambers of Commerce and other employer organisations to build awareness and provide high levels of support.

As individual's progress into work support is provided via specialist job coaches. These staff will work with the service user / employee to ensure that they develop the required work skills and liaise with the person's employer to ensure that the new employee is successful in their post. This ensures that reasonable adjustments are in place for each individual. This may include utilisation of the Access to Work programme. People are supported in employment for as long as is necessary until they are able to function independently within their job role. Where problems occur at a later date Enable staff will go back to support the person in retaining their job. Likewise, employers an also contact enable at a later date.

Enable work closely in partnership with local DWP (Department of work and pensions) /jobcentre's via the DWP Partnership Manager and the Disability Employment Advisors and other Work Coaches in Jobcentres. It also liaises routinely with Access to Work and works closely with DWP and other services (including the Council's Benefits Options service) to ensure that "better off" calculations are provided before people move into paid employment.

### **MONITORING AND REVIEW**

'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'

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.

Monitoring of progress will also be in line with the National Autism Self-assessment framework.

### SHROPSHIRE AUTISM STRATEGY IMPLEMENTATION PLAN

The aims of the autism strategy are to take forward the 15 priorities outlined on page 3 and ensure that in particular:

Staff who provide services to people with Autism are appropriately trained

A sustainable diagnostic pathway exists for adults leading to an assessment of needs for relevant services.

Appropriate planning is in place in relation to provision of services for people with Autism as they move from children to adults services.

Ensure that there is a meaningful local partnership arrangement to bring together local organisations, services and stakeholders and people with Autism.

There is preventative support and safeguarding in line with the Care Act 2014

Ensure that locally reasonable adjustments are in place to comply with Equality Act and the National health service act.

Support is available for people with complex needs, whose behaviour may challenge or who may lack capacity.

Employment is seen as a key outcome for adults and promoted as a positive outcome for the majority of those children with an EHC plan.

There is engagement between local police forces, criminal justice agencies and prisons regarding training and under the Care Act assess the care and support needs of adults who may have such needs in prisons and other forms of detention.

	Action	Lead	Target Date	Achievements and notes
1.	Training 'I want staff in health and social care services to understand that I have autism and how this affects me'			
	Consolidate existing Training pathway (see appendix1) and practice development including local conferences.	Susie McLagan Mary Johnson Christine Scott	complete	Training pathway in place
	Consideration of future specialised training around specific areas of the spectrum and or people's lives to be actioned as appropriate e.g. older people.inc discussion with SPIC	Mary Johnson Christine Scott	Feedback to Sept 17 Board meeting	
	All primary and secondary healthcare include autism training as part of their workforce development	Richard Kubilius	ongoing	This is ongoing because primary and secondary health care staff are transient. There is a work stream in the Transforming Care Partnership that is addressing training. Implementation of the new assessment service will look to include training within it.

	Action	Lead	Target Date	Achievements and notes
2.	'I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process'			
	Ensure an Integrated triangle of service delivery and pre-and post-diagnosis support for all age groups including older people  People with Autism without LD have access to the same level of clinical support as those with LD	Richard Kubilius	March 2018	0-25 year old will receive pre and post diagnostic support via the new Emotional Health and Wellbeing service which commenced in May 2017. For adults the Autism hub is the pivotal hub for which to build an effective pre and post diagnostic service from which is being developed in June/July with a view to testing the market August/September
	Communicate current arrangements/pathway to relevant people – ensure links to ASC and to HUB are in place.	Richard Kubilius	March 2018	This is integral to the development of the assessment and diagnosis service
	Ensure that data related to diagnosis numbers and outcomes is collected	Richard Kubilius	March 2018	This is integral to the development of the assessment and diagnosis service

	Action	Lead	Target Date	Achievements and notes
3.	Transition  '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'			
	New Transition protocol to be available to board for comment and input	Julia Dean Sarah Sweeney	Take to September 2017 board meeting	
	Invite new transition senior social worker to the Autism Partnership board.	Gavin Bayliss	Recruitment underway	
	Ensure that new 0-25 emotional health and wellbeing service includes effective pathway of care for adults 18-25.	Richard Kubilius	June 2017	complete
	Obtain up to date numbers of people coming through transition with a diagnosis	Richard Kubilius	August 2017	

	Action	Lead	Target Date	Achievements and notes
4.	'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'			
	Ensure wide-ranging representation on Partnership board including representatives from Autism Hub and practitioners.	Gavin Bayliss	complete	Invite new members/guests as required
5.	'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'			
	Develop mission statement, action plan and aims for Hub.	Fiona Williams Jenny Allman	End June 2017	Mission statement complete.  Quarterly meeting with hub users.
	Understand barriers to attending hub and develop ways of engaging people in rural areas allowing access to local 'hub' support	Jenny Allman Fiona Williams Board	End Sept 2017	Discussion between Shropshire Council and Hub providers
	Update Shropshire choices/resource directory as appropriate.	Gemma Jones	complete	GJ regularly seeks feedback from Autism hub members.
	Ensure advocacy support is available to people with Autism in Shropshire	Neil Evans CAAN	CAAN review Sept 17	

	Action	Lead	Target Date	Achievements and notes
6.	Reasonable adjustments in health and community services  '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'			
	Development of a 'virtual autism team' within adult services to share best practice and to improve the service user journey.	Fiona Williams Lindsey Huxtable	complete	May be further changes as CMHT makeup changes
	Public transport – discuss requirements on operators with transport commissioners.	SC transport department	Sept 2017	Arriva have recently published a guide for their staff on supporting people with disabilities
	Patient Passport – design / adapt LD passport to be ASC-specific Once a passport template has been decided A4U to include use with individuals at the hub	Richard Kubilius	March 2018	This is dependent on A4U and agreement of use but could be implemented as part of the development of the assessment and diagnosis service
	GP Health checks and health actions	Richard Kubilius	Dec 17	There is a pilot of which is expected to be complete by the end of the year. This is for LD not specifically autism. If the pilot is successful it will be rolled out across the county
	Inventory of reasonable adjustments.	Richard Kubilius Helen Bayley	ongoing	
	Encourage reasonable adjustments from arts and culture, sports and leisure services.	Autism board	ongoing	

	Maintain links with Colleges re further education adjustments	Gavin Bayliss	Check college offer July 17	Last checked for 2016 SAF
	Action	Lead	Target Date	Achievements and notes
7.	Support for people with complex needs  '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'			
	Ensure that Stakeholders feed into TCP plan and maintain links with TCP board	Gavin Bayliss Kit Roberts Board	June 2017	
8.	'I want support to get a job and support from my employer to help me keep it'			
	Promote self-employment as a real option/alternative for people with Autism and A Wavelength hub presence	Ann Johnson	Meeting Wavelength June 17	Shropshire council kitchen identified for catering start-ups for people with autism, mental health issues or disabilities
	The transition process to include employment as a routine item in educational reviews.	Julia Dean Sarah Sweeney	Review draft pathway June 17	
	Enable will aim to develop awareness of the benefits of supported internships in 2017 – 18. This will be through working into education	Jonathan Allan	Ongoing through17/1 8	

	providers (including colleges of further education), parents and carers groups and other organisations.  In addition, Enable, in partnership with Shrewsbury College, will support, in 2017 / 18, a number of young people with learning disabilities who are students on supported internship courses into paid employment.			
	Develop links with DWP and benefits advice re PIP rollout	Chris Westwood	Sept 2017	
9.	Engagement with CJ and police  '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'			
	West Mercia Police representatives to attend hub sessions and ensure that Hate crime awareness is raised	Katrina Gilman	complete	Board to feedback incidences where Police response requires improvement
	Ensure representation on Local disability Independent Advisory groups to the West Mercia Police	Board	complete	Currently Sue Stewart

	Action	Lead	Target Date	Achievements and notes
10.	'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'			
	Ensure up to date data is available for the Shropshire area	Emma Sandbach	Complete for adults and children in 2016	Adults based on 2014 data
	Autism is considered specifically in JSNA	Emma Sandbach	complete	
	Keep data for those with Autism seen by ASC, primary care, health provision and voluntary sector	Gavin Bayliss Richard Kubilius	Review in conjunction with SAF	
11	'I want to know that my family can get help and support when they need it'			
	Build on relationship with Carers trust 4 all	Gavin Bayliss	A Craven to attend board	
	Carers assessments	Carers trust 4 all	complete	

		Action	Lead	Target Date	Achievements and notes
1	2	'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'			
		Ensure that Autism board feeds into any future housing support changes or developments.	Neil Evans / Gavin Bayliss	March 2017 and ongoing	
		Ensure Housing strategy specifically identifies autism	Nick Wood	April 2017	
		Commission housing for people with a range of needs including TCP cohort	Michelle Davies Viv Hawkey TCP	complete	
1	3.	'I want to be seen as me and for my gender, sexual orientation and race to be taken into account'			
		Identify specific support or signpost hub users to specialist organisations able to support with particular issues.	Jenny Allman Fiona Williams	ongoing	

### **Glossary of Terms and Abbreviations**

CMHT Community Mental Health Team
ASC Autistic Spectrum Conditions
ASD Autistic Spectrum Disorder
AWM Autism West Midlands

CCG Clinical Commissioning Group

DoH Department of Health

DWP Department of Work and Pensions

EHC Education Health and Care

FPOC First Point of Contact

IAPT Improving Access to Psychological Therapies

JSNA Joint Strategic Needs Assessment

LD Learning disability
MH Mental Health

NAS National Autistic Society

SC Shropshire Council

SPIC Shropshire Partners in Care

SSSFT South Staffordshire and Shropshire Healthcare NHS Foundation Trust

STACS Shropshire and Telford Asperger Carer's Support

TCP Transforming Care Partnership

Appendix 1
Training and Development Pathway for workers carrying out assessments under the care act

Programme	Duration	Delivered by	Organised by	Who	
Autism Awareness Stage 1 – 'Understanding Autism'	Half day	Joint training plus expert by experience	Joint Training	Anyone involved in assessments under the Care Act Including session for Autism Hub	
Autism Awareness Stage 2 – 'Resources, knowledge and skills'	Half day	Joint Training and Professional Development Unit	Joint Training and Professional Development Unit	Anyone involved in assessments under the Care Act	
Autism Awareness Stage 3 – 'Facilitated Learning Set'	Ongoing	Professional Development Unit	Professional Development Unit	Selected Social Workers, Social Work Assistants, OTs, OTAs	
Autism and Intensive Interaction Autism Event Shropshire	Full Day	Phoebe Caldwell	Joint Training	All – 50 places (professionals, charities and family carers)	
Autism for Best Interest Assessors	Full day	Mary Johnson, Joint Training	Joint Training	BIAs	

Supporting People with Autism through Assessments	Full day	National Autistic Society – Social Work led	Joint Training and Professional Development Unit	Social Workers, Social Work Assistants, OTs, OTAs
Programme	Duration	Delivered by	Organised by	Who
Autism Conference, Telford	Two Days	National Autistic Society Conference	Professional Development Unit	
Local Conference	Full Day	Guest Speakers TBC	Joint Training and Professional Development Unit	Social Workers, Social Work Assistants, OTs, OTAs
Online training		National Autistic Society	Professional Development Unit	Social Workers, Social Work Assistants, OTs, OTAs
Autism Awareness (Tailored packages available)	Half day	Mary Johnson, Joint Training	Joint Training	Generic audience

### Autism Spectrum Conditions (ASC) and the Criminal Justice System

### What might you find when dealing with a person with ASC?

### They may:

- · have difficulty understanding you;
- · repeat things you say;
- · not give eye contact or stare;
- · be very honest and therefore appear rude;
- · appear very anxious or agitated;
- lack understanding of the consequences of the situation they are in;
- find it difficult to talk and explain themselves;
- · display obsessions and repetitive behaviour;
- seem confused about what is happening;
- not respond, rock, be in great distress, withdraw due to sensory overload or meltdown;
- not understand why their behaviour or actions are wrong;
- · admit to anything if it removes them from the situation.



### 9014/DTP/diversity

### What can you do to improve the situation?

- · Say the person's name to get their attention.
- Keep language simple and allow time for a response.
- Try to establish their favourite subject or special interest to help build up trust and calm them down.
- Provide a clear structure of what is happening and when it will happen.
- Avoid sensory overload by keeping away from noisy and crowded areas.
- Avoid touching them sensory overload may lead to an aggressive reaction.
- Contact someone they know and ensure the right support is available.
- Don't insist they look at you when you are talking.
- Try writing things down or drawing to aid their understanding of the situation.
- Make sure they repeat information you have given in their own words to check understanding.
- Try not to present too much change moving from room to room, large number of people.

### Autism West Midlands Information Line 0303 03 00 111





### **Appendix 3** – Safe Places

### Bishop's Castle

Bishop's Castle Pharmacy Information Centre Kirsty's Cafe Mace Spar The Cooperative Food

### **Bridgnorth**

Barclays Bank
Blue Cross Charity Shop
Bridgnorth, British Red Cross
Bridgnorth Library
Cafe Express
Elegance
Innage Lane Resource Centre
Mid Counties Cooperative
Murray's Healthcare
Oak Farm Ditton Priors
Parish Rooms, Low Town
The Brasserie

### **Broseley**

**Broseley Medical Centre Broseley News** Cafe in The Square Carol's Carpets **Downes Greengrocers** Edwin Davies & Son Four Paws Lady Forrester Centre, Broseley Miss Molly's Cafe Premier Rowlands Chemist Simon Gibbons Butcher Spar The Cooperative Food The Dog Shop The Friendly Bus (4 Buses)

### **Church Stretton**

British Red Cross Charity Shop Carding Mill Valley Café Chocolate Haven Church Stretton Library Family Shopper Hillside Pharmacy Holly Bush Café Hope House Charity Shop Hough and Sons

Mayfair Community Centre

Mr Bun the Baker

Newsworld

Police Station

**Rowlands Chemist** 

Sandford Hardware

**Scrappies** 

Sweet Tooth

The Co-operative Food

The Dog Shop

Teme Leisure Centre

Visitors Information & Customer Service Point Centre

### Craven Arms

Shropshire Hills Discovery Centre

The Gateway

### Ellesmere

Cakes by Lowri (formally Talgath Tea Rooms)

Ellesmere Library

Ellesmere Pharmacy

Ismay's

Premier Convenience Store

The Black Lion Hotel

The Co-operative Food Store

V Sanchi Jewellers

White Lion Antiques

### Highley

Bache's Sweet Shop

**Highley Pharmacy** 

The Café, Highley

The Cooperative Foodstore.

### Ludlow

**Boots Pharmacy** 

Brown & Francis Pharmacy

Cancer Research, 3 High Street

Castle Lodge Buttery

Castle Tea Rooms

Helena Lane Day Centre

Hope House Charity Shop

Lanyon Bowdler Solicitors

Loudwater Studios

**Ludlow Library** 

**Mobility Products** 

One Stop, 9 Tower Street

Renaissance Centre, 7-8 Tower Street

Rockspring Centre, Sandpits

SC Price & Sons (Bakery)

Spar
The Cooperative Food, Foldgate Lane
The Grape Tree
Wesley's Café
Working Together (Ludlow Ltd)

### **Market Drayton**

B & M

**Boots Pharmacy** 

Craft Revolution

Festival Drayton Centre

Festour

House of Carpets

Jone's Coffee House

Kids Corner

Madalenka

Market Drayton Library

Meadons Insurance

**Newbold Opticians** 

One Stop-Market Drayton

Salop Mobility

Salopion Care

**Sherwood Wholefood** 

Shropshire Housing Alliance

St. Mary's Church

Sue Ryder Charity Shop

The Cutting Room

The Sewing Box

**Tudor House Hotel** 

Tuesdays-Chocolate & Confectionery

Wayfarers

### **Much Wenlock**

AJ's-Home & Garden

Cuan Wildlife Charity Shop

Much More Books

Spar Supermarket

The Copper Kettle

The Wenlock Smoothie

Tony's Market

Wenlock Books

Wenlock Pharmacy

### Oswestry

Age Uk Charity Shop

Baby Bird Cafe

**Baileys** 

**Bromford New Century** 

Cambrian Medical Centre

Caxton Pharmacy

Chalk

Chalk Warehouse

Corner Patch

Derwen College

Foodbank

Grape Tree

Honey Pots

Honeysuckle

Jeff & Burgess Taxis

Lanyon Bowdler Solicitors, Oswestry

One Stop-Oswestry

Oswestry Herbarium

Oswestry Library

Oswestry Mobility

Scotty's Café

Shropshire Housing Alliance

St Oswald's Church

Station Pharmacy

The Advertiser

The Flower Gallery

Wilko's

### Shifnal

**Boots** 

Nan's Café Bar

**New Chapters Foster Care** 

One Stop-Shifnal

**Roots and Shoots** 

Shifnal Deli

Shifnal Post Office Village Café

The Village Café & Bistro

### **Shrewsbury**

A4U-Louise House

Abbots Wood Day Centre

Age UK-Mardol

Age UK-Training Centre Riverside

Age UK Charity Shop Riverside

Albert Road Day Services

Aquamira

Barclays Bank

Bon Bons

British Red Cross Charity Shop

**Button and Bear** 

Cafe Connect-Radbrook

Candleglass

Care and Share Charity Shop

Caring Angels Home Care

**Castle Carpets** 

Castlefields Digital Den

Clarriots Care (Shropshire & Telford)

Co Op Travel, Shrewsbury

Creations (Formally Two Fat Rascals)

Deliciate

Digital Den-Meole Brace

Divine

Ginger & Co Coffee

Greenacres, Baschurch

Guide Dogs Training Centre

Headway Shropshire

Home Essentials

In Good Hands

It's Epic

Lanyon Bowdler-Shrewsbury

Little Waitrose

Marie Curie Charity Shop

Mobility Homecare

Ojoy Wellness

Old Market Hall

Omega End of Life Care

One Stop -Ditherington

Oxfam Charity Shop

Peach Tree

Post Office Copthorne (inside Cooperative Food Store)

Radbrook Green Post Office

Radfield Home Care

Roy Fletcher Centre

Sabrina Boat

Sabrina Boats, Station Approach

Scope Charity Shop

Severnside Housing

Shalimar Restaurant

Shrewsbury Academies Trust, Mount Pleasant Road

Shrewsbury Ark

Shrewsbury Library

Shrewsbury Street Pastors

Shrewsbury Unitarian Church

Shropshire Housing Alliance

Shropshire MIND

Shropshire Partners in Care (SPIC)

Shropshire Trophy & Bowling Centre

Signal Hub

Snapdragon Wholefoods

St Chad's Church

Stop Coffee Shop at Shrewsbury Museum

Stop Coffee Shop at St Julian's

Stop Coffee at University Centre, Frankwell Shrewsbury

Sue Ryder Charity Shop

The Ark Charity Shop

The Blue Lemon, Shrewsbury

The Co operative Food Store-Bicton Heath

The Co operative Food Store-Copthorne

The Co operative Food Store-Heath Farm

The Co operative Food Store-Radbrook Green

The Co operative Food Store-Sutton Farm

The Donkey -Street Pastors Vehicle

The Hive

The Lantern

The Post Office Copthorne (inside Cooperative Food Store)

The Shrewsbury Coffee Shop

The Uplands Nursing Home

Theatre Severn

University Centre Shrewsbury, Frankwell

Visitor Information Centre

Wenlock Farm Food Shop, Smithfield Road

Westbury Garage

White Orchard

Wildlife Centre

### Wem

Dickin Arms

Gemini Hairdressers

Old Post Office Pub

Rowland's Chemist

Seasons Florists Ltd

The Cooperative Food Store

**Treacle Mine** 

Wem Library & Learning Centre

### Whitchurch

Big Red House

Bookshrop

**Boots** 

Café Bon Sol

Cancer Research Shop

Healing Thyme

Janini Cafe Bistro

Jone's Coffee House

Original Factory Shop

Poundstretcher

**Short Notice Care** 

St Alkmond's Church

Unique Chic

Whitchurch Library

**Appendix 4** - The Front of the card has the persons name and if they want their diagnosis or alternatively umbrella term.

On the back will tell you some things that affect them and may assist you to help the person, also contained are their likes so you can put them at ease and know a little bit more about the person.





## Autistic Spectrum Disorder in Children 2016

Autism and Asperger syndrome are both part of a range of related developmental disorders known as autistic spectrum disorders (ASD). They begin in childhood and last through adulthood and can cause a wide range of symptoms including the following:

- **problems and difficulties with social interaction** including lack of understanding and awareness of other people's emotions and feelings
- impaired language and communication skills including delayed language development and an inability to start conversations or take part in them properly
- unusual patterns of thought and physical behavior including making repetitive physical movements, such as hand tapping or twisting and developing set routines that may cause distress if broken

There is no cure for ASD, although a wide range of treatments, including specialist education and behavioral programs, can help improve symptoms.

Nationally it is estimated that 1 in every 100 children has an ASD and it is more common in boys than girls. Boys are three to four times more likely to develop an ASD than girls. The following table shows prevalence estimates for ASD in Shropshire based on the national prevalence.

Table 1 Estimated prevalence of autistic spectrum disorder in Shropshire, 2012

	Autism in children aged 9-10 years	Other ASDs in children aged 9-10 years	Total ASDs in children aged 9-10 years	ASDs in children aged 5-9 years
Shropshire	25	50	75	255

Source: Office for National Statistics, 2012. Baird, G. et al (2006). Baron-Cohen, S. et al (2009).

The following table shows the number of children in Shropshire recorded on the school census and the pupil referral unit as having ASD. It also highlights the percentage of the prevalence estimates that the recorded figures account for. However, this may not be the total figure as only children with a school action plus or a statement have a record of their specific special educational need. Therefore, children with less severe ASD may not be identified this way.

Table 2 Number of children recorded with autistic spectrum disorder in Shropshire, 2014

				Total ASDs in children aged 9- 10 years	ASDs in children aged 5-9 years
	Num	nber		58	109
Shropshire	% estir	of nate	prevalence	77%	43%

Source: School Census, January 2014, Shropshire Council

### Children with ASD in Shropshire

The following information looks at profiling children with ASD recorded on the Shropshire school census, January 2016.

### Age, gender and ethnicity

In Shropshire in 2016 82% of children diagnosed with ASD were boys compared to 18% of girls. This would support the national figures that suggest that up to four times as many boys have ASD compared to girls. The following chart shows the age and gender of all children recorded as having ASD. Boys aged 10-14 years are significantly more likely to be recorded as having ASD compared to other age and gender groups. The number of children in each category is displayed on the chart at the base of the columns.

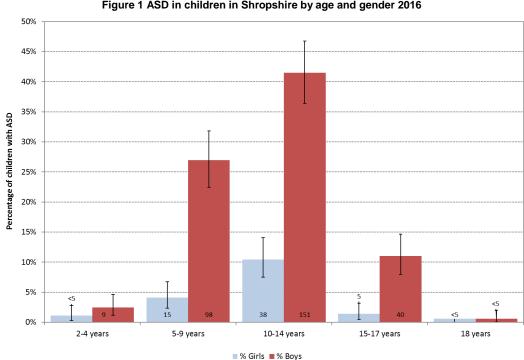


Figure 1 ASD in children in Shropshire by age and gender 2016

Source: School Census, January 2016, Shropshire Council

### **Ethnicity**

92% of children on the school census with ASD were recorded as being white British. The remaining 8% were from a variety of different ethnic groups (3.3% being from other white groups and the remaining 4.7% either not stated or from other mixed, black and minority ethnic groups).

### Geographical and socio-economic distribution of children with ASD

Although estimates suggest that around 1% of children on the Shropshire census may have ASD it is not distributed evenly in the population. understanding more about the geographical and socio-economic distribution of ASD can enable more efficient and appropriate care and enable the needs of children with ASD to be better met.

Around 30% of all children on the Shropshire school census live in the most rural areas, e.g. villages, hamlets and isolated dwellings. However, 26.4% of children with ASD live in these areas, with the remaining 70.3% live in small towns and urban areas (3.3% were unknown).

### **Local Authority Districts**

The following table shows the proportion of all children with ASD in Shropshire living in each area of the county. The number of children is also highlighted in the base of each of the columns. Shrewsbury & Atcham had a significantly higher percentage compared to all the other areas, as the largest population of children live in the Shrewsbury area. Although ASD accounted for 1% of children recorded on the school census overall, the percentage in each area varied from 0.6% of children on the school census in Bridgnorth to 1.3% of children in Oswestry. The other areas were between 1% and 0.9% of children recorded on the school census.

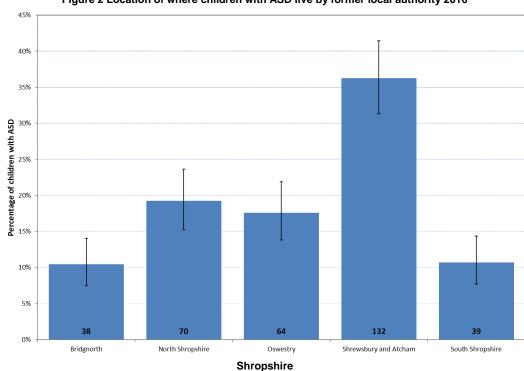


Figure 2 Location of where children with ASD live by former local authority 2016

Source: School Census, January 2016, Shropshire Council

### **Place Plans**

Calculated as a percentage of the total number of children with ASD on the school census, Shrewsbury North East had a significantly higher percentage (15%) compared to all the other place plan areas, followed by Shrewsbury South (8%) and Market Drayton (8%) and are situated in some of the most deprived areas in Shropshire. When calculated as a crude rate per 1000 of the census population with an SEN there were no significant differences between the place plan areas.

### **Deprivation**

The following chart shows the relationship with ASD and deprivation in Shropshire. There were significantly higher proportions of children with ASD living in the most deprived area compared to the least but similar to SC3. Additionally, around 20% of children with ASD in Shropshire had free school meals at the time of the school census, e.g. recorded in January 2016 as receiving free school meals. This is compared to 9.1% of the total recorded population of children on the school census.

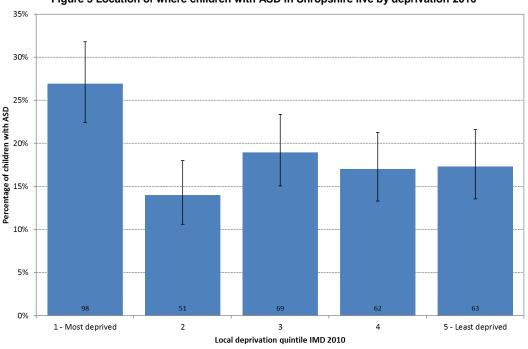


Figure 3 Location of where children with ASD in Shropshire live by deprivation 2016

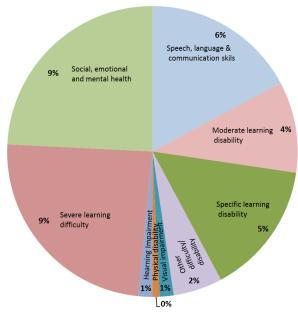
Source: School Census, January 2016, Shropshire Council

### ASD and multiple vulnerabilities

It is recognised that many people with ASD also have other conditions such as learning disabilities and sensory impairments. It is estimated that nationally 44% - 52% of people with autism have a learning disability. Overall in Shropshire 37% of children with ASD were also recorded as having another special educational need. The following pie chart highlights the type and proportion of additional special educational needs of that 37% of children recorded on the school census as having ASD in Shropshire.

The most likely additional special educational need of children with ASD in Shropshire was social, emotional and mental health needs and sever learning difficulties.

Figure 4 Additional special educational needs of children with ASD in Shropshire



Source: School Census, January 2016, Shropshire Council

### Summary

- The recorded prevalence of ASD in children is likely to be higher than that included in this report, as this is based on information from limited sources.
- Boys aged 10-14 years are most likely to be recorded as having ASD, and overall boys are more likely than girls to have ASD which is also reflected nationally.
- A significantly higher percentage of children recorded with ASD on the census came from small towns and urban areas such as Shrewsbury & Atcham Local Authority district; with a significantly higher proportion from Shrewsbury North East, Shrewsbury South and Market Drayton which are amongst some of the most deprived areas in Shropshire.
- There were significantly more children recorded as having ASD living in the most deprived areas compared to the least deprived areas.
- 37% of children recorded as having ASD in Shropshire also have a special educational need, with social, emotional and mental health needs being the most likely.