NHS Derby City and NHS Derbyshire County

Derbyshire Health and Social Care Needs Assessment for Adults with Autism Spectrum Disorder (ASD)

July 2011

With thanks for the data provided by:
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Content

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Health and Social Care Needs Assessment for Autism Spectrum Disorder (ASD) In Derbyshire

What is autism?

Autism is a lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. The three main areas of difficulty, which all people with autism share, are known as the 'triad of impairment'. They are difficulties with:

- Social communication (e.g. problems understanding verbal and non-verbal language, such as gestures, facial expressions, and tone of voice)
- Social interaction (e.g. problems recognising and understanding other people's feelings and managing their own)
- Social imagination (e.g. problems in understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine).

'Many people with autism may experience some form of sensory or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours. People with autism often prefer to have a fixed routine and can find change incredibly difficult to cope with. Many people with autism may also have other conditions such as deficit hyperactivity disorder (ADHD), a learning disability or dyspraxia.'

'Fulfilling and rewarding lives': the strategy for adults with autism in England (2010)'.

As the name implies, Autism Spectrum Disorder (ASD) covers people with a spectrum of autistic conditions. Whilst a substantial proportion of people with autism have a learning disability more than half don't. People with Asperger's syndrome (and those with higher functioning autism) are included in the definition of those with ASD, and although having higher IQ's may still suffer many of the characteristics of autism above. People with Asperger's syndrome commonly experience difficulty communicating with others and can have difficulty forming and maintaining friendships and relationships. Whilst they may be interested in forming relationships attempts at doing so may be awkward or inappropriate. This can make the person prone to bullying or social isolation, and at risk of mental health difficulties. A person with Asperger's syndrome may have difficulty with eye contact, and may find it difficult to understand non-verbal interaction such as body language and facial expression. People with Asperger's syndrome often have a need for routines, and may have very specific interests, which can impact on other areas of their lives, including maintaining employment. The needs and difficulties of people with Asperger's syndrome may not be immediately or fully obvious, and so they may have difficulty accessing support.

Improving support for people with autism

We know that – despite the significant strides made over the last decade to increase equality and tackle exclusion- adults with autism (ASD) are currently not treated fairly. This document aims to identify the health and social care needs of people with ASD in Derbyshire, identify if the services match need and to assist the decision making process of commissioning managers.

The Governments vision for transforming the lives of and outcomes for adults with autism is:

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

For adults with autism, this means:

- *Having a right to receive an assessment of need from social services*
- *Getting the same opportunities for education and further education as everyone else*
- *Being supported to get a job and stay in work*
- *Being able to choose where to live – just like anyone else.*
- *Having relationships and social networks*
- *Having their health needs properly met in a way which is appropriate for someone with autism*
- *Being safe from hate crime and discrimination*
- *Living in a society where people understand, respect and accommodate difference, and*
- *Receiving support to live independently, as appropriate*.'

'Fulfilling and rewarding lives': the strategy for adults with autism in England (2010)'.

Identifying the needs of people with autism

This health and social care needs assessment (H&SCNA) has been produced to gather information required to bring about change beneficial to the health and social care of people with autism*. It is

"a systematic method for reviewing health and social issues facing a population, leading to agreed priorities and resource allocation that will improve health and reduce inequalities"[1]. DH (2009)

There has been a wealth of data gathering from the following sources in order to gather the information needed:

- Planning4care: Derbyshire Learning Disability Needs Assessment (2011)
- APC (admitted patient care) table supplied by Secondary User Services (SUS) for period 01/04/08 to 31/03/10 using ICD10 codes F840 (childhood autism) F841 (atypical autism), and F845 (Asperger's syndrome)
- Adult Care Management Information Team data from Framework i client database.

* Health Needs Assessment. A practical guide. Health Development Agency. http://www.nice.org.uk/media/150/35/Health_Needs_Assessment_A_Practical_Guide.pdf [accessed 14/7/2011]

The population to be assessed

Health and Social Care Needs Assessment for people with autism in Derbyshire	
What is the population, where are they located and why are they chosen?	The population is adults aged 18+ with autism in Derbyshire and young people with autism aged 14 to 17 years 'in transition' from children's to adult services .
What are the aims and objectives?	The aim is to identify if people with autism have 'fulfilling and rewarding lives'. To ensure that people with autism can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents. This 'Health and Social Care Needs Assessment' will be undertaken to: • Agree a definition for autism • Identify numbers • Identify geography • Assess needs • Assess the services currently available • Assess the services currently used • Assess the transition between children's and adults services. • Assess the equity of services. • Identify gaps
Who is included in the project team?	Jane Hudson-Oldroyd and Nigel Godfrey to draw on local data to identify prevalence, supported by NHS Derbyshire County analyst team (Gail Maskalick), further scoping to be led by Asha Day (SHA).
Who is included in the stakeholder group?	County/ City Councils: Adult Care/ Social Services District Councils: Housing Department PCT Commissioners and Public Health; Primary Care Providers; Secondary Care Providers: Derbyshire Healthcare Foundation Trust; Derbyshire Community Health Services Acute Providers: Derby City Royal Hospital and Chesterfield Royal Hospital Learning Disability and Mental Health Treatment services Strategic Health Authority; JSNA Board; Youth Offending Services; Employment services, Voluntary Services
What resources are required?	Data resources: **Source of data:** Planning4care: (2011) **Source of data** : Secondary User Service (SUS) hospital data 24/6/10 using ICD10 codes: F841 (atypical autism), F840 (childhood autism) and F845 (Asperger's syndrome) **Source of data**: Adult Care Management Information Team data from Framework i Client Index. **Source of data:** Transitions data from CAYA (Children and Younger Adult) department, Derbyshire County Council re children with SEN's, residential placements, children's social care, and Derbyshire Connections clients. **Literature searches.**
Timescale of assessment	June 2010 to June 2011.

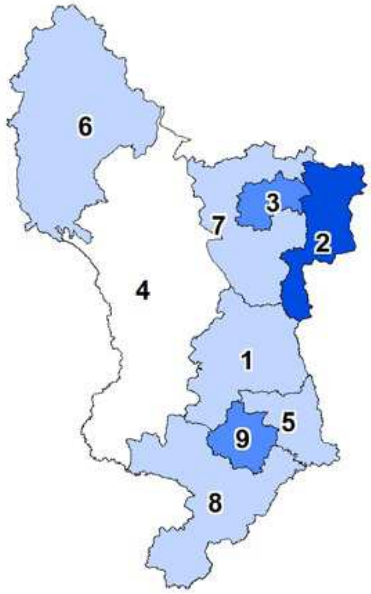
Developing a profile of the population

The Population Profile of Derbyshire

Derbyshire is a large diverse County of 985 square miles and a resident population of approximately 768,400 in 2011. Derby City has an additional population of 245,100 in 2011. Within the County are 8 districts and boroughs. It is largely rural with a number of urban areas, the largest of which is Chesterfield. The Bolsover district is within the most deprived quartile of the country and has Spearhead status. It also needs to be noted that Glossopdale with a population of some 34,000 is included as part of the County Council whereas excluded from the PCT population. This will inevitably have some effect on the data ie there is a greater resident population compared to the PCT registered population.

Health Inequalities – Deprivation in Derbyshire County - Index of Multiple Deprivation
2004 District averages

Most deprived 25%
Second most deprived
Second least deprived
Least deprived 25%



1 Amber Valley
2 Bolsover
3 Chesterfield
4 Derbyshire Dales
5 Erewash
6 High Peak
7 North East Derbyshire
8 South Derbyshire
9 Derby City

The prevalence of Autism in England

Nationally the number of people with ASD is not firmly known partly due to under diagnosis. Most prevalence studies aimed at estimating the number of people with ASD have focused on children and have estimated a prevalence of 1 in 100 (Baird 2006). The NHS Information Centre conducted a study: Adult Psychiatric Morbidity Survey (2007) looking at amongst other things, the prevalence of Autistic Spectrum Disorders (including Autism, Asperger's Syndrome and High Functioning Autism). This study also found a 1% prevalence in adults and indicated that prevalence is higher in men (1.8%) than in women (0.2%) - however it noted that caution is needed in applying the latter due to the small number of women in the sample group. A 1% prevalence figure is our best national estimate, until the Department of Health explores the rates of autism further (study finding to be released in late 2011).

According to the Office of National Statistics (2008 Population Projections), in 2011 Derbyshire has a population of 612,700 people 18 years and over, plus 155,900 people 17 years and under. Therefore the nationally estimated 1% prevalence of ASD in Derbyshire is 6,127 adults and 1,559 children and young people aged 17 and under, of which 379 are in transition (ages 14 – 17 years old)

As part of a national pilot project, Planning4care (2009) undertook an estimate of the number of adults with ASD (by age and gender) based on Bairds methodology, but incorporating local deprivation and ethnicity risk factors in the Derbyshire population (and its districts) by age band[+]. These estimates have been updated in 2011and put the Derbyshire prevalence at 7,160 adults with ASD of whom 3,420 had Asperger's Syndrome or higher functioning autism.

In 2011 Derby City has a population of 249,300: 195,700 18 years and older, 53,600 aged 17 years and under, of which 11,600 are aged 14 - 17. (ONS 2008 Population Projections). Again using the 1% estimated prevalence of ASD, this would estimate that 1,957 adults and 536 children and young people (116 in transition) are living with ASD.

[+] Local prevalence rates have been adjusted for ethnicity and deprivation using odds ratios supplied by Emerson (CeDR, Lancater)

- **The prevalence of autism in Derbyshire**

Table 1: Estimated numbers of adults with ASD in Derbyshire and Derby City (2011)

	Autistic Spectrum			Asperger's/HFA		
	All adults	**18-64**	**65+**	**All adults**	**18-64**	**65+**
Derbyshire	**7,160**	**5,530**	**1,630**	**3,420**	**2,490**	**730**
Amber Valley	**1,150**	**890**	**260**	**520**	**400**	**120**
Bolsover	**710**	**550**	**160**	**320**	**250**	**70**
Chesterfield	**960**	**740**	**220**	**430**	**330**	**100**
Derbyshire Dales	**660**	**480**	**180**	**290**	**210**	**80**
Erewash	**1,030**	**810**	**220**	**470**	**370**	**100**
High Peak	**870**	**680**	**190**	**390**	**310**	**80**
NE Derbyshire	**930**	**690**	**240**	**420**	**310**	**110**
South Derbyshire	**860**	**690**	**170**	**390**	**310**	**80**
Derby City	**1,957**	**1,570**	**387**			
East Midlands	**41,510**	**32,780**	**8,730**	**18,680**	**14,750**	**3,930**
England	**475,610**	**379,760**	**95,850**	**21,4020**	**170,890**	**43,130**

Note: Those with Asperger's/ HFA are a subset of those with autistic spectrum.

Table 2: Estimated numbers of young people aged 14 to 17 with autism in Derbyshire and Derby City. (2011)

	Autistic Spectrum		Asperger's/HFA	
	N	%	N	**%**
Derbyshire	**440**	**1.21%**	**200**	0.54%
Amber Valley	**70**	**1.20%**	**30**	0.54%
Bolsover	**40**	**1.22%**	**20**	0.55%
Chesterfield	**60**	**1.21%**	**30**	0.54%
Derbyshire Dales	**40**	**1.20%**	**20**	0.54%
Erewash	**70**	**1.21%**	**30**	0.54%
High Peak	**50**	**1.22%**	**20**	0.55%
North East Derbyshire	**50**	**1.21%**	**20**	0.55%
South Derbyshire	**60**	**1.22%**	**30**	0.55%
Derby City	**116**	**1.00**		
East Midlands	**2,630**	**1.18%**	**1,180**	0.53%
England	29,550	1.18%	13,300	0.53%

Note: Those with Asperger's/ HFA are a subset of those with autistic spectrum.
Source of data for table 1 and 2: Planning4care: learning disability needs assessment Derbyshire (2011). Derby City data are an estimate based on the 1% prevalence rates using 2008 ONS population projections for 2011.

- **Projections of prevalence of autism in Derbyshire from 20011 to 2031**

Table 3: Estimated numbers of people in Derbyshire aged 14-17, by category

	Derbyshire			% change 20011- 2031		
	2011	2021	2031	Derbyshire	East Midlands	England
Autistic spectrum	440	400	430	-2.3%	8.4%	7.8%
Asperger's/ HFA	200	180	200	0.0%	8.5%	7.8%

Table 4: Estimated numbers of adults in Derbyshire aged 18-64, by category

	Derbyshire			% change 20011- 2031		
	2011	2021	2031	Derbyshire	East Midlands	England
Autistic spectrum	5,530	5,560	5,560	0.5%	6.0%	6.2%
Asperger's/ HFA	2,490	2,500	2,500	0.4%	6.0%	6.2%

Table 5: Estimated numbers of adults in Derbyshire 65 and over, by category.

	Derbyshire			% change 20011- 2031		
	2011	2021	2031	Derbyshire	East Midlands	England
Autistic spectrum	1,630	2,110	2,620	60.7%	61.3%	53.7%
Asperger's/ HFA	730	950	1,180	61.6%	61.3%	53.7%

Source of data for tables 3, 4 and 5: Planning4care: Learning Disability Needs Assessment Derbyshire (2011). Projections have not been made for Derby City due to a lack of data.

The projections show that over the next 20 years in Derbyshire we anticipate relative stability in the number of people with ASD between the ages of 14 – 17 and 18 –64.

There is however projected to be a substantial increase in the number of people with ASD aged 65 or over by 2031, with numbers rising from 1,630 to 2,620; an estimated 61% increase.

- **Health care of people with autism in Derbyshire**

We currently have limited health data on people with ASD in Derbyshire and this is in need of improvement. Improvement in the rate of diagnosis will help, together with consistency of coding the condition.

Data collection of autism in primary care

Read codes are used in primary care, mainly to code diagnosis of illnesses and disabilities. We could try to identify the numbers of people with ASD at each practice level to get a picture across Derbyshire in terms of people within the health care service. However**,** patients who have had these READ codes applied to their General Practice records would not mean that we have identified all patients with ASD registered at a practice. A low number would NOT indicate low prevalence; just that the surgery had not coded this condition even if they had been made aware of it which equally may not have happened. The following read codes are relevant for autism.

Active infantile autism (E1400)
Residual infantile autism (E1401)
Infantile autism NOS (E140z)
Atypical autism (X00TN)
Childhood autism (XE2v2)
Suspected autism (XaIuT)
Idiot savant (Ub1Ts)
Autistic spectrum disorder (X00TM)
Asperger syndrome (X00TP

Due to the fact that this data may cause confusion, we have decided NOT to seek the current data from each practice

Recommendation: Identify and agree useful codes for use in primary care following diagnosis and include this as part of the autism training package.

Data collection of autism in secondary care

Table 6 - Admissions with diagnosis of autism or Asperger's syndrome 2008-10

	Number of patient admissions with diagnosis of autism							
	Primary		Secondary		Subsidiary		Total	
	08/09	09/10	08/09	09/10	08/09	09/10	08/09	09/10
Acute hospitals	6	10	20	21	20	18	46	49
Community hospitals	0	0	1	2	36	11	37	13
Mental health hospitals	1		0		0	2	1	2

	Number of patient admissions with diagnosis of Asperger's syndrome							
	Primary		Secondary		Subsidiary		Total	
	08/09	09/10	08/09	09/10	08/09	09/10	08/09	09/10
Acute hospitals	0	0	12	12	13	5	25	17
Community hospitals	0	0	15	8	7	8	22	16
Mental health hospitals	3	3	0	3	0	0	3	6

Subsidiary diagnosis is from the third diagnosis and onwards.

In 08/09 there were 55 admissions for young people and children under the age of 18; 47% of these were for A&E, compared to 41 admissions, with 24% for A&E in 09/10.

There were 75 adult admissions in 08/09, 72% for holiday relief predominantly for people aged 20 to 35 years old, compared to 61 adult admissions in 09/10 and 49% for holiday relief.

Recommendations: Review the support systems for young adults in the community.

Data Source: SUS 24/6/10 using ICD10 codes F841 (atypical autism), F840 (childhood autism) and F845 (Asperger's syndrome), (Historically pervasive disorder has been used but has been discounted in this data set as this could lead to confusion, awareness of this gap needs considering when analysing the data)

Limitations of the data: a person will only be coded in a hospital setting if they have had a previous diagnosis of autism or Asperger's syndrome. Only three codes were used; however there are many related codes available. 4 patients had more than one diagnosis of ASD i.e. double counted.

Table 7: Top 9 admissions (08/09) were for the following reasons:

Holiday relief care	54
Other and unspecified convulsions	8
Lobar pneumonia, unspecified	4
Other and unspecified abdominal pain	3
Epilepsy, unspecified	3
Dental caries, unspecified	3
Fracture of lower end of tibia	2
Constipation	2
Generalized idiopathic epilepsy and epileptic syndromes	2

Holiday relief admissions (08/09) to Robertson Road (23), Rockley House(23), Amberley House (7) and Ash Green (1).

- Average length of stay for all diagnoses = **6.6 days**
- Average length of stay for second and third diagnoses = **4.2 days**
- Average length of stay for primary diagnosis = **35.5 days**

(However, this is skewed somewhat as one patient had a stay of 242 days.)

- **Co-morbidity and ASD**

There are several common medical conditions occurring in people with autism spectrum disorders (ASD) that can benefit from treatment and can in turn improve the health and quality of life of people with ASD. *Coury D (2010)* carried out a review that primarily focused on these medical comorbidities, with a brief review of potential future treatments. The finding was as follows:
*'There continues to be disagreement regarding the exact **prevalence** and aetiological significance of gastrointestinal conditions, epilepsy and other abnormal electroencephalographic findings, and sleep problems'.*

Coury, D. (2010)

The summary concluded that further research is needed***.***

Epilepsy

Spence S. J and Schneider M (2009) reported that higher rates of epilepsy have long been reported in people with ASD, but **prevalence** estimates vary from as little as 5% to as much as 46%(4). However Alessandri M; Tuchman R.; Cuccaro M,(2010) reported that autism spectrum disorders (ASD) and epilepsy co-occur in approximately 30% of individuals with either ASD or epilepsy. They state that:

*'A key concept that has emerged during the past 40 years is the strong association between intellectual disability and a higher **prevalence** of epilepsy in individuals with ASD. In addition, the two peaks of seizure onset, one in early childhood and one in adolescence and continuing through adulthood may be unique to individuals with ASD*.'

Alessandri,M. (2010)

Gastrointestinal Symptoms

Ibrahim S. H. et al (2009) found no significant associations between autism case status and overall **incidence** of gastrointestinal symptoms or any other gastrointestinal symptom category. The research concluded:
'*As constipation and feeding issues/food selectivity often have a behavioral etiology, data suggest that a neurobehavioral rather than a primary organic gastrointestinal etiology may account for the higher **incidence** of these gastrointestinal symptoms in children with autism*.'

Ibrahim,S.H. et al (2009)

Learning Disabilities

The National Autistic Society identifies that estimates of the proportion of people with autism spectrum disorders (ASD) who have a learning disability, (IQ less than 70) vary considerably, and it is not possible to give an accurate figure. It is likely that around 50% of those with ASD have an IQ in the average to high range, and a proportion of these will be very able intellectually.

Psychotic, anxiety and/or mood disorders

Skokauskas N and Gallagher L (2009) carried out a review aiming to find relevant published studies on the co-morbidity of autism and Asperger's syndrome with psychotic, anxiety and/or mood disorders, the review concluded:
'There is conflicting evidence regarding the frequency of schizophrenia in this population. Depression appears to be common, although most individuals with autism do not have sufficient language skills to verbalize changes in mood. Anxiety disorders represent the most common psychiatric co-morbidity in this population.'

Skakauskas,N. Galagher,L. (2009)

Adolescence and disruptive behaviour

During adolescence, some individuals with autism engage in severe disruptive behaviours, such as violence, agitation, tantrums, or self-injurious behaviours. Périsse D. et al (2010) aimed to assess risk factors associated with very acute states and regression in adolescents with autism in an inpatient population. They concluded:
'Disruptive behaviours among adolescents with autism may stem from diverse risk factors, including environmental problems, comorbid acute psychiatric conditions, or somatic diseases such as epilepsy. The management of these behavioural changes requires a multidisciplinary functional approach'.

Perisse D et al (2010)

It is clear from an analysis of Adult Care records that a high proportion of 18 – 25 year old clients with ASD also have multiple conditions (see below).

Recommendation: To consider co-morbid factors and treatments of physical health conditions as part of the pathway, may be particularly important during the transition period. To train health professionals that work in the area of epilepsy, mental health and learning disability with regards to autism awareness

Specific problems identified by people with ASD

People with autism have highlighted that the main area of support they need is with social care. However there is a clear link between health and social care as a diagnosis of autism from a health professional should make it easier to claim benefits and access other services needed**.**

Further barriers to accessing services stem from a lack of understanding of autism; local authorities and health services have services for people with a learning disability or mental health problem, but people with autism do not necessarily fall into either of these groups.(The National Autistic Society 2008)

The National Autistic Society carried out a survey to identify the needs of adults with autism: 'I Exist: the message from adults with autism in England, National Autistic Society' *(2008).* There were 1412 responses which have been summarised below:

Adults with autism do not have good health and emotional well being:

- 63% do not receive enough support to meet their needs
- 67% have experienced anxiety and 33% have experienced serious mental health problems because of a lack of support
- over 60% of people who feel that they do not have enough support to meet their needs believe that with more support their general health would improve.

Adults with autism do not have a decent quality of life:

- 75% do not have any friends or find it hard or very hard to make friends
- 72% would like to spend more time in the company of other people.

Adults with autism are not given the opportunity to make a positive contribution:

- only 15% are in full time employment
- 66% are not working at all (including in voluntary employment).

Adults with autism do not have choice and control:

- only 14% live in their own flat or house with support
- 37% would like to live in their own flat or house with support
- only 27% have a person-centred plan or care plan.

Adults with autism do not experience freedom from discrimination:

- 60% have experienced problems trying to receive support from local authorities or health authorities.
- 42% of these people were told this was because there were no appropriate services.
- over 70% of those who live on their own have been bullied or harassed.

Adults with autism do not have economic well-being:

- over 60% rely on their family for financial support.

Adults with autism do not have personal dignity:

- only 20% of adults are receiving daily living support
- 44% of parents/carers believe that their son or daughter would benefit from this support.

Support needs of adults with autism.

Given the findings of The National Autistic Society research it might be concluded that a majority of people will need some support at some time from agencies, but we have inadequate data locally on the needs of an estimated 7,160 adults with ASD in Derbyshire to confirm this.

I Exist: the message from adults with autism in England, National Autistic Society found: "Failure to provide help at the right time has led to many adults with autism needing a greater level of support in subsequent years: 60% of parents say that a lack of timely support has resulted in their son or daughter having higher support needs in the long term". The report calls on local authorities to "fund social support services, including befriending, social programmes, social skills and life skills training for adults with autism".

Whilst a number of the findings of The National Autistic Society's research have relevance to social care, this is not just a social care agenda, but requires an interagency response aimed at addressing the mental and physical health of people with ASD, together with their housing, education, employment and social needs and support. Given the nature of autism these needs can not be met with only information but requires a proactive response from a range of agencies and organisations. Whilst there is clearly a need for social care to reduce barriers to assessment and engage with more clients, the 'Autism Strategy' will need to develop a multi organisation response if the needs of a majority of people with ASD are to be addressed (including those with Aspergers Syndrome who make up nearly half of the prevalence estimates which Planning4care have undertaken).

The SCIE Research briefing 32: Access to social care and support for adults with autistic spectrum conditions (ASC) (2010) raises a number of issues regarding the needs of people with ASD; and what is known about what works.

Key messages include:

- *Outcomes for adults with autistic spectrum conditions (ASC) are generally poor. Many people with ASC experience unemployment; mental and physical ill-health, discrimination and social exclusion.*
- *The evidence base evaluating services for people with ASC is weak.*
- *There are significant variations between individual adults with ASC, so that 'one size fits all' practices are ineffective. Evidence suggests that adults with ASC benefit from services, e.g. employment and care, which adopt autism-specific approaches delivered via specialist, multi-disciplinary teams.*
- *Access to social care is often problematic, compounded by the complexities of the autistic spectrum, by other health-related difficulties, the impact of eligibility criteria and the lack of specific services for adults with ASC.*
- *The transition period of moving from children's services to those for adults is problematic.*
- *Individuals with ASC and additional intellectual disability generally have fewer problems in accessing support, often provided by local learning disability services. However these services may struggle to support individuals with additional or complex needs.*

- *The condition and needs of more 'able' individuals with ASC may go unrecognised or be misdiagnosed.*

- *More information is needed about individuals with ASC and additional sensory processing differences to enable them to access services.*

- *Too few health or social care staff have sufficient expertise or experience for assessing or working with people with ASC.*

- *Research is needed to investigate the lower take-up of social care among people from minority ethnic and cultural groups, women and older people with ASC.*

(SCIE Research Briefing 32, 2010)

Social Care of people with autism in Derbyshire - Analysis of the data

Derbyshire Adult Care are in contact or providing services to only a small % of the adults estimated to have ASD (although this is thought to be in part due to a substantial under recording of clients with ASD which will be addressed).

Table 8 and 9 below are based on analysis of client data by Derbyshire Adult Care Management Information Team where Autism Spectrum disorder is recorded in a data field.

Table 8: Total number of Adult Care clients on Adult Care database with ASD

Client Sub Group	Age band	Derbyshire	Amber Valley	Bolsover	Chesterfield	Derbyshire Dales	Erewash	High Peak	NE Derbyshire	South Derbyshire	Out of County
All clients with ASD	18-24	121	22	10	15	4	16	12	14	12	16
	25-49	43	6	4	1	9	4	5	3	4	7
	50-64	2	0	0	2	0	0	0	0	0	0
	65+	0	0	0	0	0	0	0	0	0	0
	Total	166	28	14	18	13	20	17	17	16	23

Source of data: Management Information Team, Adult Care, November 2010
Note: In the medium term the Adult Care Learning Disabilities Commissioning lead will be seeking to improve the recording of ASD as a condition so that data identifies clients with ASD.

In total Derbyshire Adult Care have on their client database 166 clients since 2005 identified as having autism (ASD), of whom 85 (51%) also have a learning disability (Table 8 above).

In November 2010 there were 125 Adult Care ASD clients identified with 'open cases' (i.e. open to a worker) of whom 68 were recorded as having a learning disability (table 9 below). The proportion of clients with a learning disability may however be significantly higher than this, as many clients under 25 still have children's social care codes (despite now being adults), which do not code learning disability as a separate client group to disability.

Table 9: Adult Care Open Cases with ASD

Client Sub Group	Age band	Derbyshire	Amber Valley	Bolsover	Chesterfield	Derbyshire Dales	Erewash	High Peak	NE Derbyshire	South Derbyshire	Out of County
Learning Disability	18-24	31	4	4	6	1	4	5	3	0	4
	25-49	35	4	3	2	9	2	5	2	3	5
	50-64	2	0	0	2	0	0	0	0	0	0
	65+	0	0	0	0	0	0	0	0	0	0
	Total	68	8	7	10	10	6	10	5	3	9
All open clients with autism	18-24	86	15	10	12	3	10	9	12	5	10
	25-49	37	4	4	2	9	2	5	3	3	5
	50-64	2	0	0	2	0	0	0	0	0	0
	65+	0	0	0	0	0	0	0	0	0	0
	Total	125	19	14	16	12	12	14	15	8	15

Source of data: Management Information Team, Derbyshire Adult Care, 2010
Note:
i) Open cases are clients who have a named social care worker open to that client.
ii) Other: Includes clients for which 'no data' or children's client sub group code remains recorded despite the client being an adult.

Of the 125 clients identified with autism aged 18 plus and open to Adult Care just two are aged 50 plus. 86 clients (69%) are aged 18 – 24 with the remaining 39 (31%) aged 25 – 64 years. Planning4care have estimated there to be some 5,530 people aged 18-64 years old with ASD in Derbyshire. The total 166 clients aged 18 – 64 with ASD known to the department represent just 3.0% of these; and current open clients just 2.2%. Given however that more than two thirds of Adult Care clients identified with autism are between 18 and 25; and that prevalence rates for 25 – 64 year olds would be expected to be similar, this suggests an under recording of Adult Care clients with ASD aged 25 and over, and / or under diagnosis within this age group.

Very few clients aged 25 plus are shown as receiving services or direct payments. Given however that it is estimated that 30% of adult users of specialised learning disabilities services have ASD[♣] this is likely to be a substantial under recording.

Table 10: Adults with ASD receiving continuing care money from Derbyshire county PCT to live in residential placements:

	No of place-ments 09/10	Total cost	No of place-ments 10/11	Total cost	Forecast place-ments 11/12	Forecast cost 11/12
Adults with ASD in residential placement funded by NHS	14	**1,913,867**	18	**2,080,265**	**10**	**1,581,055**

These are all individual placements, over 18 years old, and funded from the NHS mental health or learning disability budget. All service users have an active review to ensure they are in the most appropriate setting and that care is close to home

[♣] p5, The Estimated Prevalence of Autism among Adults with Learning Disabilities in England, 2010

Derby City data

There was a lack of data available from Derby City. Social Services reported that they have 73 people on their database with a recording of learning disabilities/ ASD as of March 2011. Derby City PCT reported the continuing care data as follows:

Table 11: Adults with ASD receiving continuing care money from Derby City PCT to live in residential placements

People with autism and learning disability	Ages 18-24	25- 49	50- 64
Fully funded by health	2	2	
Joint funded by health and social care	**4**	**11**	**1**

Source of data: Derby City PCT Continuing Care Department March 2011. Note all people jointly funded will be double counted with social services data.

Therefore only people with autism and a learning disability have been included in any of the above data which indicates a total number of 77 people with ASD being supported by either health or social care (73 by Social Care and a further 4 fully funded by health).

Recommendations:

i) To provide autism awareness training for all social care professionals (and particularly those who work in the area of learning disability, physical disability and mental health) alongside more specialised in depth training for designated staff.

ii) To ensure groups and agencies in touch with people with autism (and their carers) are aware of the key points from the new Derbyshire Autism Strategy when finalised, including the role of health and social care with regard to their condition.

iii) To record consistently clients who have autism as a disability together with the relevant adult care client group and sub group

Transitions - Derbyshire Adult Care clients aged 18 – 25 with ASD

A desktop audit of 388 Adult Care clients with disabilities who were aged 18 – 25 and open in November 2010 was undertaken in order to establish more complete data for this age group. The audit looked at computerised Adult Care client records including recorded disabilities, assessments, reviews, case documents, provision and cost of provision. This revealed 106 clients aged 18 – 25 with ASD (27.3% of all disabled clients in this age range), the great majority of whom also have learning disabilities and / or other disabilities. The fact that this audit more than trebled the number of open 18 – 25 year old clients identified as having ASD (compared to table 9 above) confirms the need for more consistent recording of disabilities in the Framework i data field if we are to understand the number of clients with ASD or other disabilities, which is important to the development of the JSNA, development of strategies, and the commissioning of appropriate services.

Gender

In previous studies ASD has been found to be substantially more prevalent amongst males than females. Currently, for Derbyshire Adult Care open clients aged 18 – 25 the ratio is 2.4 times males to females.

Table 12: Adult Care ASD open clients aged 18 – 25 by gender

	Total	Total %	Aged 18 - 21	Aged 22 - 25
Male	**75**	**70.8%**	**41**	**34**
Female	**31**	**29.2%**	**19**	**12**
People	**106**	**100.0%**	**60**	**46**

Source of data: Adult Care Management Information Team and 'Needs & Intelligence', November 2010.

Clients aged 18 – 25 with ASD & Learning Disabilities

Of the 106 clients with ASD, 90 (85%) also had a learning disability including at least 30 (28%) with a severe learning disability. Given that research points to only between a third and 45% of all people with ASD having a learning disability, this indicates that Adult Care are not currently substantially engaged with those with Asperger's syndrome. It is also clear from a few case files that where a client had ASD but no learning disability they were ruled out of being eligible for services (although there are in fact a small number of clients with ASD only receiving services).

Based on prevalence estimates, in total Adult Care is estimated to be working with one in eight of all people with ASD aged between 18 and 25, despite the fact that The National Autistic Society estimates that: "At least one in three adults with autism are experiencing severe mental health difficulties due to a lack of support".♦

♦ I Exist: the message from adults with autism in England, National Autistic Society

Table 13: ASD clients aged 18 – 25 by ASD & Learning Disability

Learning Disability	Total	Total %	Aged 18 - 21	Aged 22 - 25
No Learning Disability	16	15.1%	5	11
Learning Disability	45	42.5%	28	17
Mild or Moderate Learning Disability	15	14.1%	10	5
Severe Learning Disability	30	28.3%	17	13
All	106	100.0%	60	46

Source of data: Adult Care Management Information Team and 'Needs & Intelligence', November 2010.

Clients with ASD and multiple disabilities

Table 14: ASD clients aged 18 – 25 with ASD & other disabilities - November 2010

Disability 2	Disability 3	Disability 4	Total
No LD	~	~	10
No LD	Mental Health	~	4
No LD	Challenging Behaviour	~	2
LD	~	~	27
LD	ADHD	~	3
LD	Cerebral Palsy	~	2
LD	Challenging Behaviour	6 of whom had combinations of cerebral palsy, epilepsy or communications difficulties	10
LD	Communication Difficulties	(including with epilepsy)	3
LD	Epilepsy	~	4
LD	Mental Health	4 of whom also had challenging behaviour together with either: a Chromosomal disorder, epilepsy, or no speech.	5
LD	No speech	With (progressive) genetic disorder with epilepsy or profound deafness	3
Severe LD	~	~	8
Severe LD	ADHD	Including with dyspraxia	3
Severe LD	Cerebral Palsy	Including with epilepsy / no speech	2
Severe LD	Challenging Behaviour	8 of whom also had combinations of no speech / communication difficulties, or epilepsy, or chromosomal disorders with global development delay, or blindness.	14
Severe LD	Other	With communication difficulties and / or chromosomal or progressive genetic disorder or hemiplegic	4
Severe LD	Epilepsy	~	2
Total			106

Source of data: Adult Care Management Information Team & Needs & Intelligence Section.
Note: Learning Disability abbreviated to LD; Profound & multiple learning disabilities to PMLD; and Severe Communication Difficulties to Communication Difficulties. Only epilepsy that is not currently controlled is included.

It is clear from the table 14 that young adults with ASD whom the department are working with predominately have multiple disabilities and high needs, rather than only ASD. Just 10 people (9%) have ASD only. The 85% who have ASD and learning disabilities also disproportionately have combinations of severe communication difficulties, challenging behaviour, mental health problems, epilepsy, chromosomal disorders or cerebral palsy.

- **Where do young people with ASD live?**

56 people (43%) live at home with their parents (including 17 who live with a lone parent or grandparent).

A further 13 (12%) are at Specialist Residential College / School, who are mainly under 23 years old. Most return home during college holidays. Most will return home once they have finished college, but a number say they will then want to move out, most commonly to supported living (where typically they will have a tenancy to live in a property with other disabled young people, with a commissioned care provider inputting care).

11 people (15.1%) of clients were living in either Supported Living Schemes (10.4%) whilst 5 people were living on their own in a flat bedsit (4.7%). The proportion living in these types of accommodation increases to 26% of 22 – 25's. Although only 5 people were living alone (including two with Aspergers syndrome), they were struggling to sustain living alone, with probably only one managing well (supported by a large direct payment). Most had a combination of problems related to drink / drugs, mental heath problems, or sexual vulnerability. One person was facing possible eviction following complaints from neighbours and another was assessed as needing to move to supported living.

24 people (23%) were living in residential care homes, with a further 3 (3%) living in Adult Care Hostels for people with learning disabilities, whilst two were currently detained under the Mental Health Act .

Table 15: Adult Care ASD clients aged 18 – 25 by where living

Accommodation Type	Total	Total %	Aged 18 - 21	Aged 18 - 21 %	Aged 22 - 25	Aged 22 – 25 %
Adult Placement / Foster Parent	<4	1.9%	<3	1.7%	<3	2.2%
DCC Residential Care	3	2.8%	0	0.0%	3	6.5%
Detained under Mental Health Act	<3	1.9%	0	0.0%	<3	4.3%
Lives with lone parent	17	16.0%	13	21.7%	4	8.7%
Lives with parents	29	27.4%	19	31.7%	10	21.7%
Registered Care Home	24	22.6%	13	21.7%	11	23.9%
Residential College / School	13	12.3%	10	16.7%	3	6.5%
Supported Living	11	10.4%	3	5.0%	8	17.4%
Tenancy (flat / bedsit)	5	4.7%	<3	1.7%	<3	8.7%
All	106	100.0%	60	100.0%	46	100.0%

Source of data: Adult Care Management Information Team and 'Needs & Intelligence'. , November 2010
Note: 'Lone parent' includes living with lone parent or grandparent.

Table 16: Adult Care ASD open clients aged 18 – 25 by District

	Total	% of all	Aged 18 - 21	Aged 22 - 25
Amber Valley	**11**	**10%**	**7**	**4**
Bolsover	**<3**	**<3%**	**<3**	**<3**
Chesterfield	**19**	**18%**	**9**	**10**
Derbyshire Dales	**3**	**<3%**	**<3**	**<3**
Erewash	**11**	**10%**	**5**	**6**
High Peak	**10**	**9%**	**5**	**5**
NE Derbyshire	**9**	**8%**	**7**	**<3**
South Derbyshire	**4**	**4%**	**<3**	**<3**
Out of County	**35**	**33%**	**23**	**12**
Unknown	**<3**	**<3%**	**<3**	**<3**
Total	**106**	**100%**	**60**	**46**

Source of data: Adult Care Management Information Team and 'Needs & Intelligence, November 2010'.
Note: District defined as where living (including those at residential college). In this table <3 denotes less or equal to 3.

The number of open clients aged 18 – 25 varies substantially by District, which to some extent may be accommodation driven for those not living with parents. A third of clients are living outside of Derbyshire (mainly in residential care or at residential college run by specialist providers).

Table 17 Accommodated outside of Derbyshire

Accommodation Type	Total	Derby City	Neighbouring County	Non Neighbouring County
Detained under Mental Health Act	**<3**	**0**	**<3**	**<3**
Registered Care Home	**20**	**4**	**11**	**5**
Residential College / School	**12**	**0**	**5**	**7**
Supported Living	**<3**	**1**	**<3**	**<3**
All	**35**	**5**	**17**	**13**

Source of data: Adult Care Management Information Team and 'Needs & Intelligence', November 2010.

- **Direct Payments and Community Services**

In addition to the residential and supported living provision identified above, 36 clients received the 42 direct payments / personal budgets and / or services as identified in Table 18 below. Whilst the great majority of the direct payments were for a PA / home care, two were respectively for NORSACA day care and day attendance at NORSACA College. In total 82 (77.4%) of the 106 clients were receiving direct payments / services or residential care / residential college from Adult care. The remaining 24 clients had no such provision, but there were a small number of clients where service inputs or a direct payment were being considered; and one client whose parents had declined a direct payment as they decided they wanted to maintain continuity of care. At least 3 clients did not 'fit the criteria of having a significant learning disability", which excluded them from assistance.

Table 18 Adult Care ASD clients aged 18 – 25 receiving direct payments or services

Provision	Number
Day Centre	7
DCC Home Care	3
Direct Payment	26
Independent Home Care	4
Day attendance at (Non Residential) Specialist College	2
Total	42

Source of data: Adult Care Management Information Team and 'Needs & Intelligence' November 2010
Note: Table 18 excludes client residential provision in table 17 above

- **Education, Day Centres & Volunteering / Employment**

Some 45 people (43%) were undertaking some full or part time education, including one person undertaking a degree course. 8 of these were also engaged in work experience or volunteering.
Of those not undertaking education 7 were attending a day centre and a further 5 were volunteering or in part time employment.
A number of people required 1:1 support to enable them to participate in the educational and vocational activities (due to the impact of ASD and / or other disabilities).

45 (43%) clients were not at college, or attending a day centre or volunteering / working (and were disproportionately in residential care). Of the 24 clients living in residential care just 4 were attending college or external day centres.

Table 19: ASD 18 – 25 clients by education, day centre or volunteering / employment

School / College (Full or P/T)	Day Centre	Employment type	Total	Aged 18 - 21	Aged 22 - 25
FE College	No	Work experience / Social Enterprise	6	4	2
FE College	No	No	13	11	2
FE College	No	Volunteer	2	1	1
FE College	Day Centre	No	2	1	1
FE College	No	No	2	1	1
Residential College	No	No	14	10	4
Norsaca College - non residential	No	No	6	5	1
No	No	Volunteer / part time employment	5	2	3
No	Day Centre	No	7	3	4
No College, day centre or employment	No	No	45	20	25
Not Known	No	No	4	2	2
All			106	60	46

Source of data: Adult Care Management Information Team and 'Needs & Intelligence' November 2010.

- **Adult Care – Cost of provision for 18 – 25 year olds with ASD**

Five clients had the whole cost of their care met through NHS 'Continuing Care' with a further 15 clients having joint Adult Care / Continuing care financing of their care. Three clients are part Independent living Funded (ILF) and at least a further 4 clients were part funded by Derbyshire Children and Young Adults (CAYA) Department and / or the Young People's Learning Agency (YPLA). It is noted that in the past year 8 clients have had their continuing care moneys reduced or stopped on review, the latter on the basis that the PCT do not consider their needs to be primarily health care needs.

Whilst the costs of services for minority of clients weren't quantified on Framework i, annualised Adult Care weekly payments of £2,898,575 were identified in respect of residential care, day care, home care and direct payments in respect of 65 clients aged 18 – 25 with ASD (or an average of £44,593 per year). These costs exclude NHS continuing care, Independent Living Fund (ILF) and YPLA payments.

A minority of packages of care are substantially more expensive, reflecting some client's high care costs. 18 clients had provision with an annualised cost of over £50,000 per year (excluding (excluding any continuing care or ILF contribution), with all but 2 of these being for external residential care. Six of these cost between £52k and £75k, four between £75k and £100k, five between £100k and £150k, with three between £150k and £162k. The average for all 18 clients was £75,000 per year.

At pages 14 and 15 above the problems identified by people with ASD and their support needs were discussed. It is clear that if these are to be addressed the ASD pathway and the commissioning of services will need to address the social care and support needs of the whole ASD population whilst continuing to provide specialist provision to meets the needs of those with ASD and multiple disabilities.

Given that nearly half of 18 – 25 year old clients live at home, the needs of carers have to also be addressed to adequately sustain continued support at home or in the community where that remains the wish of people with ASD and their carers.

Transitions: 14 – 17 year olds with ASD

Transitions is one of the key areas covered in the recently published Statutory Guidance for local authorities and the NHS on the implementing of the National Autism Strategy: 'Fulfilling and rewarding lives' (DoH 2010). It sets out expectations for interagency working including diagnosis, adult care assessments, and the provision of services where necessary. Commissioning plans are expected to be drawn up by local authorities and NHS bodies and be reviewed annually. The guidance says *'Effective transition planning should include career preparation up to age 16 and plans for education, employment, training, transport, housing and leisure from 16 to 19 and beyond. Crucially transition plans should be individually tailored to the needs and wishes of the individual young person and reviewed and updated each year.'*

DH (2010)

A 'Research Study on age appropriate services for young people with neurodevelopmental disorders' (ECOTEC 2010) looked at what types of activities or services work best for young people in transition who have ADHD or autism. The aim of the study was to investigate the issues facing young people aged 17-25 with an autism spectrum disorder (ASD) or attention deficit hyperactivity disorder (ADHD) who are about to make, or who had recently made, the transition to adulthood, in particular looking at age-appropriate support for these groups. These groups were identified as having needs that were potentially unmet by current service provision. The recommendations include:

- *targeting young adults with ADHD and autism aged between 16-25, both with or without a formal medical diagnosis, as not all young people have a medical diagnosis, but may still require additional support;*
- *prioritising young people with high functioning autism, Aspergers and ADHD, since it is for these groups where more significant gaps in services appear to be evident or can sometimes be inadequate or inappropriate;*
- *and supporting improved outcomes around life chances, access to work, education, life skills and reducing social isolation as these were key areas identified by young people.* (ECOTEC 2010)

Recommendation
The statutory guidance will need to be applied in the development of the Derbyshire autism strategy and pathway; and review of transition arrangements (including for young people with Asperger's syndrome).

• Number of 14 – 17 year olds with ASD

To inform implementation of the transitions agenda data held by CAYA (Derbyshire Children's and Younger Adults Department) has been analysed. In total 386 individual Derbyshire young people aged 14 – 17 were identified by CAYA as having ASD, which is 1.0% of all Derbyshire children in this age band. The young people were identified after matching various education, social care and connexions administrative data sets at individual level.

These 386 young people identified with ASD equate to the great majority (88%) of Planning4care's prevalence estimate of 440 (which would suggest that either most young people with ASD in this age band have in fact already been identified or that the Derbyshire actual prevalence is higher than estimated by Planning4care for this age group). At district level the number identified in table 20 below is significantly lower than the Planning4care prevalence estimates for both Erewash and NE Derbyshire (see table 2 above).

Table 20: Derbyshire young people aged 14 – 17 identified with ASD.

By District	Total	With SEN Statement	Schools Action Plus	Other Source
Amber Valley	70	29	11	30
Bolsover	46	24	7	15
Chesterfield	60	22	10	28
Erewash	34	12	8	14
High Peak & North Dales	57	18	11	28
North East Derbyshire	39	21	5	13
South Derbyshire & South Dales	59	17	12	30
Out of County	21	4	1	16
Total	386	147	65	174

Source of data: CAYA, Derbyshire County Council, 2010
Note:
i) A SEN Statement is a Special Educational Needs statement.
ii) 'Other Source': Young people with ASD 'Identified through non SEN data source' including: CAYA social care, Aiming High, Derbyshire PCT service data, Connexions and Education Services.
iii) Out of County includes 2 unrecognised addresses.

- **Special Educational Needs (SEN)**

A total of 212 of these young people were identified as having an SEN statement or 'Schools Action Plus' status which both require additional educational resources (table 20). 127 of the 147 young people with ASD and statutory SEN statements had ASD identified as their primary condition, as did 60 of the 65 of the 'Schools Action Plus' SEN pupils.

A substantial proportion of the 212 young people with ASD with a statement or 'School Action Plus' status have other conditions – including most commonly learning difficulties or 'behavioural emotional and social difficulties'.

- **Transitions – Children's social Care**

Nearly half of the 386 young people with ASD are known to CAYA Social Care teams, but are not necessarily open currently. Further analysis is being undertaken to clarify the number that are currently open; the provision currently being provided; and the number currently open who will become 18 over the next four financial years to inform transitions and Adult Care planning. There will be some additional young people who do not currently require social care whilst at school, but who are likely to need support as adults.

There are between 90 and 102 young people with ASD who will become 18 over each of the coming five years (table 22) of whom between 31 and 50 are known to children's social care (table 23).

Table 21: Young people 14 – 17 with ASD previously or currently known to Children's Social Care 2010

Area	Total with ASD	Number known to Social Care	Known to Social Care %	Number not known to Social Care		Known to Disabled Children's Team	Known to other Children's social work teams
Amber Valley	70	34	48.6%	36		20	31
Bolsover	46	15	32.6%	31		8	15
Chesterfield	60	26	43.3%	34		22	26
Erewash	34	17	50.0%	17		10	17
High Peak & North Dales	57	30	52.6%	27		21	28
North East Derbyshire	39	19	48.7%	20		8	18
South Derbyshire & South Dales	59	26	44.1%	33		15	25
Living out of County	19	11	57.9%	8		9	11
Unknown address	2	0	0.0%	2		0	0
Overall total	386	178	46.1%	208		113	171

Source of data: Management Information Team, CAYA, Derbyshire County Council, July 2011.
Note: Disabled Children's Teams provide support to severely disabled children and can provide packages of day care, home –based and residential support in response. Some young people with ASD will not meet the criteria for support from this team.

Table 22: All young people with ASD becoming 18 in:

Area	2011/12	2012/13	2013/14	2014/15	2015/16
Amber Valley	13	19	12	26	17
Bolsover	8	21	9	8	11
Chesterfield	13	14	19	14	9
Erewash	6	9	9	10	8
High Peak & North Dales	16	12	12	17	14
North East Derbyshire	8	7	9	15	12
South Derbyshire & South Dales	19	11	19	10	14
Living out of County	7	7	4	1	3
Unknown address	1	0	0	1	2
Total	91	100	93	102	90

Source of data: CAYA, Derbyshire County Council 2010.
Note: This table includes young people with ASD with a Special Educational Needs statement or Schools Action Plus status and others with ASD identified through CAYA social care, Aiming High, Derbyshire PCT, Connexions or Education Services data.

Table 23: Children with ASD known to Children's Social Care becoming 18 in:

0	2011/12	2012/13	2013/14	2014/15	2015/16
Amber Valley	5	8	9	5	12
Bolsover	<5	<5	5	7	<5
Chesterfield	<5	<5	6	8	9
Erewash	4	5	<5	<5	<5
High Peak & North Dales	8	6	8	7	9
North East Derbyshire	<5	<5	<5	6	7
South Derbyshire & South Dales	<5	7	<5	10	5
Living outside County	<5	<5	5	<5	0
Total	31	35	45	50	48

Source of data: CAYA, Derbyshire County Council 2010
Note: <5 denotes less than 5.

Adults ASD Care Pathway

Gaps, barriers and service providers in relation to the current adults ASD pathway **The following abbreviations have been made: Mental Health (MH); Learning Disability (LD); Severe Mental Illness (SMI); General Practitioners (GPs); Occupational Therapy (OT)**
Gaps
• Some MH teams lack the skills to identify people with ASD in their caseloads due to lack of awareness. • MH teams are not able to diagnose complex ASD due to lack of trained psychiatrists and psychologists • GPs only able to refer someone for a diagnosis of ASD if the patient has an IQ below 70 (LD) or severe and enduring mental health (SMI) or under 18 years old (please refer to children's ASD pathway) • If a person is diagnosed with ASD but doesn't have an IQ below 70 or SMI, there is no service available. • Ensure health facilitators in acute care can support autism • Shortage of self-help groups • Insufficient voluntary sector capacity to support • Lack of commissioning pathways • Lack of fully coordinated response across statutory and voluntary agencies with a contribution to make.
Barriers
• Not all clinicians are skilled to recognise ASD • In MH psychiatrists are not trained to diagnose ASD • In MH no staffs are trained in DISCO and therefore not able to give specialist diagnosis. • There is a lack of specialist psychological therapists trained to work with ASD. • The transition between children's and adults ASD pathways means that some people with a diagnosis fall into the group where no support is offered. • Eligibility criteria of health and social care • Expertise of assessors to recognise ASD in adult care
What are the service roles?
• GPs – need awareness of diagnosis and physical health checks, carers recognised, simple info • Secondary care- Diagnosis, psychology, OT and speech and language • Social care- needs assessed, carers needs assessed, • Voluntary services – advocacy, self help groups/ activities • Employment services, adult education and probation services- back to work programmes, learning programmes. • Police – awareness of ASD, access to referral eg young offenders. • Acute care: quality of care, ASD awareness, appropriate support and referrals. • Housing: ASD awareness, access to housing, support and advice.
How do services refer to each other?
• Not clear how progress is communicated back to GPs, clarity with regards to coding is essential in order to track prevalence. Is primary care clear about the referral criteria for ASD? • Services could track an individual with an NHS code across health and social care, this is not currently done. • In the County following a referral to health: health services can refer to social services. The individual may need another assessment at this point, plus a carers assessment. • In the City following referral to MH: care co-ordinators would co-ordinate all other services for the individual including carer's needs assessment. • Services that are considered necessary to support adults with ASD include: Psychological intervention; social support; OT; speech and language and self help groups. • There are two providers for Learning Disability Services in the County, one for the North and one for the South.
Health and social care outcomes: how should this service help?
1. **Diagnosis** – confirmation of condition, self awareness, coping strategies developed, information, carers information, trigger for further support needed. 2. **Maintenance of independence**, ability to cope with daily living and tasks, maintain accommodation, opportunities for employment. 3. **Ability to maintain a social network** of support if the individual wants to. 4. **Prevent SMI problems** and maintain positive mental health and wellbeing. **5. Reduce health inequalities** **6. Equity of service provision** **7. Reduce contact with the criminal Justice system.**

NHS

NHS Derby City and NHS Derbyshire County

DERBYSHIRE County Council
Improving life for local people

Current Adult Autism Spectrum Disorder Pathway Derbyshire 2010

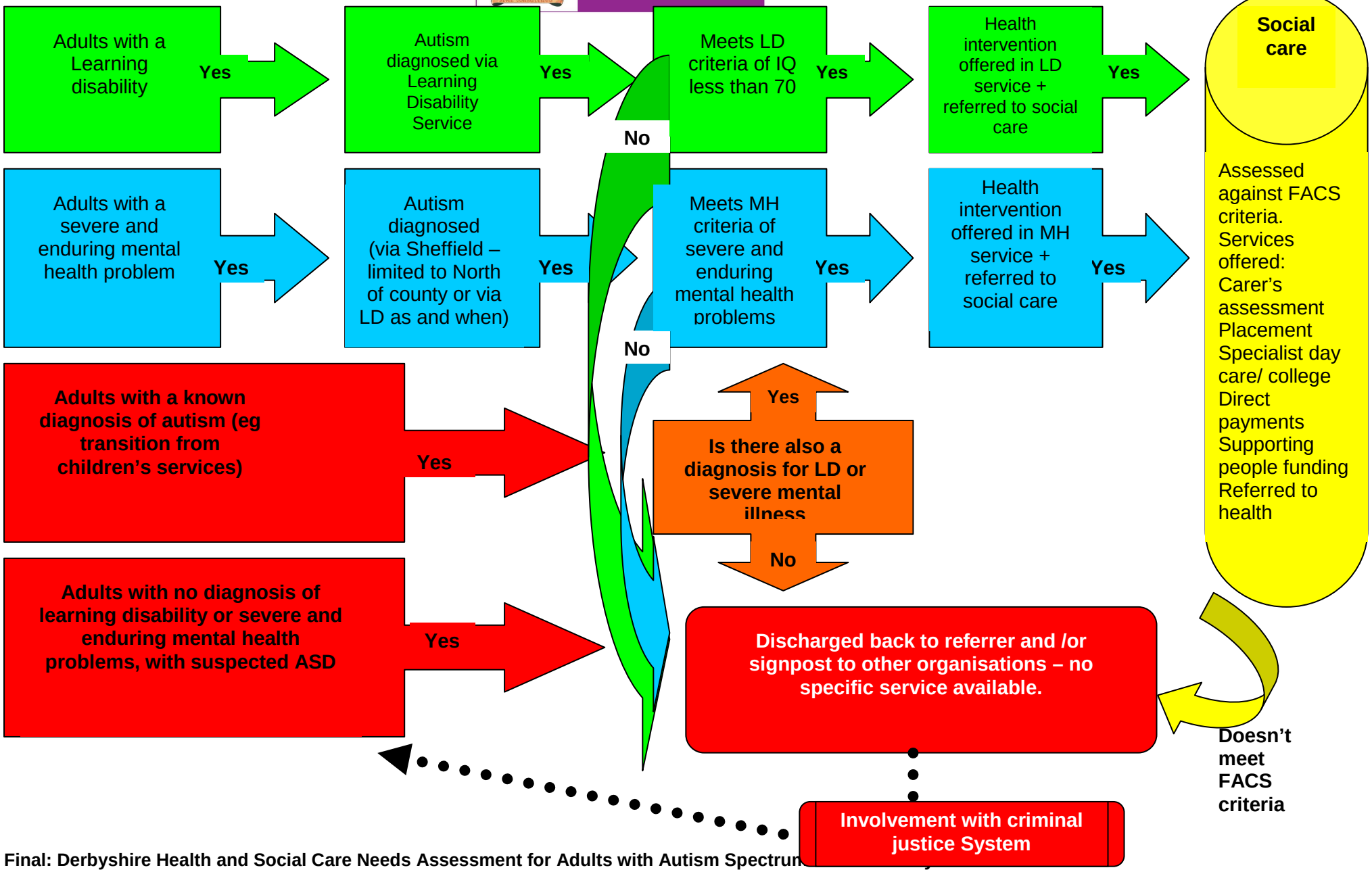


Table 24: An example of clients that have fallen into the red 'discharge' box from January to December 2010

Clients age	Referrer	Risks, background and reason for referral	Reason for discharge	Further signposting
24	**GP**	**The client is diagnosed with ASD and learning disability and is seeking further support. The client is vulnerable and still lives with parents.**	**IQ of 79, therefore doesn't meet the access criteria.**	Information given with regards to support groups and mencap employment scheme.
20	**GP, via mental health team**	**The client was referred to psychotherapy for impulsive and sexual behaviours, seeking further support and diagnosed with Asperger's syndrome.**	**IQ of 87, therefore doesn't meet the access criteria**	Information given on ASD support groups, and referred to Mental Health Team.
19	By Mother	The client has challenging behaviour, diagnosed with ASD and is at risk due to physical aggression and mental health problems. The client is living with parent	IQ too high and therefore doesn't meet the access criteria.	Referred to Mental Health Services.

In total there were 18 people diagnosed with ASD by the NHS Learning Disability Team in the south of the county but discharged back to the referrer due to not meeting the criteria for the service (IQ below 70). The NHS LD team in the North of the county did not record discharges, likewise we have no feedback from Mental Health Teams. All clients were presenting risks such as vulnerability. Of the patients recorded 14 out of the 18 were between the ages of 16 to 25 (78%), 2 out of the 18 were between the ages of 25 to 30 (11%) and 2 out of the 18 were over 30 years old (11%)

Involvement with Criminal Justice System

Research suggests that people with autism are potentially over represented within the criminal justice system. (Cache 2009) Research into the experience of people with autism in the criminal justice system is limited but does identify increased exploitation, bullying, anxiety, confrontation and social isolation due to their ASD traits. (Cache 2009)

Recommendation:
The ASD co-ordination group were concerned with the collection of data that indicated many individuals were presenting risk factors to both themselves and the community but were offered no support, and there are clear links with the criminal justice system. Better data collection and analysis needed, partnership working and awareness training for staff within the criminal justice system.

Number of people diagnosed

The data is incomplete with regards to the number of adults diagnosed with autism in any year. There is data however for the numbers diagnosed with autism via an out of area assessments (at Sheffield, as accessed by the North of the County).

Table 25: Out of area assessments for adults from Derbyshire with ASD

	09/10	Mean age	10/11	Mean age
Out of area assessments	12	31	17	38

- **Training for health and social care professionals in Derbyshire**

There is a recommended set of learning outcomes from Skills for Care: ***Learning Disability Knowledge sets (Adults, England) Series 2, Summer 2009: Supporting people with autistic spectrum condition (ASC).***

A training group has been established and available training has been scoped across Derbyshire (See Appendix 2).

- **Services currently available in Derbyshire**

The National Autistic Society recommended that people with ASD need : Befriending, social programmes, social skills and life skills training for adults with autism. A scoping exercise has been carried out to identify third sector organisations that offer services to adults and children's with autism and the equity of these services across Derbyshire (see table 26).

Codes

Red	Carers Support
Amber	Social Programmes/ Befriending
Blue	Education and Training
Purple	Respite and residential support (often includes a range of other social support)
Yellow	Language/ Therapy and 1:1 support
Green	Supporting social and life skills

Recommendation: Ensure equitable access to social/ befriending programmes and programmes that support social and life skills for adults with ASD.

Table 26 – Third Sector and Private Sector Services for Adults with ASD available across Derbyshire and Derby City.

	Chesterfield	NE Derbyshire	Bolsover	High Peak	Derbys Dales	South Derbys	Amber Valley	Erewash	Derby City
South Derbyshire Support groups - adults									
Derbyshire Autism Services Group - Derbyshire									
Autism Outreach Teachers - Derbyshire									
Help! Managing anger Parent Programme					Event in Matlock				
Challenge Consultancy & Training LTD - Derbyshire									
Portland Care Homes LTD - Derby									Referrals from adult care.
Derwent View - Derby									
St Michael's housing and support									
Heritage Care Ltd									
SLC Paragon									
Reach Housing and Enablement									
Thera East Midlands									
Self unlimited									
Real life options									
Lifeways Community Care Ltd									
Creative support Ltd									
Craegmoor									
Care solutions Ltd									
Norsaca									
Relate Derby and South Derbyshire									
Reach Housing - Derbyshire									
Voice UK - Derby	Helpline available Mon- Fri 9am – 5pm.								
ASPECT									
Peak & Dales Advocacy - Derbyshire									

Table 27 – Third sector and private sector services for young adults at transition stage (16 - 21 years) with ASD available across Derbyshire and Derby City.

	Chesterfield	NE Derbyshire	Bolsover	High Peak	Derbys Dales	South Derbys	Amber Valley	Erewash	Derby City
NCH Yew Trees - Derbyshire									
HADE additional support services	Sheffield service								

Codes

Red	Carers Support
Amber	Social Programmes/ Befriending
Blue	Education and Training
Purple	Respite and residential support (often includes a range of other social support)
Yellow	Language/ Therapy and 1:1 support
Green	Supporting social and life skills

Recommendation: Ensure equitable access to social support and life skills during the transition stage for young people with ASD.

Recommendations for the Autism Commissioning Group and ASD Clinical Group:

Assessing a health and social care priority for action

1. Assess the current and expected expenditure from the data provided to ensure opportunity costs are maximised with regards to equity, quality, range and response of services, including an analysis of out of area treatments.

2. Look at the options for a joint care pathway across both health and social care for all people who have ASD.

    - Address the needs of those individuals who have ASD but do not meet the service criteria for LD or MH. Identify support needed to manage their condition other services that may meet their needs.

3. Through collaboration, reduce the risk of offending and the inappropriate involvement of people with ASD in the criminal justice system. Explore this association further.

4. Consider the evidence-base and needs of people with ASD when developing the pathway, including:

    - Age, severity, co-morbid factors and treatments of physical health conditions as part of the pathway, this may be particularly important during the transition period.

    - The feedback of people with autism and their carers about social care needs from the survey *'I Exist - The message from adults with autism in England '(2008) The National Autistic Society and the* Research Study on age appropriate services for young people with neurodevelopmental disorders .

    - The training needs of health and social care staff and carers.
        - Ensure that staff who carry out Adult Care needs assessments or NHS continuing healthcare assessments are fully trained in autism awareness.
        - Ensure that social care support workers who come into regular contact with adults with autism are trained in autism awareness.
        - Ensure health and social care professionals who work with people with multiple illnesses and disabilities are trained in autism awareness.
        - Specific additional training to enhance the skills of staff working with people with ASD on a regular basis.

    - Reasonable adjustments that services can make in order to meet the needs of people with ASD and make appropriate recommendations.

    - Future demands on the services including the 61% rise in the 65 plus age grouping over the next 20 years need to be taken into account in the planning of services and provision.

Action planning for change

5. Develop an action plan following consultation
    - Consider - What are the risks again in terms of equity, quality, range and response of services and opportunity costs.
    - Consider – how to engage partners in promoting an interagency response which addresses the health, social care, further education, social skills needs, life skills, and accommodation needs of people with ASD.
    - Consider if the action plan meets the Statutory Guidance for local authorities and the NHS on the implementing of the National Autism Strategy: 'Fulfilling and rewarding lives' (DoH 2010)

This needs assessment identifies what we currently know about the number of people with ASD in Derbyshire and provides a baseline for improving: the consistency of ASD diagnosis, the quality of local data, the assessment of needs; and consideration of what resources can be made available for improvements in provision for a greater number of people with ASD.

Moving on and Project Review

1. Consider how the action plan, pathway and new services will be monitored and evaluated:
    - Have systems in place to accurately record the number of adults with autism in Derbyshire.
    - Monitor people with autism within primary, secondary and social care and mental health services, in order to review and plan appropriate and equitable services.
    - Ensure data collection is part of all service specifications and training.
    - Include the needs of adults with autism in commissioning strategies
    - Evaluate the use and equity of services and care pathways.
    - Confirm future process for client and patient feedback on satisfaction with provision meeting their needs.

2. Review the monitoring process

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Appendix 1

Consultations and feedback from people with ASD and their carers in Derbyshire

Service users concerns with the ASD care pathway between 2008/2010 from MHT

- Not understanding how to access services
- Being pushed from 'pillar to post'
- No tier 1 drop in cafes, support groups, etc
- No services for GP to refer to if they do not meet the criteria for either mental health or learning disability services
- Nowhere to get an assessment/diagnosis if they do not meet the criteria for either mental health or learning disability services. . . in some cases this is all the person wants to be able to understand why they are different
- Unable to or difficult to access employment, education and leisure activities
- May require low level social care support e.g. help with letters, shopping, etc, but does not meet criteria for generic services
- Needs support to live independently
- Needs support to put structure in their lives and understand the world around then
- No access to modified CBT/talking therapy services for people with ASC
- Labelled as having a mental illness

Consultation with a local parents group for children with ASD

Katie Brooks RGN/RMN, Clinical Nurse Specialist, Child and Adolescent Mental Health Service (CAMHS) had a long discussion with the parents group regarding ASD and current services and barriers for children (June 2010)

The feedback from the group was as follows:

- *'One of the difficulties is that ASD kids don't fit into any category e.g. Learning disability or Mental health. ASD always falls between or not into either classification.*

- *Regarding assessment and diagnosis this can be a different experience depending on whom you get, if it's identified in the first place. It can be a relief if someone understands you and what you are going through, but if the assessment is too quick and you get a diagnosis speedily without any supportive follow up then it's really difficult to just come to terms with it on your own. One of the families went through the communication clinic and felt they were just left to get on with things. Some of my families although the assessment took quite some time we talked all the way through and they felt they came out of the whole process with good understanding and support.*

- *Everyone felt that there are gaps in all services where some people understand ASD and a lot don't.*

- *There is a need for specialist sign posting as one service doesn't really know about other supports available (I agree)*

- *One parent was extremely worried about ASD falling under adult mental health services as she had been an inpatient herself (interestingly enough probably wrongly diagnosed as Schizophrenic and these days often Personality disorder is often given for an ASD) she was worried that adult services don't know enough about ASD.*

- *There is still an overall ignorance in the general public about ASD'*

Appendix 2

Training Data

Recommended Training for health and social care professionals (sourced from the Skills for Care)

Learning Disability Knowledge sets (Adults, England)
Series 2, Summer 2009

Supporting people with autistic spectrum condition (ASC)

1. 1. Guidance notes

What are knowledge sets?

Knowledge sets are sets of key learning outcomes for specific areas of work within adult social care. They are designed to improve consistency in the underpinning knowledge learnt by the adult social care workforce in England.

It is intended that the key learning outcomes within each knowledge set should be used by employers to develop in-house learning, and by training providers, publishers and awarding bodies to produce learning programmes, resources (CD-ROMs, videos, workbooks) and, potentially, qualifications. The key learning outcomes are intended to provide **minimum** standardised outcomes that employers may use *either* to produce their own in-house learning or learning packages *or* as a benchmark when buying in learning provision or learning packages.

Why were knowledge sets commissioned?

The development of knowledge sets is designed to empower employers to produce appropriate in-house learning sessions for their workers or to buy in learning with some degree of confidence about what will be included in the learning packages. Knowledge sets facilitate consistency in learning packages produced throughout England so that employers can have greater confidence about the learning that employees transferring from other organisations and other regions may have received.

In 2008 a first series of specialist knowledge sets for workers supporting people with learning disabilities was produced, to accompany the then new Learning Disability Qualifications (LDQ). In 2009 a further series of such specialist knowledge sets was published, of which this is one.

For information purposes, this knowledge set has been mapped to:

- the LDQ Induction Standards

- the General Social Care Council (GSCC) Code of Practice for social care workers, which all care workers should have (available free from www.gscc.org.uk)
- other knowledge sets.

In view of the change from NVQs to the QCF, forthcoming at the time of publication, this second series of learning disability knowledge sets have not been mapped to NVQ units.

Where and how are knowledge sets undertaken?

The employer and employee should decide the most suitable method of undertaking this learning in line with the needs of the service and the people who use it. Employers may choose to offer knowledge sets delivered in-house by their own trainers or on the premises of external learning providers. They may use specialists in the field in the delivery of some learning.

Who uses knowledge sets?

Employers use knowledge sets to provide knowledge and understanding in particular subjects for their workers so that the service benefits from:

- essential learning for specific tasks
- enhanced worker practice
- staff being supported to complete their qualifications by a systematic approach to underpinning knowledge.

Social care **workers** use knowledge sets to:

- assist their development of new skills to open up career options and as part of their continuing professional development
- improve self confidence
- support transition from other work settings into the social care sector, or between social care settings
- ensure their work is consistent with their direct care colleagues' 'best practice'.

Professional language or correct terminology has been used. Knowledge sets have been written primarily for employers rather than for individual learners.

Learning providers, publishers and awarding bodies also use knowledge sets in the design of training programmes, materials and awards.

Topics covered by Skills for Care learning disability knowledge sets	Cross-referenced as:
Series 1:	

• History and context of learning disability services	H&C
• Communication	C
• Relationships	R
• Accessing and using information	AI
• Independence and well being	I&WB
Series 2:	
• Working in partnership with family carers	FC
• Supporting people with autistic spectrum condition	AC
• Supporting people positively with their behaviour	SPPB
• Supporting people to be part of their community	SPPC

Published by Skills for Care, part of Skills for Care and Development, the sector skills council for social care, children and young people.

www.skillsforcare.org.uk

Albion Court, 5 Albion Place, Leeds LS1 6JL

2. Supporting people with autistic spectrum condition (ASC)

Main area	Learning outcome	Cross reference to:		
		LDQ Induction Standards	GSCC Code of Practice (workers)	Other Knowledge Sets
1. Understanding autistic spectrum condition (ASC)	1.1 Understand that ASC is a spectrum and that individuals have different needs and will be affected differently		1.1	I&WB 3.4
	1.2 Know that there are many different and evolving theories about autism			
	1.3 Understand that people with ASC can learn new things			
	1.4 Understand that people with ASC are likely to be good at some things and not so good at others (sometimes called a 'spiky profile')			I&WB 3.4
	1.5 Understand that the abilities of a person with ASC may vary dramatically depending on their emotional state and environment			I&WB 3.4 SPPB 3.5, 3.6
	1.6 Understand what diagnosis the person has and that not everyone has a diagnosis			I&WB 3.4
	1.7 Understand how labelling can be bad for a person			I&WB 1.9 SPPB 1.5, 1.6 H+C 1.3
	1.8 Know about the history and role of the 'autism rights movement'			I&WB 3.4 H+C 2.1, 2.2, 2.3
	1.9 Recognise and understand how the physical environment can impact upon an individual and the way they behave and communicate			SPPB 2.6, 3.5 FC 4.4, 4.6

Main area	Learning outcome	Cross reference to:		
		LDQ Induction Standards	GSCC Code of Practice (workers)	Other Knowledge Sets
	1.10 Understand that different people may prefer to use the term 'condition' 'disorder', 'disability' or 'differences'			I&WB 1.2 SPPB 3.5, 3.6
	1.11 Understand that some people with autism may have difficulties with: • non-literal use of language • non-verbal communication • thinking in an abstract way • predicting the consequences of their actions • being able to use their own initiative • transferring learned skills into new situations			I&WB 3.4
	1.12 Understand that some people with an ASC may be much more or less affected by particular sensory stimulus than other people			I&WB 3.4
	1.13 Recognise how ASC impacts on all aspects of identity, self esteem and self image			
	1.14 Understand how to get to know the people you are supporting	201-3.1		
	1.15 Understand what is meant by 'triad of impairments' (i.e. problems with social skills and relationships; language and communicating with others; and thinking and behaving flexibly)			I&WB 3.4

Main area	Learning outcome	Cross reference to:		
		LDQ Induction Standards	GSCC Code of Practice (workers)	Other Knowledge Sets
	1.16 Understand how the individual impairments within the triad might affect the people you support and those close to them			I&WB 3.4
	1.17 Understand how ASC: • impacts on the lives of individuals with ASC • can affect all aspects of the person's daily and social functioning • impacts on parents, families, carers* and other key people in the person's life (i.e. those people who are key to the person's health and social well-being)			I&WB 3.4 FC 4.1
	1.18 Understand how to support a structured environment			
	1.19 Understand the importance a special interest may have to a person with ASC			
	1.20 Understand why it is important to work consistently	202-4.1		C 2.3 SPPB 5.12
	1.21 Understand that a person with ASC may need support to manage change and unpredictability			

* 'Carer' is used throughout to mean family and friends of the person being supported, as distinct from care workers.

Main area	Learning outcome	Cross reference to:		
		LDQ Induction Standards	GSCC Code of Practice (workers)	Other Knowledge Sets
	1.22 Know about other conditions that may be associated with ASC, particularly: • ADHD • dyspraxia • dyslexia • bowel & bladder conditions • epilepsy • learning disability • mental health issues			I&WB 3.4
2. The law and policies	2.1 Know which laws and policies are important when you are supporting someone with ASC	202-2.1 202-4.1 203-1.1	3.3, 3.6, 6.1	
	2.2 Know how to help the person understand relevant laws and policies	202-4.1 203-1.1		
3. Getting to know the person you support	3.1 Know how to use the information you have been given			AI 8.1
	3.2 Know how to work collaboratively with families and carers, other professionals and the person themselves		6.5, 6.7	C 5.2 FC 4.1, 4.2 I&WB 6.4
	3.3 Understand how to help someone understand their own autism			
	3.4 Know what routines, timetables and structures are important to the person you support and why			I&WB 1.6
	3.5 Understand how to match your support to the person's needs	201-4.1	1.1, 1.2, 1.3	I&WB 1.2
	3.6 Know the importance of empathising with the person you support			

Main area	Learning outcome	Cross reference to:		
		LDQ Induction Standards	GSCC Code of Practice (workers)	Other Knowledge Sets
	3.7 Understand what triggers anxiety and stress for the person you support			
	3.8 Understand techniques that help the person you support to calm down if they are anxious or stressed			C 3.3
	3.9 Understand why it is important to support someone to take risks	201-6.1	4.1	I&WB 2.1, 2.2, 2.3, 2.4 SPPC 1.2
	3.10 Know what appropriate action to take when an individual's anxiety levels are likely to present a risk to themselves, others, you or the environment	202.-4.1 203-1.1	3.2, 3.3, 4.3	
	3.11 Know what is meant by • person-centred approaches • information processing • autistic spectrum • diagnostic criteria • historical perspective • theory of mind • 'unconditional positive regard'	201-1.1		C 5.1 I&WB 1.1
	3.12 Understand why it is important to check the effect your own verbal and non-verbal communication techniques have on the individual you support	202-6.1	2.2	C 2.1
	3.13 Understand the preferred communication styles of the person you support and know how to use them	202-6.1	2.2	C 1.1, 2.1

Main area	Learning outcome	Cross reference to:		
		LDQ Induction Standards	GSCC Code of Practice (workers)	Other Knowledge Sets
4. How to support the person through good practice	4.1 Understand how to support someone's communication for example with: • social stories • sequences (comic strips) • scripts • picture exchange • diaries/activity schedules • objects of reference	202-6.1		C 1.2
	4.2 Understand how to help a person with ASC protect themselves from unfairly being taken advantage of	204-2.1		SPPC 6.6 R 1.7, 1.6
	4.3 Know when to question decisions made by a person you support			
	4.4 Know about the range of approaches, interventions and strategies			
	4.5 Understand how to get advice on an approach, intervention or strategy.			AI 9.2, 9.3 SPPB 7.3, 7.4
	4.6 Recognise the importance of working consistently and the effects of change and unpredictability on the person's behaviour			C 2.3 SPPB 5.12
	4.7 Understand the importance of helping people to develop new skills and abilities that will enable them to communicate and function socially			C 5.2, 5.3 I&WB 7.3
	4.8 Know how to reflect on your own practice and where to go for help to do this		6.8	AI 9.3 C 1.4, 4.5 I&WB 7.7

Main area	Learning outcome	Cross reference to:		
		LDQ Induction Standards	GSCC Code of Practice (workers)	Other Knowledge Sets
	4.9 Understand how to create and maintain a structured environment	202-4.1		
	4.10 Understand what is meant by providing support to enable the person you support and others to identify and communicate: • any changes that have taken place or are about to take place and the likely impact of the change • the individuals associated with the change • any methods they can use or need to develop to cope with and manage the change • any risks associated with the change	201-4.1		
	4.11 Understand how to promote choice and control for the person you support, and how this might feel for the person	201-4.1	1.3	I&WB 3.1, 6.5, 7.3
	4.12 Understand the difference between caring for someone and enabling someone	201-4.1