Shropshire Autism Needs Assessment for Children and Young People aged 0-25

Contents

Executive Summary: Shropshire Autism Needs Assessment for Children & Young People aged 0-25

Introduction

Shropshire Children's Trust has identified a gap in knowledge around Autistic Spectrum Disorder in Shropshire. This needs assessment for children and young people aged 0-25 intends to address this gap in information, by compiling data around prevalence, level of need and access to services.

Legislative changes as a result of the Children and Families Act 2014 have resulted in some adjustments for organisations providing services for children and young people with ASD, as well as changes for families and young people themselves. Service providers and commissioners now must work more closely together and ensure that provision and pathways for recognition, referral and diagnostic assessment across education, health and social care are linked and cohesive. Young people and their families now have greater levels of participation in their assessment, decision-making and planning.

This assessment has tried to bring together various workstreams across organisations and sectors to understand the needs of children and young people aged 0-25 with an ASD. This includes gaining an understanding of the experiences and availability of support services to help families manage ASD.

Methodology

A working group was convened to deliver this Needs Assessment. Stakeholders on the group were from a range of backgrounds including Shropshire Council, Shropshire CCG, the voluntary and community sector and Shropshire Community Health NHS Trust.

The working group agreed the Autism Needs Assessment specification with the Children's Trust. Three key elements included understanding prevalence, understanding provision and understanding stakeholders/ service user's issues. The working group designed a stakeholder event to understand better the issues, needs and potential solutions. This event took place in November 2014; stakeholders came together to discuss the current autism pathways and to provide feedback on their experience in regard to assessment and access to services.

Information has also been gathered from existing work and data sets including evidence around prevalence and a 'snapshot of services' which was completed in autumn 2014. It was felt that further evidence and information from providers, parents & carers, and schools was required to provide more detail for assessing need across Shropshire. Therefore surveys were formed and distributed to these stakeholders. Information was also gathered through desk-based research utilising national and locally reported data from the local authority and the voluntary and community sector.

Conclusions

- As of January 2014, there were 346 children and young people aged 0-18 recorded on the school census as having an ASD. As there is not a universal, central collection of prevalence data for ASD, it is not possible to provide a more accurate figure of the number of children and young

people with ASD in the county. Population estimates using UK census data suggest that the figures of true prevalence of ASD in the county may be much higher, at around 932 children and young people aged 0-25 years.

- Prevalence estimates and future predictions indicate that we can expect to see an increase in the number of children with ASD. It is likely that this increase is linked to identification and improvements in diagnostic processes.
- Pathways for identification, referral and assessment are unclear and difficult to understand. Parents and professionals have indicated that it would be beneficial to simplify these pathways.
- Parents highlighted a lack of parenting and family support when their child has not received a diagnosis.
- There is a wide range of services available, but require improved promotion to ensure that families and professionals know what they are and how to access them.
- The schools that completed our survey feel well-equipped to respond to the needs of children and young people with autism. However, although many parents/carers have faith in the school system and its ability to support their child, many do not.
- The importance of planned and co-ordinated transition was stressed by parents. They highlighted that the process can be improved for families by early planning, dedicated support and good communication between the child or young person, their family and school and the various organisations involved.
- Families feel that services need to be better joined-up in order to support their child and this includes better information sharing.

Recommendations

Recommendation 1: Establish a local autism multi-agency strategy group with managerial, commissioner and clinical representation from child health and mental health services, education, social care, parent and carer service users, and the voluntary sector. This group would be established within existing resources and some elements may be performed as a virtual group.

Recommendation 2: Consider expanding the role of the multi-disciplinary autism team (similar to the Child Development Centre's offer for children aged 0-5) to cover ages 0-25 with core membership from a paediatrician/child and adolescent psychiatrist, speech and language therapist, clinical and/or educational psychologist. Consideration is required for how the expansion of this multi-disciplinary team can be facilitated within existing resources.

Recommendation 3: Parents have stated that information needs to be clearer, easier to access and located in a central point. This includes information about how to access the referral and assessment pathway. Families need to be 'kept in the loop' about the assessment process, with updates around timelines and outcomes.

The creation of a central point to access all information about pathways, assessment and services would facilitate families' understanding of the system and in turn help to manage expectations. This central point should provide more information that just that which is stated in the Local Offer, but should include details about pathways, expectations and responsibilities. This central point would provide information about what happens if your child receives/does not receive a diagnosis and could be used to signpost parents to appropriate support (**linked to Recommendation 7**).

Recommendation 4: Stakeholders discussed the importance of improved communication between agencies/organisations, including the sharing of information. Organisations should explore the potential for more timely and appropriate information sharing through secure email accounts to reduce time waiting for assessments and allow organisations to access a 'full picture' of a child's needs.

Recommendation 5: Establish a time-limited working group under the Children's Trust to understand the communication relationship between schools and parents. The group will work with schools and parents to establish communication and policy expectations, and develop an appropriate code of practice to communicate these expectations and standards.

Recommendation 6: Develop processes so that transitional phases are approached collaboratively with a long lead-in period, involving the child or young person and their family, as well as organisations and agencies such as the school and social worker. The role and influence of the school nurse in helping to manage the transition should be explored.

Recommendation 7: Families need to be made aware of existing provision that can provide parenting support. Increased promotion of tier 2 services, or introduction to tier 2 services as part of the assessment pathway, would enable families to access the right support as early as possible. Follow-up or arm's length contact after completing a course would be beneficial in supporting parents to continue to manage behaviour.

1. Background

Shropshire Children's Trust has identified a gap in knowledge around Autistic Spectrum Disorder in Shropshire. This needs assessment for children and young people aged 0-25 intends to address this gap in information by compiling data around prevalence, level of need and access to services.

Methodology

A working group was convened to deliver this needs assessment. In order to provide a strong knowledge base, stakeholders on the group were from a range of backgrounds. Representation included:

Shropshire Council Public Health	Shropshire Clinical Commissioning Group (CCG)
Shropshire Council Learning & Skills	Autism West Midlands
Shropshire Council Children's Services	Shropshire Parent and Carer Council
Shropshire Council Adults Services	Shropshire Community Health NHS Trust
Shropshire Council Safeguarding	Shropshire Children's Trust

The working group agreed a specification with the Children's Trust and worked together to deliver a stakeholder event. This event took place in November 2014; stakeholders came together to discuss the current autism pathways and to provide feedback on their experience in regard to assessment and access to services. Information has also been gathered from existing work and data sets including evidence around prevalence and a 'snapshot of services' which was completed in autumn 2014. It was felt that further evidence and information from providers, parents & carers, and schools was required to provide more detail for assessing need across Shropshire. Therefore surveys were formed and distributed to these stakeholders. Information was also gathered through desk-based research utilising national and locally reported data from the local authority and the voluntary and community sector.

Definition

Autism and Asperger's syndrome are lifelong conditions that affect how an individual interacts, communicates and engages with others and their environment. The term Autistic Spectrum Disorder (ASD) illustrates the range of conditions under the title of 'autism'; people will be affected by the condition in different ways and to differing degrees. As well as having difficulties with social interaction and communication, some individuals with autism may also have learning disabilities or experience over- or under-sensitivity to certain senses and stimuli such as touch, light or colours[1].

The 'triad of impairments' indicates the three main areas within which people with ASD may have difficulty. This includes:

- Social interaction

[1] The National Autistic Society. (2015). *About autism*. Available at: www.autism.org.uk

- Social communication
- Flexibility of thought (imagination)

ASD is characterized by persistent deficits in reciprocal social interaction and social communication, and by a range of restricted, repetitive, inflexible patterns of behaviour and interests and sensory sensitivities that may change in intensity, frequency and focus over the course of development. These deficits are usually a pervasive feature of the individual's functioning in all settings, although they may vary in degree according to the social, educational, or other context. In many cases, development is abnormal in infancy, although this may only become evident in retrospect. Symptoms usually emerge during early childhood, but for some individuals do not become fully manifest until social demands exceed capacities[2].

There is no known cure for ASD, however, specialist educational provision, behavioural programmes and other interventions can help individuals to manage their condition and achieve their potential.

ASD is the used term in most recent international classification DSM-V (Diagnostic and Statistical Manual) and the proposed ICD-11 (International Classification of Diseases). Individuals and groups may prefer a variety of terms, including autism, autism spectrum disorder, autistic spectrum condition, autistic spectrum difference and neuro-diversity, Asperger's Syndrome or Disorder. For clarity and consistency, ASD is the preferred term of this needs assessment, the term 'autism' is also used but it always refers to ASD.

This needs assessment has collected information about children pre- and post-ASD diagnosis; asking questions of parents and providers about children with autism or autistic traits to capture information about the early support needs of children awaiting diagnosis as well as their needs once diagnosis is made.

Not all children identified with autistic traits will go on to receive a diagnosis of autism spectrum disorder. Some may not meet the diagnostic criteria, some parents may choose not to pursue diagnosis and others may be diagnosed with other conditions that show autistic type presentations. Examples include specific speech and language difficulties, ADHD, Attachment Disorder/difficulties and Sensory Processing Disorder.

2. Context and policy

In recent years a large number of publications and guidance has been produced in order to encourage improvements in the experience of children and young people with autism. These range from legal frameworks such as the Autism Act 2009 to national policies from the Department of Health and NICE. Shropshire has produced strategies outlining local intention to support families, provide children with the best start in life and enable all young people to reach their potential[3].

[2] World Health Organization. (2015). *ICD-11 Beta Draft*. Available at: http://apps.who.int/classifications/icd11/browse/l-m/en

[3] Shropshire's Safeguarding Children Board. (2014). *Shropshire LSCB Strategic Plan 2014-17.* Available online: www.safeguardingshropshireschildren.org.uk

National context

The national directive for ensuring that children with special education needs and disabilities (SEND) such as ASD are supported to achieve is well-evidenced. The Autism Act of 2009 brought about the 'Think Autism' strategy[4] which emphasised the importance of raising community awareness, funding projects that promote innovative local services and improving data collection and joining up information and advice services.

In 2014, the Children and Families Act[5] came into force. This Act was designed to simplify the arrangements for identifying and supporting children with SEND so that children, young people and their families have greater levels of participation in their assessment, decision-making and planning, as well as raising aspirations and improving outcomes for children and young people. For service providers and commissioners, this meant committing to working more closely together to ensure that provision between education, health and social care is linked. Locally, Shropshire has responded to the Act by replacing Statements of SEN with Education, Health and Care Plans (EHCP). It has also published a 'Local Offer' that details the availability of relevant services within the area, and has enhanced the Information Advice and Support Service (IASS) for young people and families to access.

Similarly, the Care Act 2014[6] has a focus upon improving outcomes, furthering personalisation and ensuring the integration of services. The Care Act focuses upon adult social care for anyone over the age of 18, therefore young people with ASD, who are undergoing this transitional period will be affected by the legislation.

NICE guidance[7] recommends that there should be a multi-agency pathway for recognition, referral and diagnostic assessment of possible autism, and highlights the importance of timely and appropriate information and support for families. This includes all health and social care professionals working with children and young people with autism in any setting receiving training in autism awareness and skills to manage autism. It also states that the overall configuration and development of local services should be co-ordinated by a local autism multi-agency strategy group. Children and young people with autism, and their families and carers should be offered the opportunity to be involved in shared-decision making around treatment and care. NICE QS51 sets out the quality assurance statements for the care that children, young people and adults with autism should receive.

Local context

Shropshire Children's Trust aims to ensure the mental health and wellbeing of all young people in the Shropshire Council area. Autism and its related difficulties can impact upon a child or young person's (and their family's) wellbeing and can have an impact on their learning and attainment in school.

The Children's Trust is keen to understand better the prevalence of ASD, the level of service need and demand, and current provision across all sectors of health, care and education. Of primary focus is the

[4] Department of Health. (2014). Think autism: fulfilling and rewarding lives, the strategy for adults with autism in England: an update. Available online: www.gov.uk
[5] Children and Families Act. (2014). Available online: www.legislation.gov.uk
[6] Care Act. (2014). Available online: www.legislation.gov.uk
[7] Relevant NICE documents: QS51 Autism, CG170 Autism, CG128 Autism diagnosis in children and young people, CG142 Autism: adults, PH12 Social and emotional wellbeing in primary education, PH20 Social and emotional wellbeing in secondary education

aspiration to improve the assessment and diagnostic process for families and ensure that support is in place that meets the needs of all children and young people with ASD as well as their families. This will include improving points of transition, which can often be an unsettled period for young people with autism.

The Shropshire Children's Trust[8] has placed emphasis upon the safety and support of vulnerable children and young people. This includes a focus upon ensuring the emotional wellbeing of children and young people through prevention and early intervention.

Partners from across the health and care system as well as community and voluntary organisations are committed to improving experiences for children and young people with autism.

Shropshire's Joint Strategic Needs Assessment (JSNA) highlights the importance of children having the best start in life: 'much of a person's future health and wellbeing is determined by early years' development'[9]. A strong emphasis is placed upon the significance of mental health during childhood and adolescence. For individuals with special education needs or learning difficulties, who are more likely to suffer mental health problems, this is especially important. NICE guidance (PH20)[10] stresses the value of practitioners having the knowledge and skills to develop young people's social and emotional wellbeing.

Health inequalities[11]

Children and young people with ASD are likely to experience greater health inequalities than their non-ASD counterparts. This can be related to their increased vulnerability which may stem from lower attainment at school and reduced access to employment, coupled with the increased likelihood of social exclusion due to their condition. The social determinants of health, such as education, employment and housing can influence lifestyle factors (such as diet) and can increase the disparities[12]. Access to education, health and social care services can have an effect upon the experience of health inequalities, as can the community's approach to ASD. Strategies outlined in NICE guidance and the Department of Health's 'Fulfilling and Rewarding Lives'[13] suggest that concerted work to join up agencies, increase the availability of support information and involving individuals in the design of their care and support can help to reduce these inequalities.

In Shropshire, young people living in the most deprived areas of the county are more likely to have a diagnosis of ASD than those living in less deprived areas.

[8] Shropshire Children's Trust. (2014). Children, Young People and Families Plan. Available online: http://shropshire.gov.uk/media/1216935/Shropshire-CYPF-Plan-2014.pdf
[9] Shropshire Council. (2012). Joint Strategic Needs Assessment. Available at: http://shropshire.gov.uk/media/73886/Shropshire-JSNA-Summary-Document-2012.pdf
[10] NICE. (2009). PH20: Social and emotional wellbeing in secondary education. Available online at: https://www.nice.org.uk/guidance/ph20
[11] This information is based upon Shropshire Public Health Intelligence Team's reports: 'Autistic spectrum disorder in children (2014)' and 'Information on SEN provision need in Shropshire (2014)'. Please contact the Public Health department for more information.
[12] Liverpool Public Health Observatory. (2013). Learning disabilities and autism. Available online: http://info.wirral.nhs.uk
[13] Department of Health. (2010). Fulfilling and rewarding lives. Available online: www.dh.gov.uk

3. Prevalence in Shropshire

The following information utilises data collated by the Shropshire Public Health Intelligence Team[14]. Data from the 2011 UK census estimates that 1.1% of the population have autism[15]. In Shropshire this would total **932** children and young people aged 0-24 years. However there is no reliable way to check the accuracy of these estimates since there is no single record of children in the county with ASD. Data is collected by different organisations for their own purposes and as such cannot be correlated.

346 children and young people in Shropshire schools were recorded on the school census as having ASD as a primary or secondary need (as of January 2014). However not all children with ASD will be recorded as needing support in school. In addition there may be many more individuals with ASD or autistic traits who do not present to professionals and do not access services. Some children may remain undiagnosed. Particularly in very young children, ASD can be difficult to diagnose.

Table 1 shows the number of children in Shropshire recorded on the school census and the pupil referral unit as having an ASD. It also highlights the percentage of the prevalence estimates that are accounted for by the recorded figures. The recorded figures will not reflect the total figure as only children with a school action plus or a statement/EHCP have a record of their specific special educational need.

Although the school census figures do not reflect the total figure they have been used as a basis to explore the gender, locality and multiple vulnerabilities of children with ASD. However it is not known whether the children who are unrecorded reflect the same breakdown as those in the school census. This may be particularly relevant for the figures on multiple vulnerabilities.

Table 1 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
Shropshire	Number	58	109
	% of prevalence estimate	77%	43%

Source: School Census, January 2014, Shropshire Council

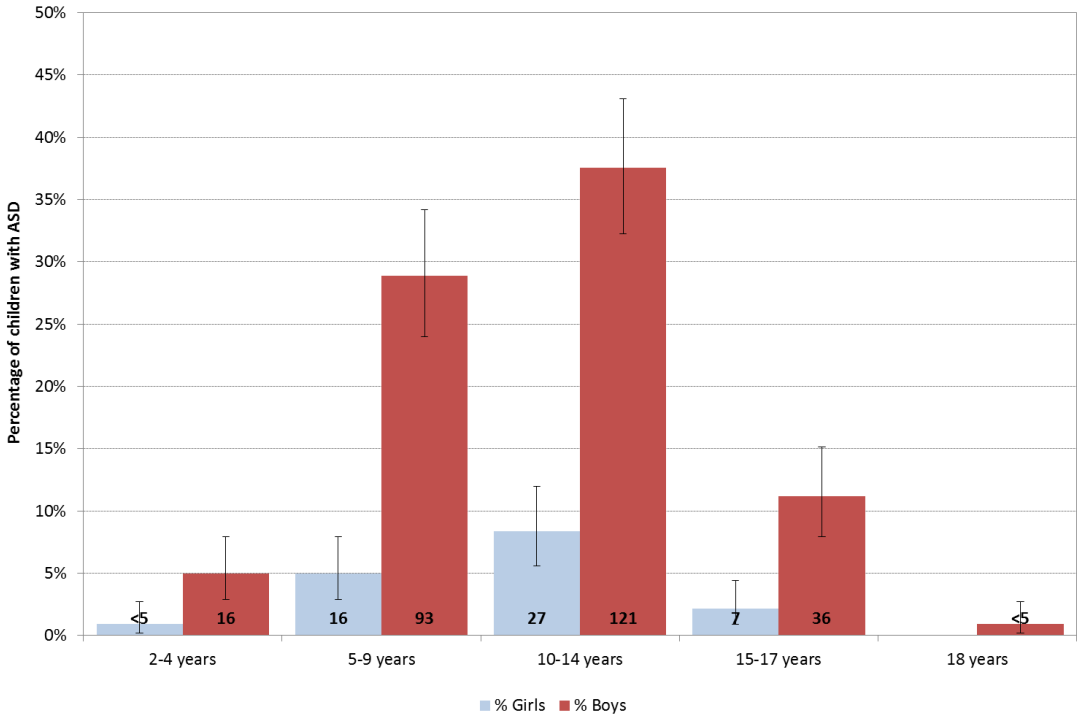
Age and gender

In Shropshire around 84% of children with ASD recorded on the school census are boys and 16% are girls. This reflects national figures which indicate that up to four times as many boys than girls have ASD. Chart 1 shows the age and gender of all children recorded on the school census as having ASD. Boys aged 10-14 years are the most likely age and gender category 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.

[14] This information is based upon Shropshire Public Health Intelligence Team's reports: 'Autistic spectrum disorder in children (2014)' and 'Information on SEN provision need in Shropshire (2014)'. Please contact the Public Health department for more information.

[15] National Autistic Society. (2015). *About autism*. Available online: www.autism.org.uk

Chart 1 - ASD in children in Shropshire by age and gender



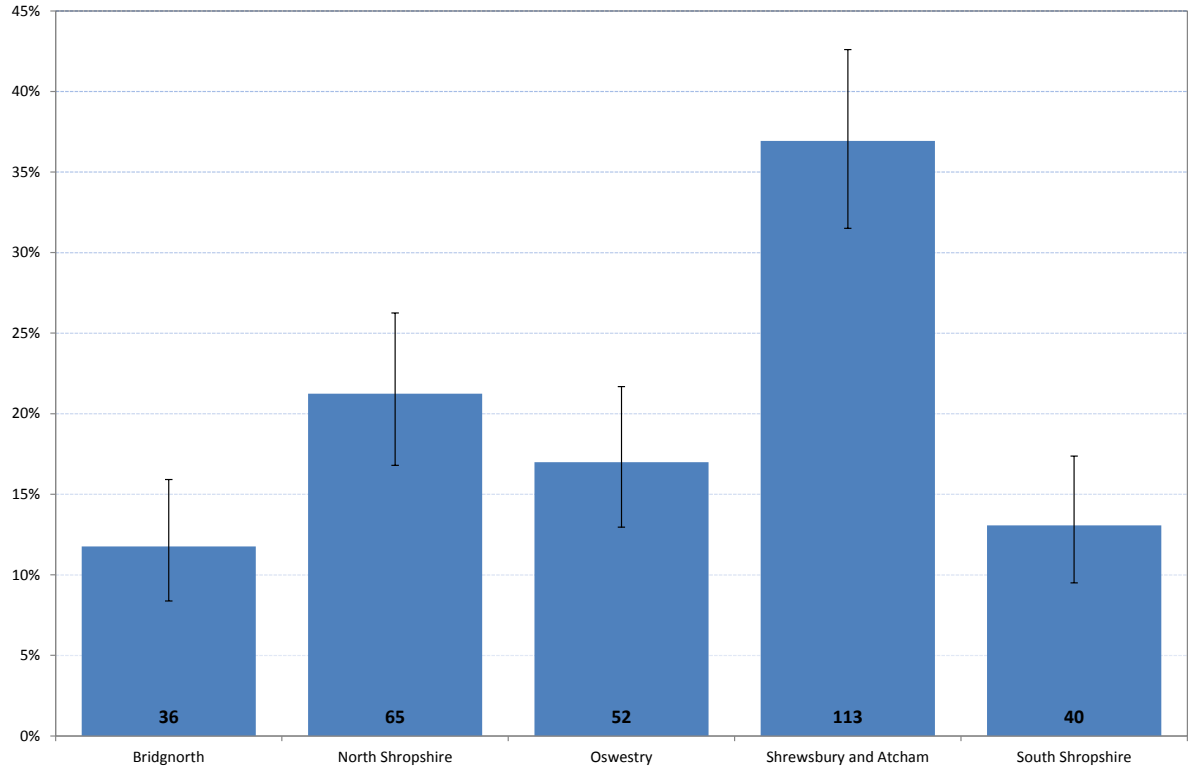
Source: School Census, January 2014, Shropshire Council

Geographic and socio-demographic distribution of ASD

Although estimates suggest that around 1% of children in Shropshire may have an ASD, the distribution of the condition is not even within the population. Knowing and understanding more about the geographical and socio-economic distribution of ASD can enable more efficient and appropriate care of children and young people with ASD, ensuring that their needs are better met.

Chart 2 shows the proportion of all children with ASD in Shropshire (as recorded on the school census) living in each area of the county. The number of children is also highlighted in the base of each of the columns. Shrewsbury had the highest percentage of children with ASD recorded on the school census, which was significantly higher than all the other areas, as the largest population of all Shropshire's children and young people live within the Shrewsbury area. Although ASD accounted for 0.9% 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 1.1% of children in Oswestry. The other areas were between 0.8% and 0.9% of children recorded on the school census.

Chart 2 - Home location of children with ASD in Shropshire by former local authority area



Source: School Census, January 2014, Shropshire Council

Table 2 below shows the rates of ASD diagnosis per 1000 of the population analysed by local authority district. Oswestry appears to have the highest rate of ASD diagnoses; however, it is important to remember that these figures are unlikely to be statistically significant as the numbers of diagnoses are so low.

Table 2 - Rates of ASD per 1000 of the population by former local authority district

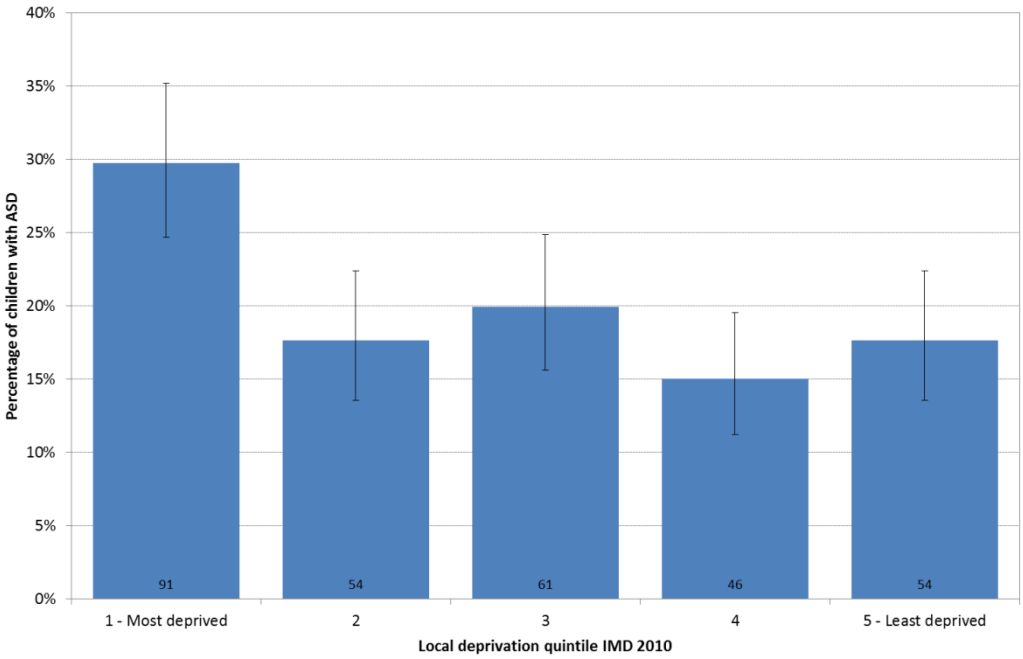
Former Local Authority District	Rates of ASD diagnosis per 1000 of the population
Bridgnorth	2.9
North Shropshire	3.8
Oswestry	4.6
Shrewsbury & Atcham	3.9
South Shropshire	3.9

Chart 3 shows the relationship with ASD and deprivation in Shropshire. There were significantly more children with ASD recorded on the school census living in the most deprived areas of the county compared to all other areas. Additionally around 19% of children with ASD in Shropshire had free school meals at the time of the school census, e.g. recorded in January as receiving free school meals. This is compared to 11% of the total recorded population of children on the school census.

A significant proportion of children with ASD (as recorded on the school census) live in the north of the county. This is congruent with other information we hold in regard to prevalence of SEND across the

Shropshire Council area: the north of the county has the most wards where the rate is significantly higher than the Shropshire average for the rates per 1000 children assessed for SEN[16].

Chart 3 – Home location of children with ASD in Shropshire by deprivation



Source: School Census, January 2014, Shropshire Council

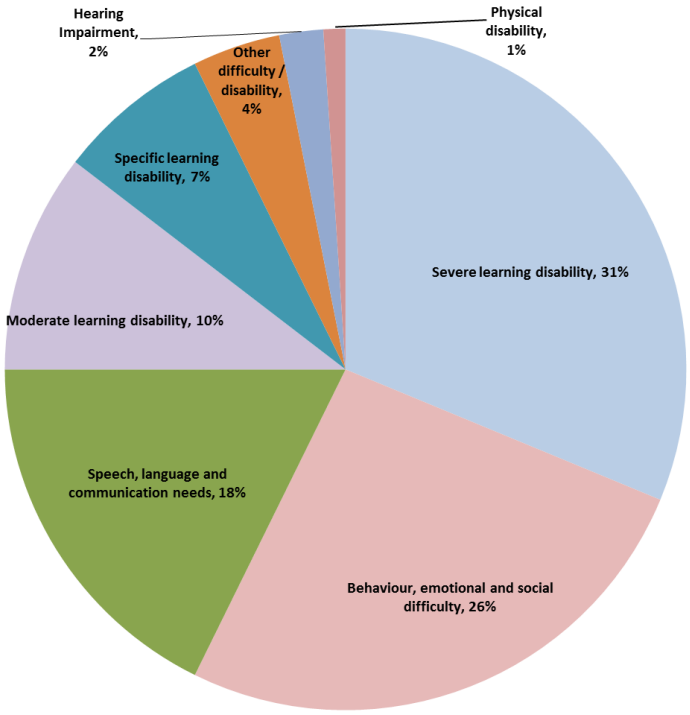
ASD and multiple vulnerabilities

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 30% of children with ASD were also recorded on the school census as having another special educational need. Chart 4 highlights the type and proportion of additional special educational needs of that 30% of children recorded on the school census as having ASD in Shropshire.

The most likely additional special educational need of children with ASD recorded on the school census in Shropshire was severe learning disabilities, followed by behaviour, emotional and social difficulties and then by speech language and communication needs.

[16] Shropshire Council Public Health Intelligence Team. (2014). *Information on SEN provision need in Shropshire*. Please contact the Shropshire Public Health department to access the full report.

Chart 4 - Additional special educational needs of children with ASD in Shropshire



Source: School Census, January 2014, Shropshire Council

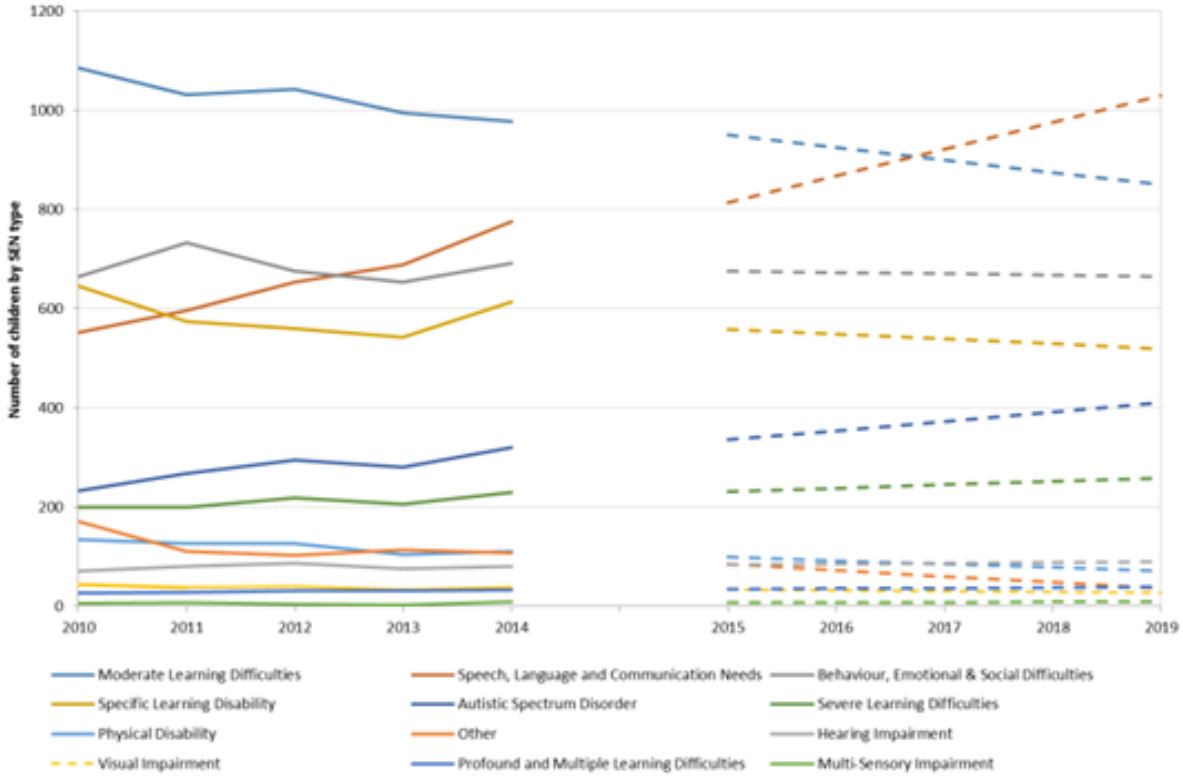
Future predictions – prevalence and need

Data from the Office for National Statistics (ONS)[17] using the 2006 based sub-national population projects estimates that the Shropshire Council area population is projected to increase by 16.9% from 289,300 to 338,000 in 2031. The increase in population may put additional demand upon services, including provision for ASD. However, ONS projects a decline in the Shropshire population among children and young people aged 10-14 years(1.3% projected decline) and those aged 15-19 years old (5.8% projected decline).

Chart 5 below indicates the trends and predictions for children with SEN in Shropshire.

[17] Office for National Statistics. (2008). 2006 Based sub-national population projections. Available at: http://www.ons.gov.uk/ons/rel/snpp/sub-national-population-projections/2006-based-projections/index.html

Chart 5 – Trends and predictions for numbers of children by SEN type in Shropshire



Source: School Census, January 2014, Shropshire Council

Chart 5 displays forecasts based on the past five years of data from the school census. The chart uses data to reflect numbers with statements of SEN (as was in January 2014) and those receiving School Action and School Action Plus. Chart 5 indicates that overall there has not been any significant change in the number of children with SEN, however, it is predicated that change is expected in some SEN types, particularly a projected increase in the numbers of children with speech, language and communication needs, ASD and severe learning difficulties. Although census projections estimate a decrease in the population aged 10-19, improved identification and assessment measures are predicted to result in increased prevalence of ASD overall.

4. Pathways into Services

Concerns about the development of a child may be raised by a variety of people. Parents or carers may discuss concerns with health professionals or a child may present at a universal setting such as a school, nursery or children's centre. Referrals for assessment take different routes depending upon the age of the child.

Please see the appendix for the complete identification and assessment pathways from CAMHS, COMPASS and Early Help.

Identification

Children aged under 5 years old are referred by a health professional (Health Visitor or GP) to a Community Paediatrician, who may refer the child on for a multi-disciplinary assessment at the Child Development Centre.

Children and young people aged 5 - 18 years old are referred through COMPASS, Shropshire Council's single point of co-ordination for Early Help Services (see pathway in appendix). Parents or carers can self-refer, or referrals can be made by schools or other universal settings. If there is sufficient evidence[18] of a possible autism specific disorder the child will be referred to CAMHS (Child and Adolescent Mental Health Service) for assessment. A targeted Early Help service may also be offered or the parents or carers may be signposted to universal services.

Children may also be referred for other assessments such as an assessment for an Education Health Care Plan (EHCP) or assessment by other services such as Occupational Therapy or an Education Outreach Service (e.g. Woodlands or Spectra). These assessments are separate from the ASD diagnostic pathway; some children will receive these assessments and others will not, but their findings can inform the assessment process.

Young people aged 18 – 25 years old will approach their GP for a referral to either the Community Mental Health Teams (CMHT) or Learning Disability Services (if they have a Learning disability as well as a possible ASD).

Assessment

Assessment for an ASD can be a lengthy process. It relies on the collection of evidence from a number of settings; home, nursery and school.

Children aged under 5 years old – the child may be invited to attend assessment sessions at the Child Development Centre where professional from different disciplines will observe the child and report their findings.

Children and young people aged 5 to 18 years – CAMHS will collect information from parents or carers, the child and from school. They will find useful any other assessments that have been done or are due to take place. The child may be invited to an assessment appointment where a structured form of assessment is undertaken.

5. Providers and Service Activity

At least 18 organisations support children and young people's autism in Shropshire. These include various services commissioned by Shropshire Council, the CCG and schools as well as other voluntary organisations and projects that operate across the county.

[18] To help Compass make a judgement around next steps it is helpful for parents & carers or others to provide evidence of their concerns around the child's behaviour.

Educational Provision

A range of educational provision exists across the Shropshire Council area. The majority of children and young people with an ASD attend mainstream schools. However, there are a number of more specialist provisions available within the county. These include:

Name of Educational Provision	Type of Provision	Age Range
Severndale Specialist Academy	Special school	Age 3-19 years
Tuition, Medical and Behavioural Support Service (TMBSS)	Specialist provision	Age 5-16 years
Woodlands School	Special school	Age 11-16 years
Kettlemere at Lakelands School	Specialist provision at mainstream school	Age 11-16 years
Severndale at Mary Webb School	Specialist provision at mainstream school	Age 11-16 years
Various independent providers such as Cruckton Hall and Overley Hall (as well as out-of-county provisions such as Bettws Lifehouse)	Specialist, non-maintained educational provision	Age 8-19 years (approximately)
Specialist, independent college provision such as Condover College and Derwen College	Specialist, non-maintained educational provision	Age 16 or 18+
Futures at Shrewsbury College	Specialist college provision	Age 16-25

Placements in independent schools can be costly. In 2012/13, 27 Shropshire students with ASD attended specialist, non-maintained provision at a cost of more than £2 million[19]. Shropshire Council Learning and Skills department has been investing in specialist provision attached to mainstream educational facilities. Most recently, in September 2014 the Kettlemere hub providing specialist teaching provision to pupils with communication difficulties opened at Lakelands Academy School in Ellesmere.

Voluntary and Community Sector

Several organisations and partnerships across the voluntary and community sector aim to improve the experience of children and young people with ASD and offer services, advice and opportunities to children and young people with autism and their families. They aim to help individuals with ASD to access the specialist care and support that they require to fulfil their potential and to lead rewarding lives. Although some voluntary and community sector organisations are commissioned to provide services, there are many that support families without this commissioner relationship.

Autism Snapshot Survey – Providers

During summer 2014, Shropshire Council conducted an autism snapshot survey amongst organisations that support children and young people's autism in Shropshire (please see Appendix for full document). Several, but not all, providers completed the Autism Snapshot Survey. The following information is garnered from responses to that survey. Therefore information from other providers (who did not

[19] Shropshire Council. (2013). Special Education Needs strategy – paper to Cabinet 20th February 2013. Available from www.shropshire.gov.uk

complete the survey) is missing. This includes several providers of Short Breaks. Table 3 below indicates the organisations that responded to the Autism Snapshot Survey in 2014.

Table 3 – Providers who responded to the Autism Snapshot Survey in 2014.

Shropshire Parent and Carer Council	Shropshire Council Education Improvement Service	Autism West Midlands	Information Advice Support Service (formerly Parent Partnership Service)
Children with Disabilities Team	Consultant Paediatricians (Shropshire Community Health NHS Trust)	Educational Psychologist Service	Speech and Language Therapy & Occupational Therapy
CAMHS (Shropshire Community Health NHS Trust)	Short Breaks	YSS – Enhance Service	SPECTRA
Albrighton Trust	Taking Part	Woodlands Outreach (ASD)	

Details of services collated from Shropshire Council's 'Autism Snapshot Survey', 2014.

Other providers who were invited to participate in the Autism Snapshot Survey included:

Early Help (Shropshire Council)	Severndale School – Outreach	Educational Psychologist Service

Commissioned Services in Shropshire

Both Shropshire CCG and Shropshire Council commission services within the Shropshire Council area.

Shropshire CCG commissions the following services:

Services Commissioned by Shropshire CCG	**Provided by**
CAMHS	Shropshire Community Health Trust
Consultant Paediatricians	Shropshire Community Health Trust
Occupational Therapy	Shropshire Community Health Trust
Speech and Language Therapy	Shropshire Community Health Trust

Shropshire Council commissions the following services:

Services Commissioned by Shropshire Council	**Provided by**
Information Advice and Support Services (IASS) (formerly Parent Partnership Service)	Telford & Wrekin CVS
Short Breaks	Various providers

Services jointly commissioned by Shropshire Council and Shropshire CCG:

Jointly Commissioned Services	Provided by
Autism West Midlands	Autism West Midlands
Community Support & Playschemes	Action for Children
Enhance Service (Early Help)	YSS and Homestart
Residential provision	Action for Children

Shropshire Council provides the following services:

Services provided by Shropshire Council
Adult's Services (including Transition)
Children with Disabilities team
Children's Services
Early Help Services (including Children's Centres, Targeted Youth Service and Parenting Support)
Education Improvement Service
Educational Psychologist Service
Safeguarding

What services are provided?

Table 4 indicates the support that each organisation provides to children and young people with autism and their families.

Table 4 – Support provided by Shropshire Council area organisations to families with autism

Organisation	Support provided
Albrighton Trust	Provides high standard facilities and offers a range of esteem-building activities for children and young people with SEND. They promote positive outdoor activities in a 'green-blue' environment. Young people can build their confidence in a safe and secure outdoor environment.
Autism West Midlands (AWM)	AWM Shropshire service supports families and professionals working with children 0-18 in the county. Support to families includes individual advice and information (via advice appointments and targeted help at home) about autism and how it affects their child; advice on managing behaviour and the provision of personalised strategies to use at home. The service also provides advice on the assessment process and accessing other services. A programme of parent training courses is delivered across the county and AWM facilitates informal opportunities for support alongside other families (coffee mornings and holiday activities). Training for professionals supporting families is also delivered. In addition to the Shropshire Council/CCG commissioned children's service AWM supports the new Adult Autism Hub at Louise House and delivers individual support to a small number of young adults via personal budgets.

CAMHS	Offers assessment and treatment for children and young people where there are concerns about a child's emotional, behavioural or mental health difficulties. Work with children, young people and their families using a variety of skills to meet needs. Specialist behavioural modification is offered to children with learning disabilities who have extreme, challenging behaviour.
Children with Disabilities Team	Support the child or young person to have an independent life and to access the community, complete assessments for safety issues in the home and help to build peer relationships.
Consultant Paediatrician	Community paediatricians have specialist skills and knowledge in child health and development. They can diagnose conditions, provide support, manage and co-ordinate community care for children with a range of developmental, sensory and physical impairments. They provide medical reports as part of the statutory process for creating an EHC plan, lead the multidisciplinary assessments in the Child Development Centres and are being trained to use the 3di Autism assessment tool.
Early Help and Compass	Early Help describes the early intervention and support that can be provided when a child or young person's needs are not being met through routine universal services but they do not meet the threshold for a specialist service. Early Help offers a range of tools and resources for professionals, training for practitioners, details of providers such as Enhance, Targeted Youth Support, Family Solutions, Lifelines and Children's Centres. Early Help pathways are co-ordinated by Compass which uses an integrated team approach to triage cases on a daily basis to progress support, as well as providing a single point of contact for professionals to obtain advice and support.
Education Improvement Service	Offers awareness training to staff and schools.
Educational Psychologist Service	The Educational Psychology Service provide psychological advice as part of the EHCP process, this helps the local authority when decision-making around placement and provision. The service provides advice as part of the Child Development Centre multi-disciplinary assessment. The service can provide consultancy advice on ASD.
Information Advice and Support Service (IASS)	Accessible, confidential and impartial information provision. Advice and support around SEN, disabilities and health and social care which increases confidence to participate in decisions and empowers families. Provision of support groups for parents and carers, SEN surgeries, signposting, paper copies of information and ASD conferences.
Occupational Therapy	Enable children and young people to function at the best of their ability and provide advice for children whose ability to carry out functional skills is compromised as well as children who are experiencing sensory processing difficulties or complex neurological difficulties. Advice and support is offered for self-care, classroom activities and leisure activities. The team provides input into multi-disciplinary assessments at the CDC (Child Development Centre).
Perry Riding	Provides short breaks to families of children with SEND. Allows families time away from responsibilities and gives children and young people the opportunity to improve their physical and mental health through education and fun with horses. Provides the opportunity for social activities amongst young people.
Severndale Academy	Offers training and pupil support to staff in all educational

Support - Severndale School Outreach	establishments and to practitioners.
Shropshire Parent and Carer Council (PACC)	Offers range of information provision, support to participate in decision-making (including opportunities to share experiences of services and influence service design), peer-to-peer support, ASD specific OASIS group 'Spectrum', awareness raising with professionals
Spectra	Provides direct pupil support through one-to-one sessions, offering specialist strategies, offers advice, targets and strategies for the school day, offers transition support, provides resources for children and young people, signposting and advice to parents/carers, delivers specialist training adapted to settings.
Speech & Language Therapy	Individual appointments, multi-disciplinary appointments at the CDC, school and pre-school visits, home visits, training and coaching for parents/carers and other practitioners, parent groups, provision of strategies, information and resources.
Taking Part	Provides short breaks to families. 'Moving & Grooving' is a physical activity session that helps children and young people with disabilities to become more active. Support and advice is also offered to families. Children and young people have the opportunity to try new activities, make new friends, improve communication, gain confidence and improve their health.
Woodlands Outreach (ASD)	Provides support to individual children and young people who present with social, emotional and behavioural difficulties, ASD and learning needs. Qualified and experienced staff can provide a range of support, materials and training for schools and professionals.
YSS – Enhance Service	Offers information and advice to families, suggest strategies and give reassurance. Supports families in gaining a diagnosis where this is appropriate and beneficial. Provides support for communication with schools and agencies.

Whilst some organisations that responded to the Snapshot Survey were able to supply information on the number of children and young people that they support, it is not possible to determine the definitive number of children and young people with ASD traits supported across the county as a whole.

Table 5 indicates the number of children with autistic traits that providers estimate they were currently supporting at the time of the Autism Snapshot Survey in September 2014.

Table 5 – Number of children with autistic traits being supported by Shropshire organisations

Organisation	Number	Organisation	Number
PACC	**167**	**Perry Riding**	**20-30**
Autism West Midlands	Total number on database: **785** with autism/autistic traits/ currently being assessed Support figures during 2013/14: **337** families receiving by individual support **102** families attended parental training **65** children supported by short	**Taking Part**	During the last quarter, **10** children with autistic traits

	breaks activities		
Information Advice and Support Service (IASS) (Formerly Parent Partnership Service (PPS))	**55**	**Consultant Paediatrician**	Data not collected
CDT Care Manager	DCT **71** Short Breaks **359** OT caseload **27**	**Education Improvement Service**	No information provided
CAMHS	CAMHS Shropshire open cases: **225** CAMHS LD: **49**	**Albrighton Trust**	Not able to quantify
YSS	**18-25** children with autistic traits at any one time	**Speech & Language Therapy**	Data not collected
Spectra	**200**	**Occupational Therapy**	Data not collected

Information around specific service activity

Short Breaks

Short breaks provide opportunities for children and young people with disabilities to spend time away from their main carers. This can include breaks spanning a day, evening, overnight or weekend and they can take place in the child's home, the home of an approved carer, or a residential or community setting. During 2014/15 there were 17 providers of short breaks including organisations such as Perry Riding, Taking Part and Action for Children.

In 2014/15, 271 children accessing short breaks were recorded as having an ASD. Of these, 205 were male and 66 were female. 209 of these children who accessed short breaks in 2014/15 also accessed short breaks in 2013/14.

Of the 271 children with ASD, 99 lived in the Central area, 106 in the North and 56 in the South of the Shropshire Council area (this reflects the earlier findings that a significant proportion of children with ASD live in the north of the county).

Of these 271 children and young people with ASD, 101 attended a special school, 129 attended a mainstream school, 5 were home educated and the other 36 did not respond.

How are services being aligned with the Children and Families Act 2014?

Part 3 of the Children and Families Act 2014 relates to 'Children and Young People in England with Special Educational Needs and Disabilities'. Local authorities and other services have a legal duties regarding:

- Ensuring that children, young people and their parents/carers are able to fully participate in decisions that affect them
- Publishing a 'Local Offer' online
- Having joint commissioning arrangements in place between local authorities and CCGs

- Having provision to conduct Education, Health and Care assessments and Education, Health and Care Plans

The Shropshire Council Learning and Skills team have been working with both the Children's and Adult's Services teams as well as Shropshire CCG and other health colleagues to develop existing services and provision to meet the SEND requirements of the Children and Families Act 2014. This has involved the development of a 0-25 strategic group to respond to these requirements. The new Education, Health and Care (EHC) assessments and Education, Health and Care Plans (EHCPs) are now used and Shropshire's Local Offer is published on Shropshire Council's website[20].

Insights from providers in Shropshire – Autism Snapshot Survey

13 providers responded to Shropshire Council's Autism Snapshot Survey in 2014. The organisations gave detail of the way in which their service operates, how the services meet the needs of children and young people with autism, and detailed gaps they perceived to exist in the provision of services. The information included indicated that:

- There are at least 68 full time equivalent and 19 part-time staff who support children with autism in Shropshire.
- There are at least 100 volunteers supporting Shropshire children and young people with autism.
- The majority of supporting organisations operate within communities or the home setting, with a smaller proportion of organisations operating in schools.
- Estimations of the number of children and young people with autistic traits being supported by organisations varies, and it is difficult to calculate the exact number of children and young people receiving support as many will access more than one service. Larger organisations such as Autism West Midlands provided support to 502 families during 2013/14 whereas organisations such as Taking Part supported 10 young people with autistic traits during the quarter April-June 2014.
- Different providers are able to provide support to different age ranges of children and young people with autism. Many are able to provide support from birth, however others have particular age ranges they support. For example Taking Part supports children in the age bracket 8-18 years.
- Different organisations work to meet the different needs of children with autism and their families. Various organisations provide the following: information and guidance, support to families, advocacy, awareness raising, clinical support, conducting of assessments and provision of diagnosis where required, provision of strategies and resources to schools and families.
- Organisations report that parents and carers find their services supportive, helpful in providing information about autism, and that as a result children and families feel more confident in managing their autism.
- Some providers consider their services to be over-subscribed and as a result, they are working beyond their current levels of capacity.
- All providers stated that they work closely with other organisations. This includes working with the local authority and clinical services as well as voluntary organisations.

[20] Shropshire's Local Offer is available at: http://shropshire.gov.uk/local-offer/

In the course of their responses, providers highlighted where they felt gaps existed in service provision. These gaps included:

- Lack of provision for young people with autism to develop their social skills and independence. Possible remedial action could include setting up a befriending service
- The diagnostic pathway is confusing for parents and carers and this is confounded by a lack of support during diagnosis
- Transition to adulthood poses concern about the lack of clarity around pathways for young people with autism
- Support is required for parents and carers dealing with significant levels of aggression from their child
- A more therapeutic approach is required so that interventions are not on a time-limited model
- Support is required for siblings of children and young people with ASD
- Appropriate support for children with co-morbidities, particularly ADHD and attachment disorders
- A lack of post-diagnostic support for parents or carers dealing with a newly-acquired diagnosis.
- Limited clinical psychology input to help with behavioural problems
- Difficulties in the CDC (Child Development Centre) multidisciplinary team being able to reassess children who do not fulfil the diagnostic criteria for an ASD at first presentation to the team. Once these children start school, their ASD may be become more evident
- There is a disparity in the levels of support that children may access through schools; some services are only provided if the school has 'bought in' to the support
- Gaps in the skills and knowledge of staff in preschool and schools

Some stakeholder engagement was also carried out by providers:

CAMHS

In October 2014, Shropshire Community Health NHS Trust published a CAMHS Parent and Carer Forum Summary Report (please see full report in the Appendix). The work to produce the report involved undertaking three focus groups with parents and carers of children and young people accessing the CAMHS service.

CAMHS asked attendees to provide comment on three questions:

- What is good about the CAMHS service?
- Where is there room for improvement?
- What solutions can we identify for improvement?

The results can be summarised as follows:

What is good about the CAMHS service?

- Staff are skilled and empathetic
- Appointment frequency
- Useful training courses
- Responsive if support is needed outside of appointments

Where is there room for improvement?

- Long waiting times
- Support pre- and post-diagnosis for parents, carers and siblings
- Poor or absence of communication whilst waiting for first appointment
- Impact of reduced funding across the economy
- Clarity about level of communication with parents and carers both in consultation and reports or outcome letters

What solutions can we identify for improvement?

- Increase staff skills through training
- Review and redesign pathways
- Introduction of parent and carer groups for support post-diagnosis and explore peer support
- Joint training with CAMHS, SENCOs and social workers working with parents and carers
- Mechanism to monitor the impact of only short-term interventions from early help provision and ability to re-access as required without repeating the referral process
- Support GPs to be confident in their skills and approach to emotional health and wellbeing of young people
- A named contact whilst waiting for diagnosis to be confirmed

Recent developments in Autism Provision

Since the Autism Snapshot Survey was completed in summer 2014, a new provision has been established in Shrewsbury. The Autism Hub is based at Louise House in Shrewsbury and is run by Shropshire Council and A4U. The Hub is well supported by Bromford Housing Group, Autism West Midlands and Shropshire & Telford Asperger Carers Support (STACS). The Hub offers support, activities and opportunities for people aged 18 and over pre- or post-diagnosis of autism. Attendees have access to a computer suite, education and information sessions, and cooking lessons. The weekly Hub works exclusively with individuals with autism and their carers and aims to help individuals by:

- Helping to create coping strategies
- Promoting independent living
- Supporting self-management

6. Stakeholder Engagement

To develop this needs assessment, consultation was conducted with schools, providers and parents/carers invited to give their feedback and experience of autism provision across the county via a survey. A decision was made not to consult with young people aged 16-25 during the development of the needs assessment. Once the recommendations and any gaps in service provision have been identified through the assessment, the Children's Trust will engage children and young people in the development of services that will help to rectify these gaps and improve outcomes for young people.

Copies of the surveys can be found in the appendix.

Stakeholder event – November 2014

In November 2014, a stakeholder event was held to gather the views and experiences of practitioners and parents and carers. In total, around 65 individuals were in attendance.

At this event parents and carers, practitioners and professionals were invited to hear presentations from professionals involved in the assessment process, the delivery of services and the provision of advice and guidance to families of children and young people with autism. Stakeholders were asked to select two age-related areas from a selection of four (Early Years, Primary School, Secondary School and Transition to Adulthood) for the workshops session. Groups were asked to discuss:

- What is working well?
- What is not working well?
- What needs to be better joined up?
- Where do services connect well and what is good about it?
- How could services connect if they do not already?
- How can we use our resources better?
- Other ideas

The full feedback notes from the stakeholder event can be found in the appendix. Highlights from the findings include:

What's working well?

- Support from the VCS including impartial, objective and honest information
- CDC works well for those children that access the process
- Multi-agency approach is best
- Specialist schools – once children gain access – they are well co-ordinated, there is information, staff have good knowledge and skills and learning is tailored to the child
- When transition starts early (this may be a year or more in advance)
- Direct payments and personal budgets (on the whole)
- Autism West Midlands' support is brilliant – they are experts with a lot of ideas
- Having an understanding SENCo
- Services connect well around issues of child protection
- 'You're Welcome' GP scheme is good
- The health multi-disciplinary team is responsive to need
- Short breaks and respite can be good
- EHCP has helped

What's not working well?

- Support and resources for those who don't meet the eligibility criteria for SaLT (Speech and Language Therapy) etc. Currently, accessing the right support relies upon diagnosis
- A lot of change results in families being unsure of what is available and how they can access it
- Poor identification in early years
- Professionals not understanding, particularly when behaviour at school may be different to at home
- Teachers and GPs require a better understanding of SEN
- CAMHS is good but the waiting list is too long
- If needs are not picked up at primary school it takes too long to gain support at secondary school
- SaLT is under-resourced and resources reduce as the child gets older

- Gap in service for those who do not access universal services (e.g. not in school nor visit GP)
- Services cannot be confirmed over a longer time period or are time limited

How could things improve?

- Better data sharing across services and agencies to save families having to complete forms over and over and share the same story – need to overcome issues around data sharing
- Families are not always aware of what is going on or is available in the local area
- Diagnosis is not important – the support is
- A single key worker – consistency
- Antenatal support with parents could help to develop positive and healthy attachment
- The Local Offer should help services to connect
- Need a stronger support network for families – peer networks, could use parents as volunteers to handle calls from other parents. Would be great to have a forum for families.
- Need support for decision making (age 14 etc) including an allocated social worker from adult services for age 14+ review
- Life skills and independence need to be a part of the curriculum
- Services need to be available outside of school hours
- SDC care assessments should begin earlier (age 14)
- Universal services such as Brownies and youth clubs need to be made accessible
- Need to increase resilience – not just managing the environment
- Explore the role of the School Nurse for transition
- Link with the 'adult' autism hub
- Large numbers of professionals at meetings is overwhelming
- Families need to be provided with clear information by people who know the system

Ideas?

- Develop a 5-8s virtual team based at the CDC
- Regular social activities for families to come together
- Use secure email address to enable sharing of information and improved communication between agencies
- Virtual meetings or video conferencing to allow individuals to submit information if they can't be at a meeting in person
- Special Schools could be used more as a resource to the wider community
- Parents can help to collate information on what is available
- Celebrate and share good practice to gain momentum. Shropshire autism charter mark?
- An initiative to raise awareness in schools
- Teen mentors or buddies in school and community
- Resource library in schools for parents to borrow resources
- Provision of a 'menu' of services available for those who will be going through transition

Feedback from consultations: Surveys - March-April 2015

During March 2015 three consultations were opened to invite feedback from parents/carers, schools and providers. The questionnaire for parents and carers was available on the Shropshire Council website and was promoted widely through Shropshire Newsroom articles, voluntary organisations and schools. The surveys for schools and providers were sent only to appropriate contacts. The survey for schools was distributed via the schools' bulletin (the invitation was sent to independent schools separately) and

reminder emails were sent to schools. The survey for providers was distributed through the autism steering group to 22 providers. The survey for parents and carers was distributed via members of the 0-25 Autism Working Group (through organisations such as Autism West Midlands and PACC) to their contacts, published on the Shropshire Council newsroom page, promoted by social media, the Family Information Service, Healthwatch and others. The link to the survey was also sent to all schools via the Schools' Bulletin alongside a letter that could be sent or emailed to parents/carers. Some schools requested paper copies of the survey and letters for parents and carers.

The full analysis of the survey responses (completed by Shropshire Public Health Intelligence Team) can be found in the Appendix of this assessment.

Schools' responses to the survey

In total, 25 of Shropshire's 166 state schools, independent schools, specialist schools and nurseries responded to the survey. The majority of responses (84%) were from primary schools. On average, each school had around 2 children with a diagnosis of ASD, with an average of nearly 5 (4.7) further students per responding school demonstrating autistic traits.

- The majority of responding schools expressed that they felt the numbers of children with autism or demonstrating autistic traits had either increased (44%) or remained the same (36%) over the past 2-3 years. Only 4% of schools felt that the numbers had decreased.

One school commented that:

"Increased staff and parent awareness has led to greater numbers of children being recognised"

- Similarly, most responding schools (60%) stated that they now saw more children with complex needs. A further 32% of responding schools felt that the level of need had remained the same.

- All responding schools were able to describe the steps that they would take to understand better the needs of a child demonstrating autistic traits but not all schools would use the same process or contact the same agencies. Responding schools indicated that a variety of mechanisms are used to support children and young people with ASD. The most featured named support included:

    - Local authority services such as TAMHS, All In and Early Help (60% named these services)
    - External assessors and support such as Severndale Outreach and Woodlands Outreach (48% named these services)
    - Voluntary and community sector organisations such as Autism West Midlands and the Parent Partnership (36% named these services)

- In terms of knowledge and understanding of autism, the majority of responding schools (68%) indicated that they either agreed or strongly agreed that their staff had sufficient levels of knowledge.

- The majority of schools 52% (combined charitable external training and external training) said that they had received ASD training from external sources such as Autism West Midlands, Spectra, Severndale and Woodlands Outreach; whilst 40% indicated that they used a variety of internal ASD training resources including: CPD, increased general awareness, sharing of ASD training and 1:1 child

ASD working experiences. Schools indicated that they would welcome further training, particularly with regard to areas such as:

- Understanding ASD
- Help with communication strategies and materials
- Funding for training
- Whole staff training
- Training in reducing the anxieties of children with ASD

- The majority of the responding schools (72%) indicated that they felt either confident or very confident in their schools' ability to meet the needs of a child with ASD. Only 8% of respondents felt that they were not very confident to do this. Comments from schools who were confident in their ability to meet need included:

"We have been particularly successful in supporting ASD/Asperger's pupils with statements and have used the same strategies with children (undiagnosed) who have similar needs"

Those who felt not very confident cited difficulty in schools ever being able to 'fully meet' the needs of a child with ASD:

"It depends on 'meet the needs'; we manage children with ASD very well and I believe we are doing our very best, but whether we are fully meeting their needs? I doubt it".

- Similarly, the majority of schools (60%) either agreed or strongly agreed that their staff understood which services other services were available to support children with autism and their families; 8% of schools disagreed with this statement. Schools felt that levels of understanding varied across school staff, but that the SENCo would be more knowledgeable. Comments from schools where staff felt that they understood the availability of services included:

"This is again dependent upon the member of staff, but hopefully with the help and support from the SENCo, we can pool resources and understanding to best support the child and family"

"We have recently had to temporarily exclude a child with ASD and suddenly all kinds of support, of which we were previously unaware, came into force. We know now who does what and what is available better than we did before. However, CAMHS is always difficult to access and, in my experience, they don't work in partnership with us as a school. There is definitely a lack of 'joined up thinking'. I think all the changes of services/re-organisation, change of names etc. has made it difficult for everyone. Don't know what the answer to this is".

Where the response was neither agree or disagree, a typical comment was:

"I would hope staff would seek advice from SENCo. Not convinced we know all services available but would know to access the local offer directory"

And where schools disagreed, comments included:

"We know some services but there may be others we are not aware of"

- 64% of responding schools either agreed or strongly agreed that their staff understood how to access services to support children with autism, whilst 28% neither agreed nor disagreed and 8% disagreed. It was suggested by respondents that it can be very difficult to access the professionals who can give a diagnosis.

- In terms of whether staff felt they had sufficient knowledge and understanding of how autism has an impact upon families, views from responding schools were mixed. Whilst the majority (36%) agreed that staff did have sufficient understanding (combining 'agree' and 'strongly agree', this total rises to 56%), 20% of responding schools did not feel that they had sufficient knowledge of how families are affected by autism. Some schools saw themselves as the 'first line of support' for families as they try to get a diagnosis for their child. Comments included:

"Our knowledge of the impact of autism on families is particularly acute as we are the first line of support for these families as they try to get a diagnosis for their child which is often a cause of a lot of stress for the families".

"Again, varies between staff. This is something that we need to address in order to further improve the working relationship between school and home, to support children and their families"

- The majority of schools either agreed (52%) or strongly agreed (28%) that all staff were able to access training around ASD. Schools mentioned the cost of training and the difficulties this brings for small schools. Comments received from those who agreed or strongly agreed included:

"*A teacher with a child who exhibits ASD tendencies, recently attended a course on how to support girls with ASD, which she found extremely useful*"

"*We try as a school to provide training in ASD"*

Examples of comments made by those who disagreed or neither agreed or disagreed included:

"We currently are funding 2 members of staff to attend a 6 week course run by Acorns. The cost implications are great for a small school. I would like all my staff to have quality training".

- The majority of ASD training accessed by schools was through alternative providers (44%) such as Spectra, Severndale and Woodlands Outreach. 40% stated that training was provided internally though CPD.

- When asked to provide examples of good practice in terms of working together with other organisations to support children with autism and their families, results from schools indicated that the following spectrum of links were utilised (see table 6 below):

Table 6: Good practice links to other organisations

Category	Numbers of schools	%	Examples
LA	9	36.0%	TAMHS, SENCo, BST, TMBSS
School support - internal	7	28.0%	Working with parents, TAC Meetings, Parent training,
External provider	6	24.0%	Woodland Outreach,
Charitable organisations	5	20.0%	Autism West Midlands, Parent Partnership, Riding for the Disabled
Health organisaiton	5	20.0%	CAMHS, SALT
Advisory	<5	4.0%	Spectra
Total Number of Schools	25		

Source: Shropshire School Autism Survey 2015

- Other comments included arranging opportunities for parents/carers to speak with a representative from PACC and providing training for parents/carers and staff. Examples of comments relating to good practice are as follows:

"*We run an SEN coffee morning group every half term with (a person from) the Parent and Carer Council. This gives parents an impartial person to chat to about their child's needs. We encourage Autism West Midlands to attend SEN parent meetings to ensure that ASD needs are added to PCPs. We take part in Autism Awareness Month and encourage parents to attend workshops at school"*

"Working with parents to access support from a range of services- providing training for parents and staff and ensuring a shared approach occurs so that the child feels secure and happy"

"SENCO working with parent and CAMHS to achieve a diagnosis and ensure the pupil is supported and has a smooth transition into Y6 and then to secondary school"

"We work alongside Spectra to provide small group intervention for children who are diagnosed or have ASD traits"

- Schools were asked to give examples of barriers that hindered working with other organisations to support children with autism and their families. A lack of funding (36%) was cited as the main barrier, followed by referrals into organisations such as CAMHS and TAMHS (32%). 24% of respondents also cited a lack of available information for ASD service provision and general information for families. Comments received from respondents on barriers to working with other organisations included:

"*We have found parents to be a barrier to getting further help or assessment. Where teachers have identified ASD traits, parents have not wanted to take it any further"*

"*Difficult to contact CAMHS - when finally receive a response, generally children do not meet the threshold for support. GPs do not refer to any professionals but constantly pass back to school. Lack of funding for Ed Psych/Woodlands/Ta support in small school budget"*

"Lack of funding, time, awareness, disruption to family life"

"We have felt that when we refer children to CAMHs for autism they do not seem to take on board what the school is saying and parents may be resistant to a diagnosis of Autism and CAMHs seem to put more emphasis on this. We are often left then trying to support a child showing signs of Autism but unable to access further support because of the CAMHs report.

- Additional comments were invited at the end of the survey, the majority of which related to more ASD support in diagnosis, school transition and generally within the school environment. Further ASD staff training was also raised as an issue. Examples of comments included:

  "It is very difficult to get a diagnosis of ASD in Shropshire as it is virtually impossible to get children appointments with CAMHS where their difficulties can be appropriately diagnosed by the relevantly qualified professionals. A diagnosis is not a cure, but it can be enormously reassuring for a child and family to know why certain behaviours are being exhibited. As one child said recently on being told he had ASD 'Good. At least now I know I am not mad!'"

  "We still find the Inclusion Development Plan materials on ASD a very useful tool for working with new staff. Parents report they still find little support when they move on from our setting (support groups). We do signpost families towards support. One of our families has set up a Facebook group for families whose children have ASD"

  "*I am so pleased that this survey is being conducted. ASD is such a complex area as children have so many different needs. Honestly I feel we struggle to do the best for these children. There seems to be a paucity of skilled advice or maybe I expect too much. We were told by one outside agency, when feeling totally out of our depth with one child who was scaling walls to get out of school and physically attacked staff, that we should be pleased he was in school and wouldn't worry about literacy and numeracy. Is that acceptable? Some guidance on this would be very, very welcome".*

Providers' responses to the survey

22 ASD service providers in Shropshire working in a variety of teams from ASD specialists to safeguarding and voluntary/charitable organisations were e-mailed a copy of the survey; 11 of which completed the survey (50%). Small responder numbers resulted in inconsistences in responses; where themes occurred, these have been put into tables (see Appendix for full analysis). The survey was comprised of 19 questions.

- Providers were asked about the type of data that they collect. 45% of the providers that responded said that they stored assessment information such as diagnosis, statements EHCP and other disabilities. 27.3% stored demographic data and the majority (54.5%) stored additional information related to visits and conversations.

- 72% of respondents said that there had been an increase in the number of children with autism/autistic traits being referred to their service over the past 2-3 years. The remaining 28% said the numbers had remained that same and that they had remained the same for between 5-10 years.

- 45.4% of respondents indicated that they had seen an increase in the proportion of children with autism/autistic traits who use their services. Of those 45.4% who stated they had seen an increase, 40% said that the average age had remained the same whilst 40% said the average age had decreased. 27% said that the proportion of use had remained the same.

- Providers were asked about the levels of need and any trends in needs of those accessing their service. Of the 11 responders to the survey, 45.4% said that they now see children with more

complex needs whilst 36.3% said that they hadn't notices any change in need. Examples of trends cited in Q8 included:

- Higher anxiety levels
- More challenging behaviours
- Attachment difficulties
- Greater intolerance of others
- Low self-esteem
- Decrease in basic personal skills ie. toileting
- Greater levels of attention deficit

- Providers were asked to detail any other observations of trends they considered to be of importance when planning services for the future. Of those providers who responded 36% highlighted the need for improved awareness of service provision for both parents/carers and schools as well as improved funding for existing services. Examples of comments included:

  "Parents need to be able to access specialist services and support - such as Autism West Midlands, and IASS (previously Parent Partnership) but they also need to be able to access universal services where there is strong knowledge and understanding about Autism - and the pathways available, and the services and support on offer".

  "Person centred approach, gathering the most amount of information possible to enable more effective support can be given. Diversity in autism reflects the need for us to be able to adapt our service".

  "Self-esteem/confidence and mental health issues are hard to gain support for without a huge costs to school and it would be good to have more availability on this"

- Questions 10-14 reflected on staff or team levels of knowledge and understanding of autism, how this impacts on family life, knowledge on what other services are available and access to training. Table 7 shows the responses to the relevant questions. In all questions the majority of respondents either strongly agreed or agreed (combined) that they had sufficient knowledge or access.

Table 7 Result from survey questions around knowledge and understanding of autism and services

Question	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
Q10: Do you feel your team has sufficient knowledge and understanding of autism.	36.4%	36.4%	0.0%	27.3%	0.0%
Q11: Do you feel your team has sufficient knowledge and understanding of how autism impacts on families	27.3%	54.5%	9.1%	9.1%	0.0%
Q12: Are all members of your team who need access to autism training, able to access it?	45.5%	18.2%	27.3%	9.1%	0.0%
Q13: Does your team understand which other services are available to support children with autism and their families?	27.3%	36.4%	27.3%	9.1%	0.0%
Q14: Does your team understand how to access services to support children with autism and their families?	9.1%	45.5%	36.4%	9.1%	0.0%

Source: Shropshire Providers Autism Survey 2015

Comments made in respect of Q10-14 included:

Q10: "*We have had one training day on Autism which gave us a slight introduction. All the staff were really enthusiastic and enjoyed the session but we feel we could do with a lot more information"*

Q11: *"Staff and volunteers are included in the assessment process and sharing information that is relevant to assist their engagement with the individuals they support, which means they build up relationships with families as a whole"*

Q12: "*As well as undertaking training we mentor new staff and volunteers and are continually looking at new concepts and ways to support most effectively"*

Q13: "*It would be helpful if the other services you refer to are listed, to indicate if we knew of them or not. We are aware of Early help, sure start and CAMHS, the Empathy group, but not others. We tend to contact AWM straight away because of good user feedback*"

Q14: *"The way that services can be accessed changes periodically and this information needs to be clearly shared with other relevant services"*

- Providers were asked what they felt was working well for their service and what could be improved. Respondents typically said that the following worked well for their service:

  - Providing respite care
  - Trust with families
  - Strong relationships with other organisations such as Autism West Midlands

- 36.3% of respondents said that increased funding and resources would improve their service provision; whilst 18% thought that communication was a problem and that a central comprehensive ASD on-line information hub or booklet on (local and national) service provision would be a useful tool for parents/carers and schools.

- Respondents were asked to give examples of good practice in terms of working with other organisations to support children with autism and their families. Respondents cited the following as examples of good practice:

  - Hosting a stall at an Autism West Midlands (ASM) conference
  - Shared CAMHS case meetings
  - AWS sibling workshops
  - Information sharing (within sharing protocols)
  - Hosting parent training courses

- Providers were asked to give examples of barriers to working with other organisations to support children with autism and their families. Responses included:

  - Funding
  - Communication/Information sharing

- Time constraints
- Mistrust of new organisations

Comments included:

> *"Meetings with other agencies, such as CAMHS or AWM or wider county meetings on autism, are not funded and so although very beneficial, the participation of Spectra in these meetings is at a cost to the service*"
>
> *"It is difficult sometimes for some organisations to have an understanding of life within school and sometimes / recognition and trust for what schools do and this can cause barriers"*
>
> *"Lack of understanding about the remit and role of each service"*

- Responders stated that found the following services useful resources for signposting parents and carers:

  - Autism West Midlands
  - Compass
  - Empathy for Special Children
  - Face2Face

Parent and carer's response to the survey

In total, 366 parents/carers responded to the autism needs survey. The full results of the survey are included in the Appendix. Main findings are bullet-pointed below:

- The majority of parents or cares responding to the survey answered the questions about a child of primary school age or secondary school age.

- Of the 366 responses, 66% of the children had received a diagnosis of an ASD and a further 16% were awaiting an assessment.

- The majority of respondents were from the Central Shropshire/Shrewsbury area.

- 45% of parents or carers said that their child also had a learning disability as well as ASD, whilst 34% reported that their child had no other additional needs.

- A significantly higher percentage of ASD was diagnosed by CAMHS (39.9%) whilst 29.5% of cases were still undiagnosed. The remaining 30.6% were either diagnosed by a paediatrician, CDC or 'other' which included: awaiting CAMHS diagnosis, educational psychologist, hospital and SaLT.

- For children who have a diagnosis of ASD, the majority received their diagnosis whilst at primary school.

- 280 responses were received in regard to the type of school that their child attends. 55% of children attended a mainstream school, nursery or early years setting.

- A significantly higher percentage of parents/carers said that their child/children accessed additional support services through Autism West Midlands (AWM) (45%) and CAMHS (Child and Adolescent Mental Health Services) (36%) compared to all the other additional support services listed.

- Whilst the majority of respondents said that their child had not been referred to assessment in the last 2 years, out of those who had experienced the assessment process more recently, there was no significant difference between rates of satisfaction (from very satisfied to very dissatisfied). However, a slightly higher percentage of parents/carers who gave a satisfaction rating said they were 'fairly satisfied'.

- Most comments in regard to assessment were around timing issues (36%), the assessment process (25%) and the diagnosis process (11%).

Example comments in regard to this included:

'It only took 3 months for a diagnosis but had taken 3 years to get a referral to the right person and we have had to push for meeting and assessments to be done. I appreciate that there are too few people with a big work load but my child has suffered because of this and that should not be the case.

'I was very satisfied with the assessment process but the wait to see someone when your child is falling apart and not coping is unacceptable.'

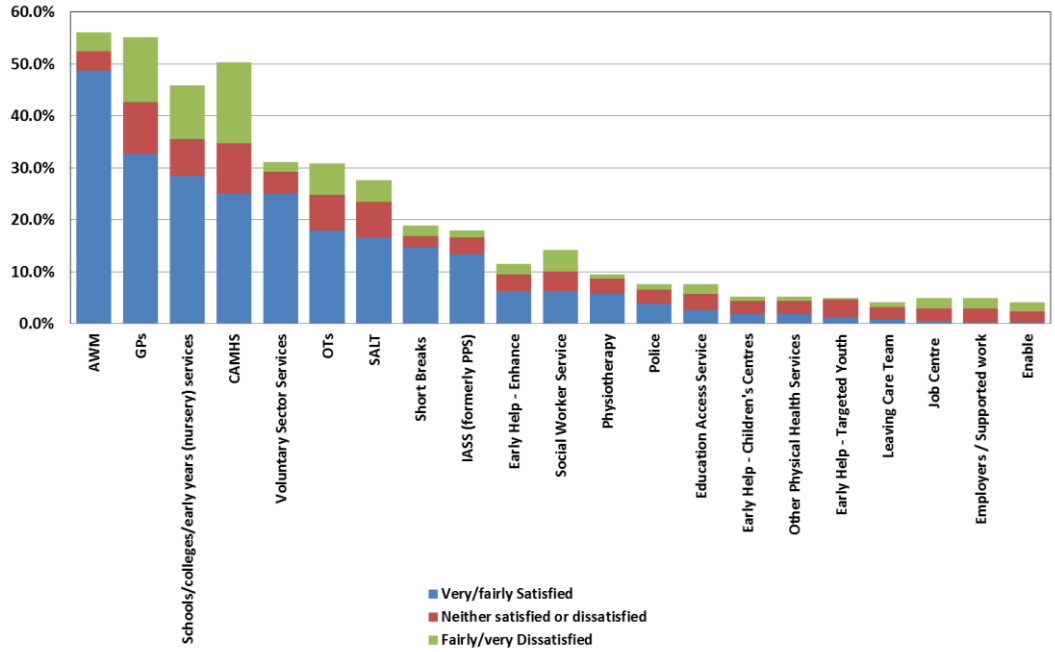
'I have been fighting for a diagnosis for 7yrs. Eventually saw Dr S who is fantastic. After having 2hrs with Dr S my son was diagnosed with ADHD'

'Once we were seen it was fantastic support. Took a long time to be seen by CAMHS'

'The process was long, confusing and I found myself repeating and explaining my child to different health professional/ teaching staff- there was no cross reference, almost no communication between team around child'

- Parents/carers highlighted the services that they accessed. The most accessed services were: Autism West Midlands, GPs and CAMHS.
- Chart 6 below measures satisfaction with services based on the proportion of people that had used the service out of the total respondents (366). The services on the chart with the lowest percentage were those that fewer respondents in the survey had used:

Chart 6: Support services accessed by families (percentage of families accessing the service by satisfaction rating)



Source: Shropshire Parent's Autism Survey 2015

Example comments from parents/carers around services included:

'We find that GPs/hospital staff/other NHS staff can be either fantastic with our daughter, or fail to understand her/autism at all. We feel that it is essential for all medical staff to have a deeper understanding of autism. It is difficult to always have to explain her/ourselves; for example she misunderstands her own pain and that is upsetting when you have to explain that you're not sure what she's done/where she hurts/how bad it is to somebody who doesn't understand. It worries us for her future when we might not be there to translate for her.'

'Unsure, in many instances, what these services offer, the relevance to my child and how to access them.'

'Limited support for academically very able child who has Asperger's. No statement due to ability, but struggled with bullying throughout school, has diagnosed sensory difficulties and social immaturity which causes untold anxiety leading to physical conditions. Short breaks unsuitable as straight after school (most parents do have to work!) Or just plainly not suitable for my child. He struggles with children with additional needs as they are not on the same level as him and never any activities for bright under 10s! No OT support has ever been offered. Given a diagnosis and dropped from a great height to get on with it!'

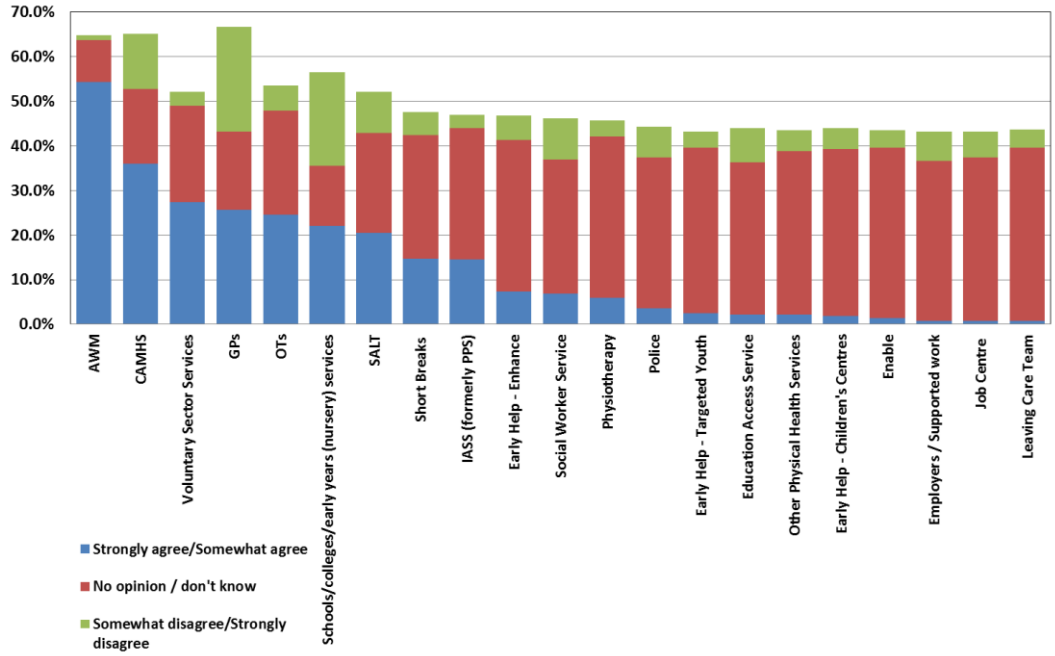
'A4U is the best support we've received; they have listened and supported. Secondary school also helpful as possible but no funding. CAMHS very disorganised and impersonal, although the physiatrist attached has been great. The diagnosis route is poor and does not support parents. Enhance try but are inexperienced. Help is hard to come by, parents need advice that is quick and easily accessible'

'Waiting lists are a big, big problem. You just watch your child deteriorate and feel powerless to help them.'

'Autism West Midlands are a fantastic support & without them I wouldn't have been able to "fight" the battle you come up against as a parent. AWM point you in the right direction as well as giving you hope that ASD is not something of a negative. Without their support & guidance my family wouldn't be where they are now.'

- Parents/carers were asked to state how much they agreed with the statement that 'professionals understand the impact of ASD on family life'. Chart 7 measures the level of satisfaction or agreement that the service understand the impact of ASD based on the proportion of people that had used the service out of the total respondents (366). The services on the chart with the lowest percentage were those that fewer respondents in the survey had used.

Chart 7: Satisfaction rating of whether professionals understand the impact of ASD on family life



Source: Shropshire Parent's Autism Survey 2015

Example comments in relation to professional's understanding of the impact of ASD on family life included:

'Many professionals claim to understand Autism Spectrum Disorders based on years of research and training. However, many do not live with the impact that a child/children on the spectrum has on family life. Even if a child does not get a diagnosis of autism - what happens next? The child will still continue to have emotional/social issues at school and home. Very often parents are left in limbo not knowing what to do next and unsure about where to go for support and understanding. Our GP is excellent, however even he wasn't quite sure 'where to go' when we approached him. Autism WM provide the support, understanding and knowledge of how Autism affects different families. The network of other parents you meet through coffee mornings (Autism WM/PACC) can be just as helpful and supportive as seeing other 'professionals.' Professionals sometimes seem skilled at looking for obvious autistic characteristics but not aware that for some individuals it can be very subtle and not apparently obvious.

'We think that schools need to appreciate the impact on siblings. It is not just the autistic child who needs understanding and support but the siblings too; especially the emotional impact which can be huge.'

'Unless you have a child with autistic traits it is hard to understand how it impacts on so many aspects of your life. Some individuals within some organisations are understanding whilst others are not, it gets better as they get to know us and our child but is still difficult at times.'

- Parents/carers were asked how much they agreed with the statement that 'support services help my child to become as independent as possible'. 280 parents/carers responded to this question with 23% selecting agree/strongly agree, 43% selecting neither agree nor disagree, and 34% selecting disagree/strongly disagree
- Parents/carers were asked how much they agreed with the statement that 'support services help my child's transition to adulthood'. 280 parents/carers responded to this question with 13% selecting agree/strongly agree, 60% selecting neither agree nor disagree, and 27% selecting disagree/strongly disagree.
- Parents/carers were asked how much they agreed with the statement that 'support services join up well to support my child'. 257 parents/carers responded to this question with 16% selecting agree/strongly agree, 30% selecting neither agree nor disagree, and 54% selecting disagree/strongly disagree.

Comments from parents/carers included:

'Services are very hit and miss and very reactive as opposed to proactive. I'm not sure that services support my child to become independent - her disability is managed. Services can 'join up well', but everything is a battle.'

'As someone with an 8 year old recently diagnosed I haven't really been offered any information on services for my daughter apart from being offered medication from CAMHS.'

'The services we access (CAMHS, SaLT etc) are fabulous, and while we understand that time and financial constraints mean sharing information isn't easy, we do feel we are often the messenger between services, and the 'messages' we pass on would be better delivered directly between each specialist.'

- The majority of services are accessed in the Shrewsbury area (53%). Parents/carers have indicated that they would like to access services more locally.
- The majority of parents/carers (56%) do not use directories. Of those who do use directories, the majority use the Family Information Service. Only 3.8% of parents/carers have accessed the Shropshire Local Offer website.
- 45% of parents/carers who access directories rated them as either useful or very useful.
- When asked if they would be happy for organisations to share information about their child, of the 72% who responded, 36% indicated that they would be happy for inter-service shared information. However, 21% stated that it would depend on factors such as the appropriateness of sharing and with whom the information was being shared.

Comments from parents/carers around the sharing of information included:

'I think each child should have an online database that any professional can access to add to or take from at any time. This way a comprehensive picture of the child is available to all who are involved in the case.'

'If info relevant and would help my daughter, not shared for the sake of it.'

'Consent being asked for particular information. Parents should always have ultimate control over the sharing of information and consent to share one piece of information does not imply consent for all information to be shared'

- Parents/carers were asked how much they agreed with the statement that 'services and organisations in Shropshire share information suitably to support my child'. 257 parents/carers responded to this question with 22% selecting agree/strongly agree, 44% selecting neither agree nor disagree, and 34% selecting disagree/strongly disagree.

- Parents/carers were asked how much they agreed with the statement that 'I know where to go for help with regards to my child's behaviour'. 260 parents/carers responded to this question with 39% selecting agree/strongly agree, 21% selecting neither agree nor disagree, and 40% selecting disagree/strongly disagree.

- Parents/carers were asked how much they agreed with the statement that 'I know where to go for support with other areas of family life that are affected by autism'. 260 parents/carers responded to this question with 30% selecting agree/strongly agree, 23% selecting neither agree nor disagree, and 47% selecting disagree/strongly disagree.

- Parents/carers were asked how much they agreed with the statement that 'professionals understand how services work together and are able to guide me/us'. 260 parents/carers responded to this question with 21% selecting agree/strongly agree, 30% selecting neither agree nor disagree, and 49% selecting disagree/strongly disagree.

- Parents/carers were asked how much they agreed with the statement that 'talking to other families helps'. 259 parents/carers responded to this question with 65% selecting agree/strongly agree, 29% selecting neither agree nor disagree, and 6% selecting disagree/strongly disagree.

Comments from parents/carers around support included:

'After diagnosis we were offered absolutely no support or guidance at all we were left to our own devices and left to struggle with an autistic child alone'

'I know where to go with regard to getting help but actually being eligible to receive support is another question.'

'The stock answer we seem to receive from professionals is 'that's not down to us that's down to.....' One service will state it is the others responsibility to provide support, this in turn leads to no support.'

'We have no idea where to go for things like sensory integration therapy or how to get occupational therapy, or what the health and care parts of the EHC plan cover.'

'The most useful information that I have been given has been from Autism West Midlands and PACC rather than Council services'

'Had lots of info via other families. School SENCo currently very good at keeping us informed.'

- Parents/carers were asked to detail the support that has worked well to help their child and family. The most common themes mentioned were:
  - Autism West Midlands support - 17.7%
  - School support – 13.6%
  - CAMHS support – 5.3%
  - Support from other families – 4.9%
  - Other – 39%

Comments about support that has worked well included:

'AWM saved our lives with unwavering support over a sustained period of time. Without their commitment we would never have brought the professionals together to see the whole picture and get our children the resources and support they needed. Empathy has given us the opportunity to repair some of the damage the years of fight did to our family'.

'At primary school the staff responded to our son's individual needs and there was a sense that people really knew him. The communication between the school's staff at all levels was good and we felt very involved in decision making. He flourished and achieved.'

'Our son's school has a great understanding of what works well for him. They listen to our concerns and to his ideas and act upon them. We feel he is being treated as an individual.'

'Listening to what other parents have tried with their children if they have the same traits.'

'Meeting with other parents and families - sharing information and experiences.'

'The specialist school Severndale they are fantastic!! And my GP is fantastic too... But in the start my son's Health Visitor was fantastic too…So as you can see I've been lucky with support.'

'An educational statement; CAMHS supervision; Occupational Therapy. As a parent finding out everything I can to support my child and attending every training course I could find.'

- Parents/carers were asked to detail 'what one small thing would make a big difference to you and your family?'. Common themes to answers included:
  - Service provision
  - Family support
  - School support
  - More information
  - Communication
  - Clubs
  - Key worker

Comments included:

'An Autism Strategy for Shropshire to ensure that both my son and those that care for him have services for as long as they need it ..... life'

'For everyone to work together so everything didn't take so long, shorter waiting times'

'Support for my daughter into mainstream hobbies. Also help with support for the family. A key worker we could contact. Talk to when things get tough; I feel we are left to it! Professionals understanding what ASD is and means. Signposting for parents when they are given the news. Early intervention would have helped my daughter. She was not severe so not picked up early. More support for those children who are in mainstream education... Understanding of society!!!!'

'Really fun groups/ activities/ short breaks that my son could access WITH his siblings so we wouldn't feel we were sending him away and he wouldn't feel he was being punished / sent away. Or services that could come in to our lives consistently to support us.'

'My child is approaching 6th form age and has expressed a preference of college and university. Support to enable him to undertake his chosen route to employment would make a massive difference to both him and us. I have spoken with several people who have tried to follow this route and suffered because of inconsistencies in approach in institutions.'

'Better understanding in schools that children show different behaviours in and out of school'

'A central point of information to help with finding out what opportunities are available for young people - social, leisure, employment, benefits etc.'

'One service to act as a point of contact to coordinate all of the services required to support our child. Clear decisions concerning the provision of services so we all know who provides what.'

'Consistent support and advice. All children with diagnosis/traits/suspected given the same advice and support including working parents who can't always do regular hours. Opportunities offered to my child without making him feel different-ie work experience, I suppose the most difference would be if ADHD/ASD were more understood then it wouldn't been seen as poor behaviour with an excuse'

'More support for the youth clubs and young carers groups, which may seem expendable to council leaders, but can make a huge difference on a daily level to the children who use them, by offering children a chance to be themselves and have fun, away from home worries, with others like them.'

'Understanding. We would love to open the world's eyes to Asperger's; it's so misunderstood and it needn't be all doom & gloom!'

- Parents/carers were invited to provide any further comments to the survey: a small section are included below. Please see the full analysis in the Appendix for more information.

'I think support in Shropshire (including support for parents) is a lot better now than 12years ago when my son was diagnosed. The main thing I worry about now is as my son is getting older opportunities for him to do clubs etc. seem to be getting less. I hope Shropshire continue to support these young adults for as long as they need. It is important that they can continue to develop all their skills in an environment that they feel safe and secure in.'

'I don't think enough support goes to the families who are going through diagnosis. Living with a child that has autistic traits but hasn't got the diagnosis is so difficult mentally, physically, emotionally. There have been days that I have cried and prayed it would all go away and times I think I'm going crazy!'

'I am a well-educated and articulate health professional and I am having a long hard slog to find out what is available for my son; goodness knows what happens to those who are not so fortunate. Accessing the right services must be made easier and be publicised widely.'

'Better education and knowledge in schools to read the signs, know what strategies to use and support to give. Shorter waiting lists. Centralised information pack directing parents to service providers. I have never felt so alone and frightened during my wait to be seen, it was torture. My child should not have experienced the crippling anxiety day after day after day. We should be protecting our children not leaving them with memories of a childhood filled with fear and confusion. My son is doing great now and has a good team around him but he will never forget what he went through prior to this.'

Other Research and Stakeholder Engagement

Autonomy has published a study into health and social care access issues for adults with Asperger's Syndrome and High Ability Autism in Shropshire. 'Mind the Gap'[21] was produced to understand the healthcare experiences of individuals with autism and to see how improvements could be made to make services more accessible. Whilst the individuals surveyed varied in age (the youngest survey respondent was in the age range 21-25 and the oldest was over 50 years old), it is likely that many of the findings are applicable and can be useful when considering the experiences of young people with autism.

The report recommended that:

- All Shropshire health and social care professionals should access an ASD awareness training programme
- Services should appoint an Autism Champion
- All people with a diagnosis of ASD (including Asperger's syndrome and high-ability autism) should receive an annual health check, and be supported to attend the appointment if necessary
- There should be a clear autism/Asperger's syndrome diagnostic pathway with easy to locate initial referral contact details. This should include a single phone number for accessing the service that should be answered by a real person
- The diagnostic waiting time should be no longer than 3 months. During the waiting period and after diagnosis, individuals should be provided with ASD specific mentoring support

7. Conclusions

Legislative changes as a result of the Children and Families Act 2014 have resulted in some adjustments for organisations providing services for children and young people with ASD, as well as changes for families and young people themselves. Service providers and commissioners now must work more closely together and ensure that provision and pathways for recognition, referral and diagnostic

[21] Autonomy. (2014). *Mind the Gap*. Available online: www.shropshireautonomy.co.uk

assessment across education, health and social care are linked and cohesive. Young people and their families now have greater levels of participation in their assessment, decision-making and planning.

This assessment has tried to bring together various workstreams across organisations and sectors to understand the needs of children and young people aged 0-25 with an ASD. This includes gaining an understanding of the experiences and availability of support services to help families manage ASD.

Main findings:

- As of January 2014, there were 346 children and young people aged 0-18 recorded on the school census as having an ASD. As there is not a universal, central collection of prevalence data for ASD, it is not possible to provide a more accurate figure of the number of children and young people with ASD in the county.
- Population estimates using UK census data suggest that the figures of true prevalence of ASD in the county may be much higher, at around 932 children and young people aged 0-25 years.
- Schools feel that they are seeing more child demonstrating ASD traits and that they are seeing more children with more complex needs. 45% of providers that responded to our survey said that they felt they were seeing more children with ASD traits and more children with more complex needs.
- Proportionate to population size, there are more children with ASD (as recorded on the school census) living in the north of the county.
- There is a higher prevalence of ASD in areas of deprivation.
- The majority of children and young people received their diagnosis of an ASD whilst at primary school. Around 40% of diagnoses were received through CAMHS.
- Pathways exist to refer children and young people for identification and assessment of ASD. Feedback from professionals and parents indicates that these pathways are not always clear and that there exist several possible routes to assessment and diagnosis. Parents, schools and providers indicated that the diagnostic pathway is confusing and that there is can be a lack of support for families during the diagnosis process.
- There is a wide range of support services available, from statutory services to voluntary support. However, parents and professionals may not be aware of the breadth of available support, nor how to access it. Parents and professionals felt that the range of services and support should be better communicated.
- Parents highlighted a lack of parenting and family support when their child has not received a diagnosis.
- Most support services are accessed in the Shrewsbury area: parents and carers expressed a desire to access service more local to their home area. The services accessed by the largest number of parents are Autism West Midlands, GPs and CAMHS.
- The majority of schools and providers that responded to our survey indicated that they feel they have sufficient knowledge and understanding of autism and how it affects families. Whilst families strongly agreed with this statement for some organisations such as Autism West Midlands and CAMHS, some families were less satisfied that schools and GPs had a good understanding of autism.
- A large number of parents indicated that they do not know where to go for support. Whilst many parents were satisfied with the skills and empathetic nature of staff in CAMHS, many felt that long-waiting times, coupled with a lack of support pre- and post-diagnosis made the waiting

period very difficult. Families also emphasised their struggle to get the right referral in order to receive an assessment for their child.

- The importance of planned and co-ordinated transition was stressed by parents. They highlighted that the process can be improved for families by early planning, dedicated support and good communication between the child or young person, their family and school and the various organisations involved.
- The majority of parents and carers felt that support services do not join up well to support their child and stressed the importance of information sharing across agencies to aid their child's support.
- Many parents indicated that they do not use directories (online or otherwise) to find information. Of those who do use directories, most use the Family Information Service.
- Summary of stakeholder consultation (parents/carers and professionals):

  - What is going well?
    - Voluntary sector support
    - Direct payments and personal budgets
    - CAMHS service (once accessed)
    - Education Health and Care Ps
    - The Child Development Centre (CDC)

  - What is not going well?
    - Families are unsure what support is available and how to access it
    - Waiting times at CAMHS
    - Availability of support and resources for those who do not meet the eligibility criteria for provision

  - How can things be improved?
    - Improve information sharing across agencies/multi-agency working
    - Better promotion of what is available/simplifying information around pathways, providing families with clear information from people who understand the system
    - Celebrate and share good practice
    - Ensure early start to transition

What does this Autism Needs Assessment tell us?

- Prevalence estimates and future predictions indicate that we can expect to see an increase in the number of children with ASD. It is likely that this increase is linked to identification and improvements in diagnostic processes.
- Pathways for identification, referral and assessment are unclear and difficult to understand. Parents and professionals have indicated that it would be beneficial to simplify these pathways.
- There is a wide range of services available, but they require improved promotion to ensure that families and professionals know what they are and how to access them.
- The schools that completed our survey feel well-equipped to respond to the needs of children and young people with autism. However, although many parents/carers have faith in the school system and its ability to support their child, many do not.

- Families feel that services need to be better joined-up in order to support their child and this includes better information sharing.

8. Recommendations

Follow and adopt the NICE guidance recommendations

NICE guidance CG128[22] outlines the evidence-based recommendations for best practice for the recognition, referral and diagnosis of children and young people with autism. To follow and adopt the recommendations outlined in the guidance, Shropshire would need to develop two structures (outlined below). Stakeholders have commended the work of the Child Development Centre (CDC) for its multi-agency approach and are keen to see this developed for children and young people in older age groups. These structural developments would not require additional funding but would require the restructuring of existing services.

A. Local autism multi-agency group

Recommendation 1: Establish a local autism multi-agency strategy group with managerial, commissioner and clinical representation from child health and mental health services, education, social care, parent and carer service users, and the voluntary sector. This group would be established within existing resources and may meet as a virtual group. The aims of this group should be to:

- Improve the early recognition of autism by raising awareness of the signs and symptoms of autism through multi-agency training
- Make sure that relevant professionals (healthcare, social care, education and the voluntary sector) are aware of the local autism pathway and how to access diagnostic services
- Support the smooth transition to adult services for young people going through the diagnostic pathway
- Ensure robust data collection and audit of the pathway is completed

B. Multi-disciplinary autism team

Recommendation 2: Consider expanding the role of the multi-disciplinary autism team (similar to the Child Development Centre's offer for children aged 0-5) to cover ages 0-25 with core membership from a paediatrician/child and adolescent psychiatrist, speech and language therapist, clinical and/or educational psychologist. Consideration is required for how the expansion of this multi-disciplinary team can be facilitated within existing resources. The team will be able to:

- provide advice to professionals about whether to refer children and young people for autism diagnostic assessments
- decide on the assessment needs of those referred or when referral to another service will be needed
- carry out the autism diagnostic assessment
- share the outcome of the autism diagnostic assessment with parents and carers, and with children and young people if appropriate

[22] NICE. (2011). CG128: Autism diagnosis in children and young people: recognition, referral and diagnosis of children and young people on the autism spectrum. Available at: https://www.nice.org.uk/guidance/cg128

- with parent or carer consent and, if appropriate, the consent of the child or young person, share information from the autism diagnostic assessment directly with relevant services, for example through a school visit by an autism team member
- offer information to children, young people and parents and carers about appropriate services and support.

Communication and managing expectations

Issues regarding communication were a recurrent theme throughout this needs assessment and in comments from stakeholders. There are multiple pathways for referral and assessment, these are found to be unclear and can be difficult to navigate. Communication needs to be improved between:

A. Professionals and parents

Recommendation 3: Parents have stated that information needs to be clearer, easier to access and located in a central point. This includes information about how to access the referral and assessment pathway. Families need to be 'kept in the loop' about the assessment process, with updates around timelines and outcomes. Parents need to have a clear understanding about the evidence that they can gather in advance of discussions with professionals to improve the accuracy and timeliness of the referral process.

The creation of a central point to access all information about pathways, assessment and services (see Recommendation 2) would facilitate families' understanding of the system and in turn help to manage expectations. This central point should provide more information that just that which is stated in the Local Offer, but should include details about pathways, expectations and responsibilities. This central point would provide information about what happens if your child receives/does not receive a diagnosis and could be used to signpost parents to appropriate support.

B. Organisations

Recommendation 4: Stakeholders discussed the importance of improved communication between agencies/organisations, including the sharing of information. Organisations should explore the potential for more timely and appropriate information sharing through secure email accounts to reduce time waiting for assessments and allow organisations to access a 'full picture' of a child's needs.

C. Schools and parents

Recommendation 5: Establish a time-limited working group under the Children's Trust to understand the communication relationship between schools and parents. The group will work with schools and parents to establish communication and policy expectations, and develop an appropriate code of practice to communicate these expectations and standards.

Transition

All stakeholder groups raised queries around transition and gave examples of good practice for improving and increasing successful transitions.

Recommendation 6: Transitional phases are approached collaboratively with a long lead-in period, involving the child or young person and their family, as well as organisations and agencies such as the school and social worker. The role and influence of the school nurse in helping to manage the transition should be explored.

Parenting support

Some stakeholders reported that there was a lack of support particularly:

A. whilst waiting for the outcome of a diagnosis, where parents still require support to manage their child's behaviour
B. post-assessment where the child has not received a diagnosis but where parents require support to manage their child's behaviour

Parenting support exists through Early Help and various voluntary organisations. 'Understanding Your Child' courses are available through Sure Start Children's Centres and the Parenting Team (via the Family Information Service). Some school clusters also deliver parenting support courses.

Recommendation 7: Families need to be made aware of existing provision that can provide parenting support. Increased promotion of tier 2 services, or introduction to tier 2 services as part of the assessment pathway, would enable families to access the right support as early as possible. Follow-up or arm's length contact after completing a course would be beneficial in supporting parents to continue to manage behaviour.

Some stakeholders indicated that there is an expectation that having a diagnosis of an ASD will mean that the child or young person will have a SEN and will require additional support in school.

9. Next Steps

- The Children's Trust is to approve the recommendations of this Needs Assessment.
- Once approved, this Needs Assessment should be published and made accessible to professionals and the public.

10. Appendix

Shropshire Council. (2014). Compass assessed need pathway 2014.

CAMHS. (2014) CAMHS pathway for ASD 2014.

Shropshire Council. (2014). Shropshire Council Guidance for making a request for an EHC assessment.

 Shropshire Council. (2014) Snapshot of Services Autism. Responses to the survey.

 CAMHS. (2014). CAMHS Parent and Carer Forum Summary Report.

 Public Health. (2015) Final ASD Survey for Parents 2015.

 Shropshire Council. (2015). ASD Survey for Providers 2015 (completed via SurveyMonkey).

 Shropshire Council. (2015). ASD Survey for Schools 2015 (completed via SurveyMonkey) .

 Shropshire Council. (2015). Full feedback notes from the November Stakeholder Event – Autism 0-25.

 Public Health. (2015) Results of the Autism Needs School Survey 2015.

 Public Health. (2015). Result of the Autism Needs Provider Survey 2015.

 Public Health. (2015). Results of the Autism Needs Parent Survey 2015.