

## Children and Young People with Autism

### Summary

- Nationally the prevalence of autism is around 1%.
- It is estimated that there are 2,802 children and young people aged 0-17 years or 3,823 children and young people aged 0-24 years living with autism in Hampshire.
- There were 738 children recorded with Autism Spectrum Disorder (ASD) being educated in a Hampshire maintained school in 2012.
- There were 185 children with ASD identified, in need of social care on Hampshire's social children's services database in January 2012.
- There are no health data available to confirm the number of children with ASD accessing health care services in Hampshire.
- The age distribution of children in need associated with ASD suggests that teenagers with ASD are currently more likely to be in need of children's social care services than younger children.
- The ratio of girls:boys with ASD on the Hampshire education database is 1:7 which is a lower number of girls than the 1:4 national estimated ratio would suggest.
- There is a higher recorded prevalence of children with a diagnosis of ASD living in the north and west of the county, compared to those in the south and east of the county.
- In Hampshire, most children with ASD of primary school age are in mainstream schools. However, once they reach secondary age, a greater proportion of children attend special schools. There are no comparator data.
- It is likely that a number of children and young people living in Hampshire with ASD have yet to be diagnosed.

### Recommendations

- Partnerships with a strategic interest in ASD across Hampshire should be identified and their role in developing the children and young people with autism strategy for Hampshire explored to optimise collaborative working.
- NHS commissioned services should consistently specify the diagnostic codes that record the children referred to them for assessment and diagnosis of ASD.
- Data sharing across agencies would improve inter-sectorial working and improve outcomes for children and young people with ASD.
- The difference between the proportion of children on the education database diagnosed with ASD in the North and West of the County compared to South and East should be investigated.
- A referral, assessment and diagnosis pathway should be developed with clear referral criteria and processes at each stage.
- Assessment and diagnosis services should be audited against the NICE guidelines.
- Once NICE guidelines on the management of autism in children and young people are available, the interventions and support in Hampshire can be compared to this national best practice.
- Children and young people with autism and their families may require support to identify suitable mainstream activities to meet individual needs. These should be made available by locality.

# Children and Young People with Autism

- Common progress and outcomes measures should be identified and used across sectors to if the children's needs are being met.
- An audit of ASD basic awareness training should be undertaken across statutory services and training commissioned for any gaps identified.
- Schools may benefit from the dissemination of good practice regarding managing and supporting children and young people with ASD.

## 1. Introduction

Autism can be defined as a lifelong developmental 'hidden' disability that affects the way a person communicates with and relates to, people and the world around them.<sup>1</sup> People with autism have a wide spectrum of need and no two people are the same. There are three key areas of difficulty known as the 'triad of impairments' that all people with autism are likely to experience:

- Social communication – difficulties understanding and using verbal and non-verbal language, such as gestures and tone of voice.
- Social interaction – difficulties recognising and understanding other people's feelings and managing their own.
- Social imagination – difficulties in understanding and predicting other people's intentions and behaviour and adapting to new or unfamiliar situations.

In addition, many people with autism are over-sensitive or under-sensitive to particular things such as smells, tastes, colour, sounds or touch.

The Autism Act 2009 made provision to address the needs of adults with autism.<sup>2</sup> In response, the Hampshire Autism Partnership Board was established and developed a Hampshire Autism Strategy for Adults. This was the first of a two part 'across the lifespan' autism strategy, with the Hampshire Autism Strategy for Children to follow. This health needs assessment for children and young people with autism will inform the children's strategy. In keeping with the Hampshire adult strategic approach, this needs assessment uses the term 'autism' to reflect the full spectrum of autistic disorders and includes the diagnostic categories of Asperger's Syndrome, High Functioning Autism, Pervasive Development Disorder, Autism Spectrum Disorder and Autism Spectrum Condition. In recognition of the spectrum experienced by children and young people, the term Autism Spectrum Disorder (ASD) is used throughout this chapter.

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<sup>1</sup> Hampshire Autism Partnership Board. Hampshire Autism Strategy for Adults. 2012-2015 <http://documents.hants.gov.uk/adultservices/publications/AutismStrategy86468fullguide.pdf>

<sup>2</sup> Autism Act 2009 <http://www.legislation.gov.uk/ukpga/2009/15/introduction>

# Children and Young People with Autism

## 2. Level of need in the population

### 2.1 Estimated prevalence based on Hampshire population data

Data on children with ASD are limited, therefore numbers have been estimated. Studies suggest that the prevalence of ASD is at least 1% in the population<sup>3</sup>. The Hampshire 2010 mid-year population estimate enables us to suggest there to be about 2,802 children with ASD living in Hampshire.

Studies suggest that ASD is much more common in males than females, with an estimated ratio of 4:1.<sup>3</sup> This male:female ratio has been applied to the population data for Hampshire, shown in Table 1.

**Table 1: Estimated number of boys and girls with ASD in Hampshire, based on 2010 mid year population estimates**

	<b>Total number of children in age group living in Hampshire</b>	<b>Estimated number of boys in age group in Hampshire with ASD</b>	<b>Estimated number of girls in age group in Hampshire with ASD</b>
<b>0-17 years</b>	<b>280,151</b>	<b>2,241</b>	<b>560</b>
<b>18-24 years</b>	<b>102,135</b>	<b>817</b>	<b>204</b>
<b>Total aged 0-24 years</b>	<b>382,286</b>	<b>3,058</b>	<b>764</b>

### 2.2 Concurrent conditions

50% of people with ASD are estimated to have an intellectual disability, defined as an IQ (intelligence quotient) below 70. 70% of people with ASD meet the diagnostic criteria for another psychiatric disorder that also affects their functioning, such as attention deficit disorder (ADHD) or depression, in addition to ASD.<sup>3</sup> Table 2 shows the number of children and young people with ASD in Hampshire estimated to have concurrent conditions.

Children and young people with ASD are also thought to have a higher prevalence of some other medical, developmental and functional problems, such as epilepsy, cerebral palsy, sleep problems, motor problems, vision or auditory deficits and gastrointestinal problems. However, estimates of the prevalence of these conditions are not precise.<sup>3</sup>

<sup>3</sup> National Institute for Health and Clinical Excellence. Clinical Guideline 128 Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum. September 2011. <http://publications.nice.org.uk/autism-diagnosis-in-children-and-young-people-cg128>

## Children and Young People with Autism

**Table 2: The number of children and young people with ASD in Hampshire estimated to have an intellectual disability, or concurrent psychiatric disorder based on 2010 mid year population estimates**

	Estimated number of children aged 0-24 years in Hampshire with ASD and an intellectual disability	Estimated number of children aged 0-24 years in Hampshire with ASD and another psychiatric disorder
<b>Girls</b>	382	535
<b>Boys</b>	1,529	2141
<b>Total children</b>	1,911	2,676

### 2.3 Recorded prevalence from Hampshire data sources

#### 2.3.1 Health data

There has been a lack of detailed health care service use data available relating to children and young people with ASD. This included general child health services as well as specialist services such as paediatric services commissioned to assess and diagnose ASD and Child and Adolescent Mental Health Services.

#### 2.3.2 Hampshire Education data

Education data from Hampshire County Council's Education Information System (EIS) dataset were analysed. This dataset includes Sixth Form, Academies and Education Centres. Children at independent schools, Further Education Colleges, Further Education Sixth Forms, children educated outside Hampshire County boundaries, or educated at home are not included. Children below school age are not included. It contained less than 5 children with ASD in the years aged 17 years and above, therefore they were excluded. The analysis below includes the children aged 4-16 years. Of the 167,669 children surveyed, 738 (0.4%) were recorded as having ASD.

#### 2.3.3 Age and gender

Table 3 shows the children with ASD on the educational database by age. There are 92 girls and 646 boys, giving girls:boys ratio of 1:7. There are slightly higher numbers of boys compared to the 1:4 expected ratio.

**Table 3: Children with ASD recorded on the Hampshire school census database, by age**

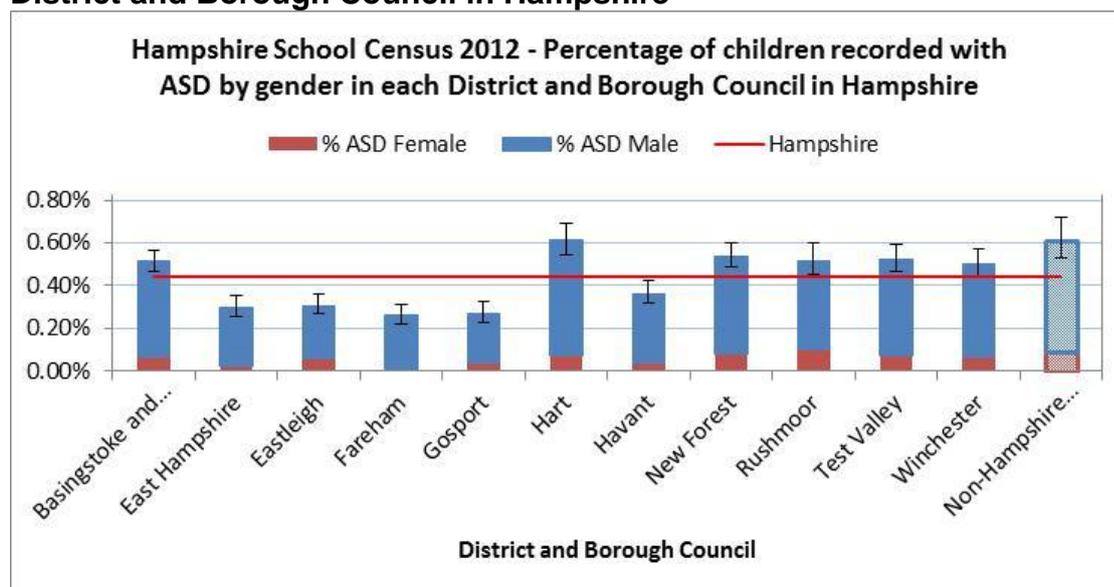
Age of child (yrs)	4	5	6	7	8	9	10	11	12	13	14	15	16
<b>Number children</b>	19	28	53	50	56	66	67	66	79	79	60	73	32

## Children and Young People with Autism

### 2.3.4 District

Figure 1 shows the children with ASD as a proportion of all children, by district which show variation across the county. There is a significantly higher recorded prevalence of children with a diagnosis of ASD living in the North and West of the County, and residing outside the county, compared to those in the South and East of the County. There are a range of possible explanations for this variation and further work should be carried out to investigate this.

**Figure 1: Percentage of children recorded as having ASD by gender and District and Borough Council in Hampshire**

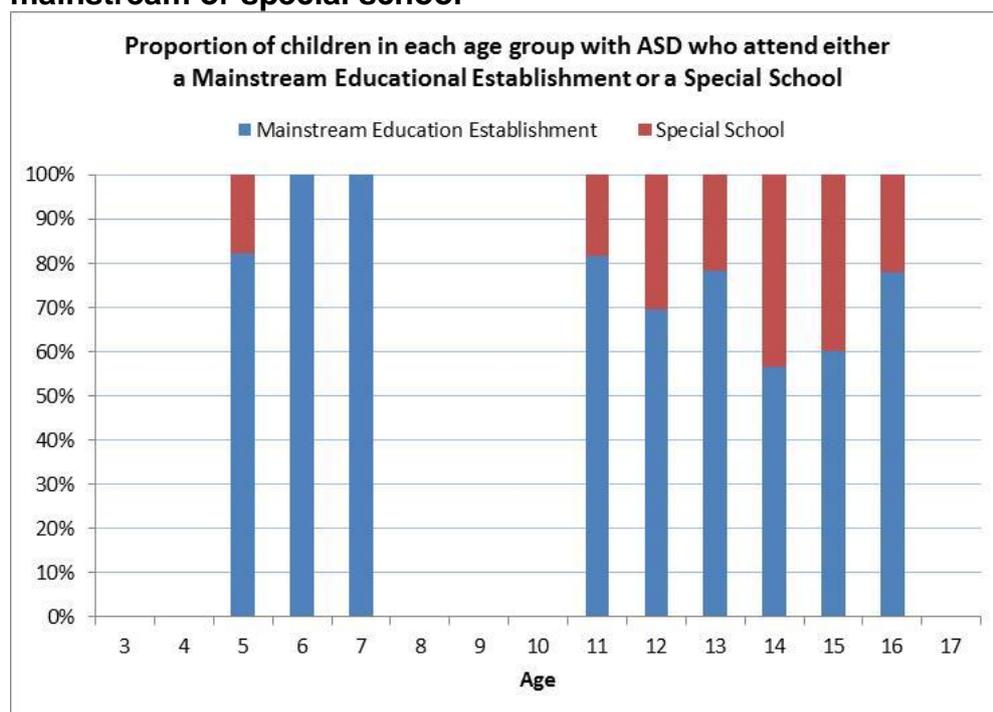


### 2.3.5 Educational establishment

Of the 738 children recorded with ASD, 606 (82.1%) are recorded as attending a mainstream education establishment and 132 (17.9%) a Special School. Figure 2 shows that most children of primary school age are in mainstream schools. However, once they reach secondary age, a greater proportion of children attend special schools. The graph suppresses some age groups, where numbers are less than 5.

## Children and Young People with Autism

**Figure 2: Proportion of children in each age group attending either a mainstream or special school**



### 2.3.6 Hampshire social care data

The number of children classed as 'in need' of social care in Hampshire was captured from the county's Children in Need database undertaken in January 2012. The database included children and young people aged 0-21 years.

One hundred and eighty five children with ASD were recorded on this database as needing of social care. This compares to 738 on the education database. This difference highlights the fact that ASD is a spectrum disorder. The majority of children with ASD will not meet Hampshire Children's Services criteria for social care and will therefore not be on the Children in need database.<sup>4</sup>

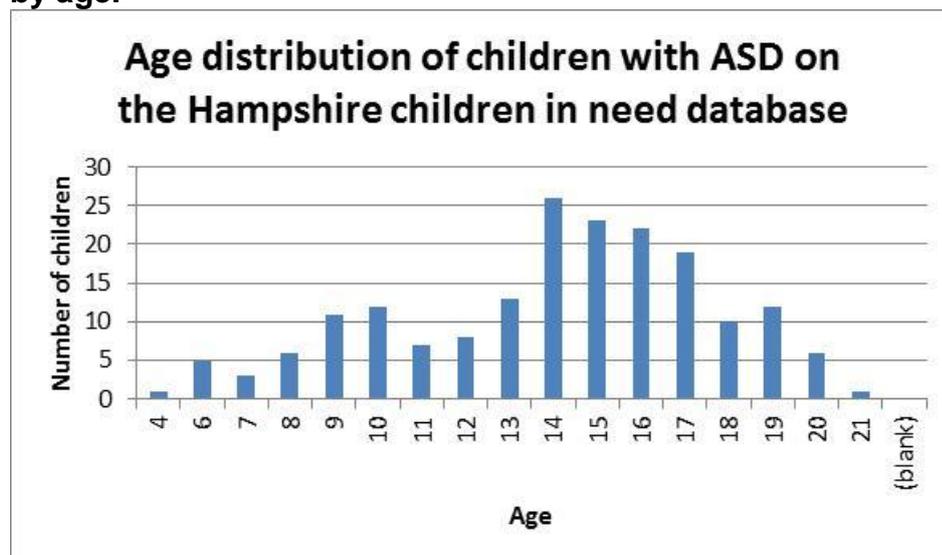
Of the 6,447 children on the database, 185 (2.9%) had a health need of autistic spectrum condition. 30 (16%) of these children were girls, and 155 boys, as might be expected when compared to national studies of gender ratios of children and young people with ASD. 31 of these children were care leavers and 55 looked after either part-time or full-time, suggesting 46.5% of those had been in the care system at some point.

The age range of these children is shown in figure 3; suggesting teenagers with ASD are more likely to be in need of children's social care services, than younger children.

<sup>4</sup> Hampshire County Council Criteria for Specialist Children's Services <http://www3.hants.gov.uk/childrens-services/specialneeds/shortbreaks/eligibility-criteria.htm> accessed February 2013

## Children and Young People with Autism

**Figure 3: Distribution of children with ASD on the Children in need database by age.**



### 3. Projected service use and outcome in 3-5 years and 5-10 years

Table 4 shows the estimated projected numbers of children and young people in 2018 likely to be diagnosed with ASD in Hampshire, based on the 2010 mid year population estimates. Whilst some districts may see changes in demand for services over time, these changes are relatively small.

### 4. Current services

#### 4.1 Health services

##### 4.1.1 Paediatric Services

Children and young people in Hampshire receive a diagnosis of ASD after detailed assessment and diagnosis by paediatric services. A survey of the providers of these services revealed a lack of information about the local diagnosis process and outcomes.

We are currently unable to estimate either the number of children and young people referred for assessment for autism, or the number diagnosed with ASD. No interpretations can be made about whether or not assessment and diagnostic services are meeting need, nor whether this provision is equitable across the county. Data collection needs to improve if we are to understand the need for, capacity of, quality and outcomes of these services.

## Children and Young People with Autism

**Table 4: Estimated number of children with ASD by district, in 2018, and difference from 2010, based on ONS Interim 2011-based subnational population projections for 2018**

<b>COUNTY DISTRICTS</b>	<b>Estimated number of CYP aged 0-24 years in 2018</b>	<b>Estimated children aged 0-24 with ASD in 2018</b>	<b>Estimated number of children aged 0-24 years with ASD in 2010</b>	<b>Difference in expected number of children with ASD 2010-18</b>
Basingstoke & Deane	52,205	522	504	18
East Hampshire	32,974	329	330	-1
Eastleigh	38,462	385	372	13
Fareham	31,716	317	305	12
Gosport	25,254	253	252	1
Hart	27,247	272	270	2
Havant	34,277	343	348	-5
New Forest	45,498	455	448	7
Rushmoor	29,934	299	306	-7
Test Valley	32,519	325	333	-8
Winchester	37,136	372	357	15
<b>Hampshire</b>	<b>387,221</b>	<b>3872</b>	<b>3,823*</b>	<b>47</b>

*\*Please note totals may not add up due to rounding*

### 4.1.2 Child and Adolescent Mental Health Service

The Child and Adolescent Mental Health Service (CAMHS) is provided for all Hampshire children and young people by Sussex Partnership NHS Trust. In 2012 they reviewed services across the county to compare historical ASD service provision, with the aim of making service access equitable. They identified three areas for development.

- The variation across Hampshire in terms of clinician skills in assessment and intervention with children with an Autistic Spectrum Condition.
- The variation across Hampshire in the working relationships with local paediatric services.
- The lack of routine data collection regarding activity relating to children and young people with ASD.

# Children and Young People with Autism

## 4.2 Education

Children who have been identified by their school as requiring additional support may be referred to an Educational Psychologist. While this could be for a range of issues, it could include a diagnosis of ASD or children with symptoms or behaviours similar to ASD. An Educational Psychologist will assess the child and advise on meeting the educational needs of the child. Children with ASD who attend Hampshire schools access education in one of 3 ways:

- Mainstream school – with advice from the Educational Psychologist about adapting the school environment to meet the child's needs.
- Mainstream School with special provision.
- Special School.

There is currently no standard method across Hampshire of measuring the breadth of the needs that children with ASD live with. Identifying common measures that could be used across education, health and the third sector would enable the monitoring and evaluation of the effectiveness of interventions and outcomes across health services, education and social care for children with ASD against their needs.

## 4.3 Social care

Hampshire County Council's Children's Services, in consultation with parents and professionals, developed a set of eligibility criteria to identify children with disabilities most in need of specialist services<sup>56</sup>. The assessment is based on an individual child's abilities and needs, rather than their diagnosis.

As ASD is a spectrum condition, many children will not be identified as 'in need' of specialist services. A planning meeting will be held for those children identified as 'in need'. Further assessment will identify these needs and the type and level of service to meet this assessed need. Children not identified as 'in need' will be offered information about other services and support available to them.

## 5. User and provider views

### 5.1 Partnerships

There are a range of partnerships and strategic groups looking at the needs of people with ASD in Hampshire. It would be useful to map these partnerships, identify any overlaps and review the relationships and communications between these groups to identify if partnerships could be strengthened.

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<sup>6</sup> Hampshire County Council Criteria for Specialist Children's Services  
<http://www3.hants.gov.uk/childrens-services/specialneeds/shortbreaks/eligibility-criteria.htm> accessed February 2013

# Children and Young People with Autism

## 5.2 Public consultation

Prior to developing the Hampshire Autism Strategy for adults, a consultation took place with people in Hampshire who considered themselves to be on the autistic spectrum or who lived or worked with those who were<sup>7</sup>.

This consultation concluded that good experiences for people with ASD and their parents and carers are dependent on the following being in place:

- ASD aware, supportive, understanding and actively-listening staff within all services that have direct contact with people with ASD.
- Early ASD recognition leading to a timely diagnosis, identification of post diagnostic support needs and establishment of interventions if required.
- Resourced and appropriate school placements within mainstream and special educational needs (SEN) schools, where teachers and staff are very ASD aware, make adjustments and are skilled in supportive interventions.
- Collaboration and clear communication between organisations and the person with ASD and their parents/carers during all transitional periods i.e. preschool to primary school, primary to secondary education, secondary to further education, further education to higher education or employment.
- Activities and places to go where social opportunities are available, either ASD specific or mainstream.
- Availability of sibling support and parent and carer respite opportunities.
- Eligibility for statutory services or signposting to alternative available resources and/or services.
- Clear, accessible information and advice on volunteering, employment, benefits, education, housing, support services, therapeutic interventions and activities for people with ASD.

As the consultation included both adults and children, some of the responses may reflect individuals' past experiences of services for children and young people with ASD. Further work should take these responses into consideration.

## 6. Evidence of what works

### 6.1 Recognition, referral and diagnosis

The NICE guidance 'Autism spectrum disorders in children and young people: recognition, referral and diagnosis'<sup>3</sup> aims to improve recognition, referral and diagnosis of ASD in children and young people with autism. It recommends the following priorities for local implementation:

1. A local pathway for recognition, referral and diagnostic assessment of possible ASD, through

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<sup>7</sup> R Dittrich et al. Autism Participation, have your say. Hampshire's pre-consultation. Developing a Hampshire autism strategy to meet local needs. Hampshire County Council. 2011  
<http://www.hants.gov.uk/pdf/autism-participation-report-september2011.pdf>

## Children and Young People with Autism

- A local autism multi-agency strategy group. The aims of the group should include:
    - improving early recognition of through multi-agency training
    - making sure the relevant professionals are aware of the local autism pathway and how to access diagnostic services
    - supporting the smooth transition to adult services for young people going through the diagnostic pathway
    - ensuring data collection and audit of the pathway takes place
  - The group should appoint a lead professional to be responsible for the local autism pathway
  - A multidisciplinary group (the autism team) in each area. Provide a single point of referral for access to the autism team.
2. Autism diagnostic assessment for children and young people
- A case coordinator in the autism team should be identified for every child or young person who is to have an autism diagnostic assessment.
  - Comprehensive ASD diagnostic assessments that meet standards specified in the guidance and consider differential diagnoses for autism
3. Communicating with parents and professionals about the results from the autism diagnostic assessment. With parental or carer consent and, if appropriate, the consent of the child or young person, the profile should be made available to professionals in education and, if appropriate, social care.

### 6.2 Management of ASD

NICE guidance on the management of autism in children and young people has been consulted on and is expected autumn 2013.<sup>8</sup> There is no 'cure' for ASD. However, different interventions may help children and young people, their families and their carers to manage some symptoms and behaviours. ASD has a spectrum of need, so interventions will vary by the level of need with respect to that behaviour or symptom.

## 7. Recommendations

### 7.1 Governance

- Partnerships with a strategic interest in ASD across Hampshire should be identified and their role in developing the children and young people with Autism strategy for Hampshire explored to optimise collaborative working.

### 7.2 Data and intelligence

- NHS commissioned services should consistently specify the diagnostic codes that record the children referred to them for assessment and diagnosis of ASD.
- Data sharing across agencies would improve inter-sectorial working and improve outcomes for children and young people with ASD.

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<sup>8</sup> National Institute for Health and Clinical Excellence. Autism – management of autism in children and young people <http://guidance.nice.org.uk/CG/Wave25/4>

## Children and Young People with Autism

- The difference between the proportion of children on the education database diagnosed with ASD in the North and West of the County compared to South and East should be investigated.

### **7.3 Recognition, referral, assessment and diagnosis**

- The difference between the proportion of children on the education database diagnosed with ASD across the County needs investigating.
- A referral, assessment and diagnosis pathway should be developed with clear referral criteria and processes at each stage.
- Assessment and diagnosis services should be audited against the NICE guidelines to identify strengths and gaps.

### **7.4 Interventions and support for children and young people with ASD**

- Children and young people with autism and their families may require support to identify suitable mainstream activities to meet individual needs. These should be made available by locality.
- Once NICE guidelines on the management of autism in children and young people are available, the interventions and support in Hampshire can be compared to the guidelines.
- Common measures should be identified and used across sectors, to monitor children's progress and review if their needs are being met.

### **7.5 Training**

- An audit of ASD basic awareness training should be undertaken across statutory services and training commissioned for any gaps identified.
- Schools may benefit from the dissemination of good practice regarding managing and supporting children and young people with ASD.