Needs Assessment for Adults and Young People with Autistic Spectrum Conditions in Nottingham, Nottinghamshire and Bassetlaw.

Acknowledgement

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1. Introduction

1.1. Aim

To assess the needs of adults and young people in Nottinghamshire, Bassetlaw and Nottingham with respect to the diagnosis of Autistic Spectrum Conditions (ASCs), social care assessment and transition from children's to adult social care services.

1.2. Scope

The Learning Disability Strategic Commissioning Group agreed that the primary focus of this needs assessment will be the pathways to adult diagnosis and the subsequent social care assessment, and the transition from children's to adult social care services that currently operate in Nottingham, Nottinghamshire and Bassetlaw.

The key to accessing services and receiving timely assessment and support is an accurate diagnosis. There is anecdotal evidence from local stakeholders that some individuals experience difficulty in accessing services that are able to provide a diagnosis. This is particularly the case for people with an ASC without a learning disability (IQ ≥70), generally known as high functioning autism or Asperger's Syndrome. In addition, it is unclear whether the processes for transition from children's to adult services are consistent and robust, and facilitate seamless transition and the maintenance of high quality care.

The first requirement of the National Strategy for Adults with Autism, *Fulfilling and Rewarding Lives* (DH 2010a), is the need for adequate provision of services to diagnose ASD, and that positive diagnosis automatically leads to the offer of a social care assessment. It also highlights the need for clear arrangements for the transition from children's to adult services.

2. Why autistic spectrum conditions are a priority

2.1. Policy Context

In recent years there have been a number of national government publications released relating to ASCs, many specifically relevant to adults as they are a group thought to have a number of unmet needs. The *Autism Act 2009* (UK Parliament 2009) was passed in November 2009 and has significant implications for local areas in relation to the support they provide to adults with an ASC. The most significant of the policy papers include the National Audit Office (2009) report *Supporting people with autism through adulthood*, *Better Services for People with Autistic Spectrum Disorder* (DoH 2006), and the National strategy for adults with autism in England; *Fulfilling and Rewarding Lives* (Department of Health 2010a).

The crux of the "*Better Services*.." paper is a clarification that many other policies including *Valuing people, Our Health, Our Care, Our Say: A New Direction for Community Services* and *Fair Access to Care*, are relevant to people with an ASC and their needs must not be ignored. The relatively new

developments in policy and legislation place an obligation on local areas, to improve the way they meet the needs of people with autistic spectrum conditions.

2.2. Legal Framework

The Autism Act 2009 is the first piece of legislation designed to address the needs of a specific impairment group, and is such is unique. It placed a statutory requirement on the Government to publish guidance for the NHS, including NHS Foundation Trusts, and Local Authorities by December 2010. The guidance is to be treated as though it were issued under section 7 of the Local Authority Social Service Act 1970 (LASS Act). This means that local authorities must "follow the path chartered by the guidance, with liberty to deviate from it where the authority judges on admissible grounds that there is good reason to do so, but without freedom to take a substantially different course."

Though the LASS Act does not apply to NHS bodies, section 3(2) of the Autism Act 2009 states that for the purposes of the statutory guidance "an NHS body is to be treated as if it were a local authority within the meaning of the LASS Act".

NHS bodies and local authorities that do not follow the guidance and cannot provide a good reason may be liable to judicial review or default action by the Secretary of State (DH 2010b).

2.3. Local review

A recent local health needs assessment for adults with Asperger's Syndrome highlighted the absence of a clear mechanism to obtain a diagnosis, particularly for people with higher functioning autism and Asperger's Syndrome. In some cases this has manifested itself in requests to the Individual Funding Request (IFR) process, but it is likely that many adults are either misdiagnosed with mental health conditions, or fail to obtain any diagnosis. Failure to correctly identify people with an ASC and offer appropriate intervention and support can lead to isolation and vulnerability. Over time this may result in the need for crisis intervention and costly intensive support.

3. Methodology

3.1. Process

This needs assessment was led by a Registrar in Public Health at NHS Nottinghamshire County and was overseen by the Learning Disability Strategic Commissioning Group for Nottinghamshire and Bassetlaw.

This assessment draws on published national and international literature, needs assessments undertaken in other areas of England, and local intelligence from a range of statutory and non statutory service providers and commissioners.

A multidisciplinary workshop was organised to bring together relevant stakeholders in order to understand current service arrangements for both adult diagnosis and the transition from children's to adult social care services. In addition, individual meetings and discussions were convened with colleagues from health and social care and third sector organisations in order to further explore and understand some of the issues that were raised from the workshop.

Data was collated from a range of local services including the Special Educational Needs departments at the City and County Councils, adult social services, and Nottinghamshire Healthcare Trust as well as national datasets and published research.

3.2. Limitations

A number of limitations have been encountered which have a bearing on the information presented:

- Services across Nottinghamshire and Nottingham City differ significantly. For this reason the description of current service provision and recommendations have been presented separately for each area. This is less of an issue for Bassetlaw as the mental health and social care providers are common to Nottinghamshire County and Bassetlaw PCTs.
- There are specific barriers to identifying the prevalence of ASC locally.
    - Services do not routinely collect data on the number of clients with autism.
    - The issue of 'diagnostic overshadowing' means that some clients with learning disabilities or mental health problems accessing services may also be suspected of having ASC, but are not diagnosed.
    - Clients with Aspergers may not be accessing statutory services or eligible to receive support. It is likely that there are more people with ASC than those known to statutory agencies.
    - Individuals can access diagnostic services from a range of private providers and may, therefore, not be known to local NHS providers.

Because of these limitations the prevalence estimates have been developed using the best available research literature applied to the local population. However, this data should be interpreted with caution as most studies are based on child and adolescent client groups and conducted among white populations. It is unclear whether these prevalence estimates can be applied to an adult population and whether there are differences in prevalence between ethnic groups.

4. Autistic Spectrum Conditions

4.1. Definition

ASCs are complex lifelong conditions defined in the ICD 10 (WHO 2007) and DSM-IV-TR (American Psychiatric Association 2000) under Pervasive Developmental Disorders. This paper will refer to Pervasive Developmental

Disorders as Autistic Spectrum Conditions (ASCs) as the terms are interchangeable. The condition is characterised by impairments and difficulties in three main areas: social interaction, social communication and social imagination (known as the triad of impairments). People with an ASC also display inflexible, repetitive behaviours and often have hyper or hypo sensitivity to sensory stimulus (e.g. sound, light, touch). The condition can be significantly disabling for many people, even those who have an IQ in the above average range. Often difficulties are hidden due to there being no obvious physical indication of the presence of a disability. The term "spectrum" is used as there are significant variations between individual cases, including the severity and presentation of the triad of impairments such as differing IQ levels; sensory difficulties and general functional abilities. All people with an ASC, regardless of IQ level, experience difficulties to a greater or lesser extent in relation to the triad of impairments. The triad of impairments is described in more detail below.

1. Social interaction:
    - Problems in acquiring and using social skills.
    - Difficulty processing social and emotional information.
    - Often unable to initiate social contact so can become very isolated.
    - Alternatively, craving social contact but initiating it inappropriately and unable to work out social rules.
    - Difficulty forming and sustaining friendships/relationships.

2. Social Communication:
    - Delay of language acquisition (or in some cases can be mute). This is not the case seen in those with Asperger Syndrome, who appear to develop language at a normal rate but may still not use language in a socially appropriate way.
    - Difficulties interpreting, understanding and using speech, body language, intonation, mood, gesture, personal space, writing and visual symbols.

3. Social imagination:
    - Unable to use social imagination and therefore empathise with others and distinguish real from imagined.
    - Find it difficult to:
        - initiate actions without prompting;
        - inhibit behaviour;
        - switch their attention; or
        - reflect on learning/experiences.
    - Exhibit repetitive behaviours and rituals and have an obsessional interest.

4.2. Terminology

There are a range of terms used to describe conditions on the autistic spectrum including autism, autistic spectrum disorder/condition, high functioning autism and Aspergers or Asperger syndrome.

The term 'high functioning autism' is often used to describe people with an IQ level of 70 or above. This term may be particularly misleading as many people with ASC and an IQ of 70 or above still experience significant difficulties with social interactions, social communication and behaviour that can make them particularly vulnerable. A small but significant number of people with an ASC and IQ above 70 require intensive care and support, such as residential placements. Most of those with an IQ level of 70 or above would have a diagnosis of Asperger Syndrome or High Functioning Autism. Further explanation of the subgroups of ASCs is given Table 1 below. Although subgroups exist, their use may not be considered helpful in some cases. For instance, a child diagnosed with "Autistic Disorder" may develop into an adult presenting symptoms closer to Asperger Syndrome or High Functioning Autism. The condition appears to change over time, as do the abilities of the person with the condition.

For the purposes of this report, ASC with an IQ of 70 or above (i.e. in the absence of a LD) will be regarded as equivalent to Aspergers.

4.3. Causes of ASC

The causes of ASCs are multi-factorial, with the most likely explanation being an interaction between genetic and environmental factors. Current evidence appears to confirm a strong genetic link, whereas studies on environmental factors are not yet able to confirm specific environmental causes.

4.4. Diagnosis

4.4.1. Process

ASCs are diagnosed based on a qualitative analysis against a set of behavioural criteria. The ICD-10 and the DSM-IV-TR are generally in agreement regarding the criteria used to diagnose an ASC, which include:

- Early emergence of the condition (before 3 years of age)
- Qualitative impairments in social interaction
- Qualitative impairments in communication (and imagination)
- Restricted and repetitive interests in activities

The diagnostic tools most readily used to diagnose an ASC include:
- Diagnostic Interview for Social and Communicative Disorders "DISCO" (Wing 2002)
- Autism Diagnostic Interview-Revised (Lord et al. 1994)
- Autism Diagnostic Observation Schedule-Generic (Lord et al 2000)
- Asperger Syndrome Diagnostic Interview (Gillberg 2001)

4.4.1. Barriers to diagnosis

There are a range of factors which compromise the ability of individuals to access a reliable diagnosis. These include lack of awareness of ASCs in the community and by professionals, variable presentation of ASCs between individuals and across time, inherent difficulties diagnosing a condition in someone who has communication difficulties, the reliance on early childhood information, risk of misdiagnosis and the high cost of purchasing a diagnosis. These issues are further explored below.

Table 1. Autistic Spectrum Conditions (adapted from ICD-10, Diagnostic Statistical Manual IV and the National Autistic Society website)

Autistic Spectrum Condition	Description
Autistic Disorder (also known as Classic Autism or Kanner's Autism)	Autistic Disorder is considered to be at the severe end of the Autistic Spectrum. It is characterised by the presence of the "triad of impairments", which include impairments in: (1) social interaction abilities; (2) communication abilities; (3) presence of repetitive, stereotyped behaviours. Onset is also before the age of 3 years. The presentation of the disorder is different across individuals depending on their developmental level and chronological age.
Asperger Syndrome (AS)	Asperger Syndrome is also characterised by the presence of the triad of impairments, however there is no delay in the development of language and IQ is in the average to above average range (IQ≥70). Difficulties in motor skills and coordination are often present.
Pervasive Developmental Disorder- Not Otherwise Specified *(Also referred to as "Atypical Autism- ICD-10)*	This diagnosis is given if the criteria for another autistic disorder is not met (i.e. one of the triad of impairments may not be present or it is difficult to determine whether onset was before age 3).
High Functioning Autism (HFA)	High Functioning Autism is not currently recognised by either the ICD-10 or the DSM-IV, but is nevertheless referred to in the literature. Those with High Functioning Autism also present with the triad of impairments and language delay in childhood, but are found to have IQ levels in the normal range (IQ≥70). Adults with HFA present similarly to those with Asperger Syndrome.

Each behavioural criteria used to diagnose an ASC may present differently in different individuals. In regards to the behavioural criteria of impairment in social interaction, an individual may present with inappropriate 'over friendly' behaviour whereas another may appear aloof and indifferent to others. In the case of communication, an individual may present with complete muteness at one end of the spectrum, to another who appears pedantic and literal in their use of language at the other (MRC 2001).

To further add to the complexity of diagnosis, ASCs appear to change over time from child to adulthood, even in the same person. A child may lack social imagination, which is evident by their lack of ability to 'pretend play', whereas in adulthood a lack of social imagination may show as a lack of interest in fiction and a fascination with facts (e.g. memorising insignificant dates) (MRC 2001).

Asperger Syndrome or those with higher levels of functioning may be missed if diagnosis is carried out by only one professional without sufficient time or input from sources such as parents, family, school and others in contact with the person (Ghaziuddin 2005). Difficulties can be subtle and difficult to pick up without thorough investigation by experienced clinicians.

Persons with an ASC may be misdiagnosed with schizophrenia, attention deficit hyperactivity disorder, obsessive compulsive disorders, affective disorders and a number of other psychiatric conditions or developmental disorders. Accordingly, interventions and treatments based on a misdiagnosis are ineffective and in some cases could result in a deterioration of the ASC (Fitzgerald & Corvin 2001). It would seem diagnosis based on qualitative analysis and clinical observation is highly vulnerable to misinterpretation. Therefore, it is recommended that only those with high levels of experience in diagnosing ASCs should have this responsibility in cases where there is confusion about a diagnosis (RCP 2006).

The Royal College of Psychiatrists states that psychiatrists should be able to diagnose an ASC in “clear-cut” cases (RCP 2006). However, diagnosis is likely to be more difficult in adults compared to children for a number of reasons. It is likely that children are more readily identified and referred for diagnosis due to their frequent contact with health professionals and teachers during early years. The low awareness of ASCs in the past may have resulted in many adults who have Asperger Syndrome not being identified in childhood, therefore they may not realise they have a diagnosable condition. The need for an accurate early childhood (prior to age three) developmental history is needed by many diagnostic tools. This is unlikely to be available for most adults.

4.4.2. Timing

The majority of those diagnosed with an ASC receive their diagnosis in childhood. Misdiagnosis and very late diagnosis are significant problems faced by people on the higher functioning end of the autistic spectrum (i.e. those with Asperger Syndrome). People on the higher functioning end of the spectrum are diagnosed on average several years later than people on the lower functioning end of the spectrum (Gillberg 1989).

Late or misdiagnosis are a problem not only for the individual and their family but also because the most effective interventions and management strategies are those that start at an early age (Howlin 1998).

4.4.3. Triggers

For individuals without a concurrent learning disability, a number of factors may be the trigger to seek diagnosis. These include a general sense of not fitting in and a desire to understand why, problems with social settings and in maintaining relationships or employment, involvement with the criminal justice system and contact with mental health and/or substance misuse services.

Those at the higher functioning end of the spectrum may, over time, have developed coping strategies which then fail at times of crisis, resulting in an apparently sudden need for diagnosis and support. This crisis management

has adverse consequences for the individual and is often costly in terms of health and social care services.

Importantly, obtaining a diagnosis is often a necessary step in accessing support services for the individual and their carer(s).

4.5. Co-occurring conditions

A number of other conditions occur at a higher rate in people with an ASC compared to the general population. These include learning disabilities and difficulties, epilepsy, attention deficit hyperactivity disorder, mental health problems and other less common genetic conditions such as fragile X syndrome, cerebral palsy, phenylketonuria (PKU), neurofibromatosis, Downs-syndrome and other rare conditions.

The majority of these co-occurring conditions are rare; the most common are discussed below. It is necessary to understand the range of co occurring conditions in order to manage all conditions in the most effective way and to facilitate the identification of people who may be undiagnosed.

4.5.1. Learning Disabilities

Estimates of the number of adults with a learning disability who also have an ASC vary widely. Cooper et al (2007) estimated that 7.5% of people with a learning disability also had an ASC. However, a recent study supported by the DH following the publication of *Fulfilling and Rewarding Lives* estimates that between 20% and 33% of adults with learning disabilities known to Councils with Social Services Responsibilities also have an ASC (Emerson & Baines 2010a). The lower rate is in line with the median rate in all studies included in the review. The higher rate is based on studies using community based samples of adult users of specialised learning disability services, and recent studies of autism in children which show 34% of children with learning disabilities also have an ASC.

Similarly, estimations of the number of people with an ASC and co-occurring learning disability have been conducted, with varying results. Fombonne (2005) estimated that 30% of people with an ASC have normal to above average intelligence (IQ ≥70), 30% have a mild-moderate learning disability and the remaining 40% have serious to profound learning disability. However, The National Autistic Society suggests that approximately 50% of people with an ASC have normal to above average intelligence (IQ ≥70) and the other 50% have below average intelligence (IQ<70) (NAS 2009). The difference is likely to be attributed to the NAS including all people with autistic like traits in their estimations, whereas epidemiological studies tend to be stricter in their criteria for inclusion in a study.

From applying the National Autistic Society prevalence estimates to the estimated ASC population of Nottinghamshire, Bassetlaw and Nottingham City, it is estimated that locally 5164 people over the age of 15 have an ASC and learning disability.

4.5.2. Epilepsy

A number of studies have examined the association between ASCs and epilepsy, with a lower IQ being associated with a higher risk of having

epilepsy (Tuchman & Rapin 2002; Canitano 2007). A recent meta-analysis found that 21.5% of people with an ASC and a learning disability also had epilepsy, whereas 8% of those with an ASC and no learning disability had epilepsy. In addition females with an ASC were found to be at higher risk of having epilepsy than males with an ASC (Amiet 2008). The lowest prevalence rate (4%) of epilepsy is said to be found in those with Asperger Syndrome (Cederlund 2004) whereas the highest prevalence (77%) is found in those with childhood disintegrative disorder, a form of pervasive developmental disorder (Mourisden 1999). It is important this medical condition is managed in this already vulnerable group. In addition there is potential for undiagnosed people with AS to be identified and referred for diagnosis through epilepsy services.

4.5.3. Mental Health Problems

Evidence suggests that persons with an ASC are much more likely to have mental health problems than the general population, in particular depression and anxiety. Estimates of the prevalence of common mental health problems amongst persons with ASC vary but may be as high as 35%. This is in comparison to the general population prevalence estimate of 17.6% (PANSI 2010).

In a large scale survey of parents of adults with Asperger Syndrome it was reported that 30% of those with Asperger Syndrome had experienced a mental health problem at some point in time, over half experiencing depression (Barnard et al 2001). The presence of an ASC may potentially mask the appearance of a mental health problem due to the reduced ability of the person to convey feelings and emotions, therefore rates may in fact be an underestimate.

The expression of autistic traits may be misinterpreted as a mental health problem leading to an individual being misdiagnosed with a mental health problem. This obviously has significant implications including the possibility of incorrect intervention/treatment provision and cost of care packages which may not be entirely necessary had the correct diagnosis and support been given at an earlier stage. The individual and family would also likely experience frustration and distress from an incorrect diagnosis.

Not all of those with an ASC experiencing a mental health problem will require specialist mental health services. The less severe, more common mental health problems such as depression and anxiety would most often require low intensity support that can be provided through primary care, such as a modified version of Cognitive Behavioural Therapy, which is shown to be effective in this population for the treatment of common mental health problems (Attwood 2003, Hare 2004, Anderson & Morris 2006). The traditional form of Cognitive Behavioural Therapy is not appropriate for those with an ASC due to their unique cognitive style and inability to use social imagination.

It is thought the majority of less severe mental health problems could be prevented if individuals are provided with timely support to access employment, educational opportunities, social skills training and social groups. Without the appropriate low intensity support mental health problems

could escalate resulting in need for intensive high cost crisis intervention. This comes at a high social and emotional cost to the individual and financially can cost up to £300 per day (Curtis 2008).
Ensuring those with an ASC have access to primary care mental health services is important, as is ensuring preventative support such as employment, education, social skills training and social groups are made available.

4.5.4. Attention Deficit Hyperactivity Disorder (ADHD)

Evidence suggests persons with an ASC can be misdiagnosed with ADHD in childhood due to the similarities in presentation of the two conditions (Ghaziuddin 2005). In addition, co occurring ADHD and ASC is reported to be very high: up to 43% (Hofvander et al. 2009). The number of prevalence studies looking at co-occurring ADHD and ASC are minimal therefore this rate should be interpreted with caution. It may in fact confirm the theory of a high rate of misdiagnosis. Again, as above, this is a potential route for identifying undiagnosed or misdiagnosed cases of AS therefore staff in ADHD services should receive specialist training on ASCs.

4.5.5. Other less common co-morbid conditions

ASCs have been found to co-occur with a number of other genetic conditions, further supporting the strong genetic aetiological explanation for the condition. The definitions of these conditions can be found in the Glossary. The most common co-occurring genetic conditions are described below.

- **Fragile X Syndrome:** This condition is the most common cause of inherited mental handicap with an estimated prevalence of 1 in every 1000 males and 1 case of generally milder mental handicap in every 200 females. In males it is characterized by moderate to severe mental handicap, long thin faces with prominent jaws, large protuberant ears and autistic features. (WHO 1996). Fragile X syndrome is estimated to occur in 2.1% of ASC cases (Kielinen et al. 2004).

- **Phenylketonuria (PKU):** this disorder is characterised by an increase in phenylalanine in the blood as the body is not able to produce the enzyme to metabolise it. If PKU is not treated, phenylalanine, which is acquired through a person's diet, can build up to harmful levels in the body, causing intellectual disability and other serious health problems. It has been associated with the expression of autistic traits if left untreated.

- **Tuberous sclerosis:** Tuberous sclerosis is a condition where tuber like growths on the brain calcify with age and become hard. Abnormal tuberous sclerosis growths can affect almost any other organ of the body (including the skin, eyes, heart, kidneys and lungs) but they may cause little in the way of problems. The condition is said to occur in 1 in 7,000 of the population, though many are unaware they have the condition as it does not cause problems in all people. Approximately 25% of people with tuberous sclerosis are autistic and another 25% show aspects of autistic spectrum disorder, including

higher functioning autism or Asperger Syndrome (Tuberous Sclerosis Association 2001). Estimates of prevalence in those with an ASC ranges from 0-4% and as high as 8-14% in those with an ASC and seizure disorder (e.g. epilepsy) (Volkmar et al. 2005, Wong, 2006, Smalley, 1998).

- **Neurofibromatosis**: Is a genetic condition that can cause mild learning difficulties, or at the more serious end can cause hearing loss, deafness and mobility problems. (Neurofibromatosis Association UK 2009). It has been associated with autistic traits.

5. Adults and Young People with an ASC in Nottinghamshire, Nottingham and Bassetlaw.

5.1. Prevalence estimates

5.1.1. Method 1

Due to the problems in accessing data in respect of the actual number of individuals with ASC in Nottinghamshire, Bassetlaw and Nottingham City the best available national prevalence estimates have been applied to local demographic data. The figure of 1% is derived from a study by the NHS Information Centre (2009) conducted by Brugha et al. The NHSIC study was based on a small sample and the rate should be interpreted with caution, however, it is supported by the National Autistic Society and is therefore commonly used. It is further validated by two large scale prevalence studies in children (Baird et al 2006, Green et all 2005).

Table 2 shows the estimated prevalence of Autistic Spectrum Conditions in Nottinghamshire County, Nottingham City and Bassetlaw. Based on a prevalence of 1% applied to the **resident** population it is estimated that 12,319 persons living within the three PCT areas are likely to have an ASC.

Approximately 6160 persons are likely to have an ASC and have an IQ of 70 or above. This estimate reflects that used by the National Autistic Society, whereby 50% of people with an ASC are thought to have an IQ at 70 or above (NAS 2009).

Table 2. Estimated prevalence of ASC using method 1

	Nottinghamshire County		Nottingham City		Bassetlaw	
	All ages	15+	All ages	15+	All ages	15+
Population estimated to have an ASC	7991	6702	3179	2667	1149	961
Population estimated to have an ASC with IQ ≥ 70	3995	3351	1590	1333	575	480

5.1.2. Method 2

An alternative method of estimation is based on the association between ASC and LD. This method is not used in any published literature or research but has been employed in an attempt to validate the estimates produced by method 1.

Estimates of the LD population in County, City and Bassetlaw were obtained from PANSI (2010). These estimates are based on prevalence rates in a report by Emerson and Hatton of the Institute for Health Research, Lancaster University, entitled Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England, June 2004. The authors take the prevalence base rates and adjust these rates to take account of ethnicity (i.e. the increased prevalence of learning disabilities in South Asian communities) and of mortality (i.e. both increased survival rates of young people with severe and complex disabilities and reduced mortality among older adults with learning disabilities). Therefore, figures are based on an estimate of prevalence across the national population; locally this will produce an over-estimate in communities with a low South Asian community, and an under-estimate in communities with a high South Asian community.

Using estimates of the proportion of people with LD who also have an ASC, and applying this to the estimated LD population it is possible to estimate the number of people with an LD and ASC. This is then doubled to take into account the fact that 50% of people with an ASC have an LD. The estimates of prevalence obtained from this method are given in table 3.

The availability of data for method 2 is not in the same format as that available for method 1. It is not therefore possible to separately identify Nottinghamshire County and Bassetlaw or to use the same age bandings in both methods. Consequently the estimates are not directly comparable. However, it can be seen that method 2 produces a substantially lower estimate of prevalence than method 1 for Nottinghamshire County and Bassetlaw. Both methods are based on prevalence estimates derived from surveys and studies. Because method 1 allows the separate identification of Bassetlaw, all further demographic breakdowns have been based on the results from method 1.

Table 3 Estimated prevalence of ASC using method 2

	Nottinghamshire County incl. Bassetlaw	Nottingham City
	18+	18+
Population estimated to have an ASC	4668	2150
Population estimated to have an ASC with IQ ≥ 70	2334	1075

5.2. Age profile

There is no data to suggest the prevalence of ASC differs across age groups. However, it is likely that there are significant differences in the number of people with a **diagnosis** of ASC due to the relatively recent advances in our understanding of ASC, and the fact that younger age groups are more likely to be identified and diagnosed because of their higher level of contact with health and other professional. Also, because of the strong association between ASC and LD and the reduced life expectancy of people with LD (Emerson & Baines 2010b), LD is more prevalent in younger adult age groups (Emerson & Hatton 2004, Inst. Public Care 2009). Consequently areas with younger demographic profiles would be expected to have an increased number of adults with LD and ASC. It is not possible to model the effect of differences in the demographic age profile, and so the prevalence by age band is a crude estimate based on the application of a 1% prevalence figure applied across all age bands.

The estimated number of individuals with ASC and Aspergers (IQ ≥ 70) in Nottinghamshire, Bassetlaw and Nottingham City, broken down by age group is shown in figures 1, 2 and 3.

Figure 1. Estimated prevalence of ASC and ASC with IQ≥70 in Nottinghamshire County by age band

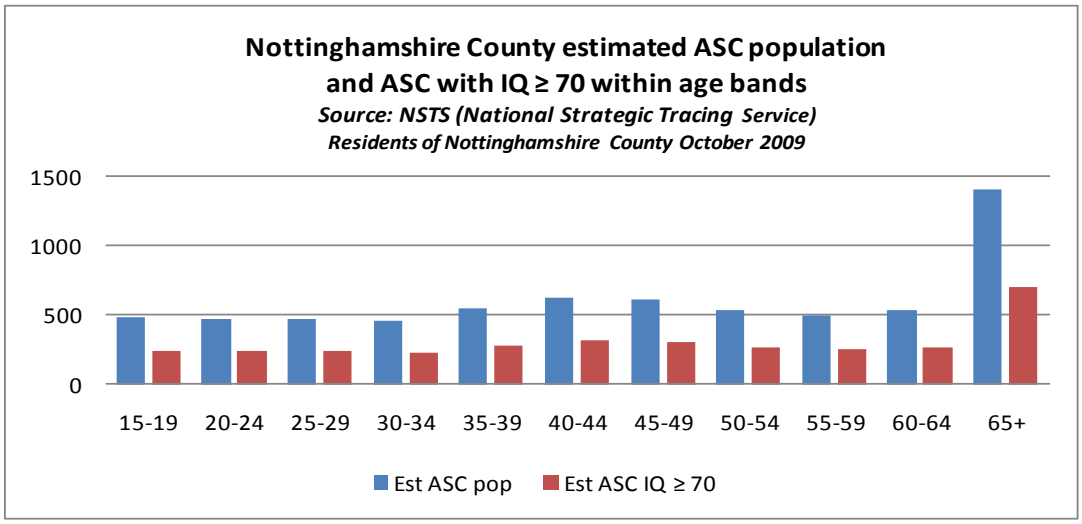


Figure 2. Estimated prevalence of ASC and ASC with IQ≥70 in Bassetlaw by age band

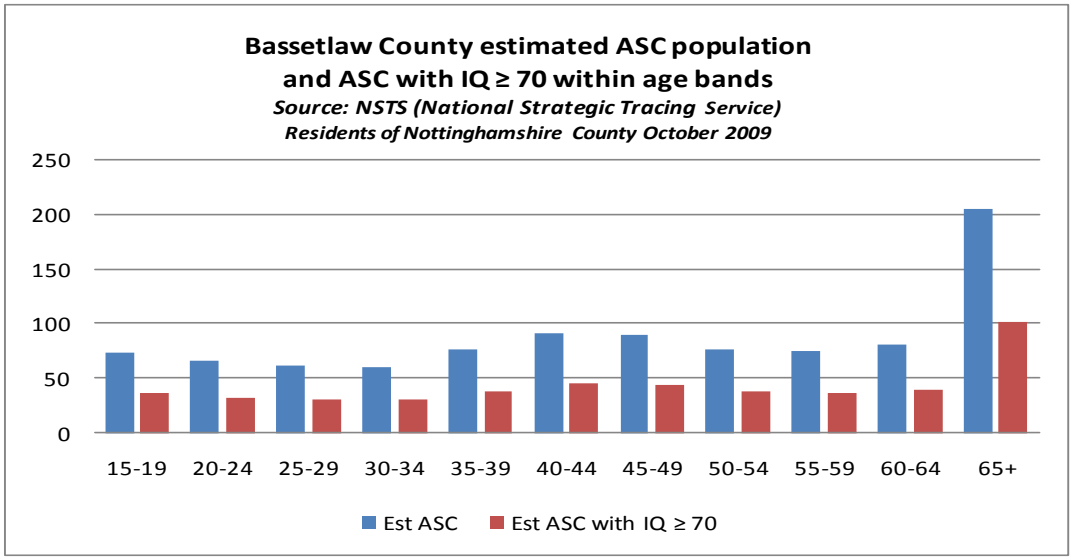
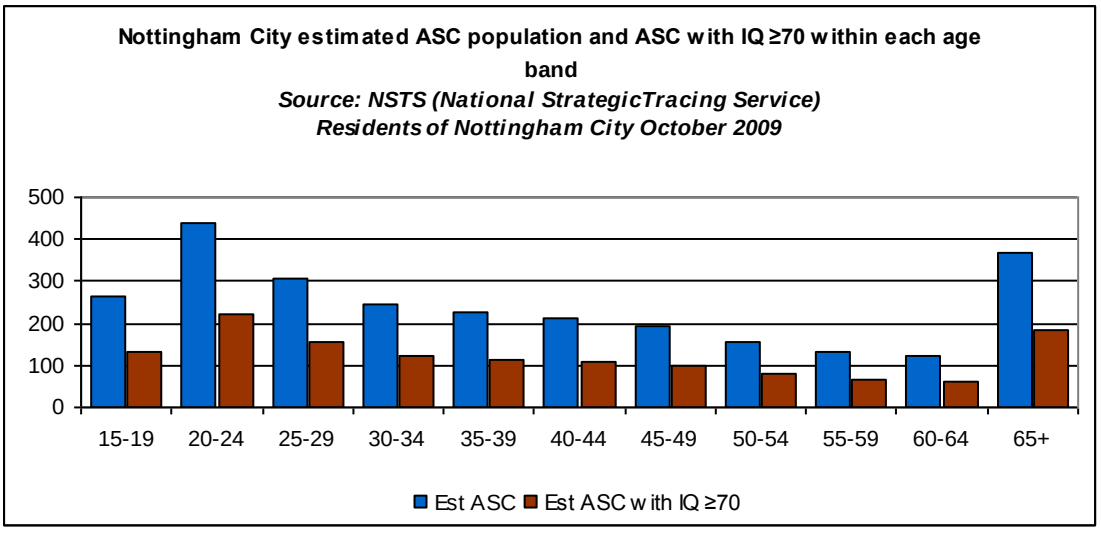


Figure 3 Estimated prevalence of ASC and ASC with IQ≥70 in Nottingham City by age band



5.3. Gender

There are gender differences in the prevalence of ASC with men experiencing a higher rate than women. However, the literature is not consistent in respect of the male to female ratio. According to the American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders, the ratio is 4:1 (APA 2000). In contrast, the NHS Information Centre's recent study found a ratio of 9:1 (NHSIC 2009). Referral data from the Nottingham City Asperger Service suggests the local experience is in line with the APA ratio of 4:1. It is this ratio, that has been used to estimate prevalence, by gender, and the output is shown in table 3.

Table 4. Estimated prevalence of ASC by gender

	Nottinghamshire County		Nottingham City		Bassetlaw	
	Males 15+	**Females 15+**	**Males 15+**	**Females 15+**	**Males 15+**	**Females 15+**
ASC total	5362	1340	2134	533	769	192
ASC with IQ ≥ 70	2681	670	1067	267	385	96

Source: NSTS – Residents of Nottinghamshire County October 2009
Expected split in ASD between males and females – 4:1 (APA 2011)

5.4. Ethnicity

The majority of prevalence studies involve white population groups. There is conflicting evidence of ethnic differences in prevalence. One small study (Fombonne 2005) found differential rates but suffered from methodological flaws and statistical insignificance. A UK based study by Powell et al (2000) concluded that rates were comparable across ethnic groups. More recently the NHSIC prevalence study had insufficient data to evaluate associations with ethnic groups (NHSIC 2009). Given the current state of research it is not possible to determine with any confidence whether there are differences in prevalence between different ethnic groups. However, severe LDs are more common amongst Pakistani and Bangldeshi children, and as a result communities with higher proportions of young Bangladeshi and Pakistani adults would be expected to have an increased number of adults with LD and ASC. These associations are not sufficiently well understood to enable the modelling of the effect of differences in the demographic ethnic profiles of City, County and Bassetlaw PCTs.

5.5. Other demographic factors

There is a significant association between educational attainment, housing and the presence of ASC (NHSIC 2009). People living in social housing were more likely than those owning their own homes to have an ASC. Similarly, prevalence of ASC was higher in those with the lowest educational qualifications. No significant association was found with Index of Multiple Deprivation, marital status, receipt of welfare benefits, household income and verbal IQ. However, it should be noted that the survey identified only 19 people with an ASC and, therefore, may not have been sufficiently powered to detect significant associations with a demographic factor where an association may exist but not be particularly strong.

5.6. Future trends

The number of cases of ASC identified has increased significantly over recent years. This is thought to be primarily due to increased awareness leading to better identification, a broadening of the definition of autistic spectrum disorders and changes in diagnostic processes. It is likely that such changes will continue to contribute to an increased number of individuals being diagnosed, at least in the short to medium term. In addition population growth will also contribute to changes in the number of individuals with ASC living in Nottinghamshire, Bassetlaw and Nottingham City.

All age prevalence estimates based on population growth projections alone are given in table 5. Year on year growth projections are shown in figures 4, 5 and 6. It is estimated that an additional 1373 people with an ASC will be living in the three PCTs areas by 2028 compared to the current prevalence estimates. However, these numbers are based on ONS projections, which are commonly thought to be over-estimated for Nottinghamshire due to variations in the way populations behave within the area.

Table 5. Estimated number of cases of ASC based on population growth projections

	2008	2018	2028
Nottinghamshire County			
ASD	7733	8256	8850
ASD with IQ ≥ 70	3867	4128	4425
Nottingham City			
ASD	2966	3328	3620
ASD with IQ ≥ 70	1483	1664	1810
Bassetlaw			
ASD	1113	1162	1222
ASD with IQ ≥ 70	557	581	611

Source: ONS 2008-based Subnational Population Projections

It should be noted that some adults with an ASC are able to live relatively independently in the community unsupported by statutory agencies (NAO 2009b). Some individuals with Asperger Syndrome are able to cognitively learn how to manage social situations and live successfully without involvement of health or social care. It is, therefore, unlikely that the entire population of individuals with an ASC will seek health or social care support. However, there are no data to suggest what proportion of the ASC population does require support and will seek diagnosis and/or assessment.

Figure 4. Yearly increase in ASC cases based on population growth

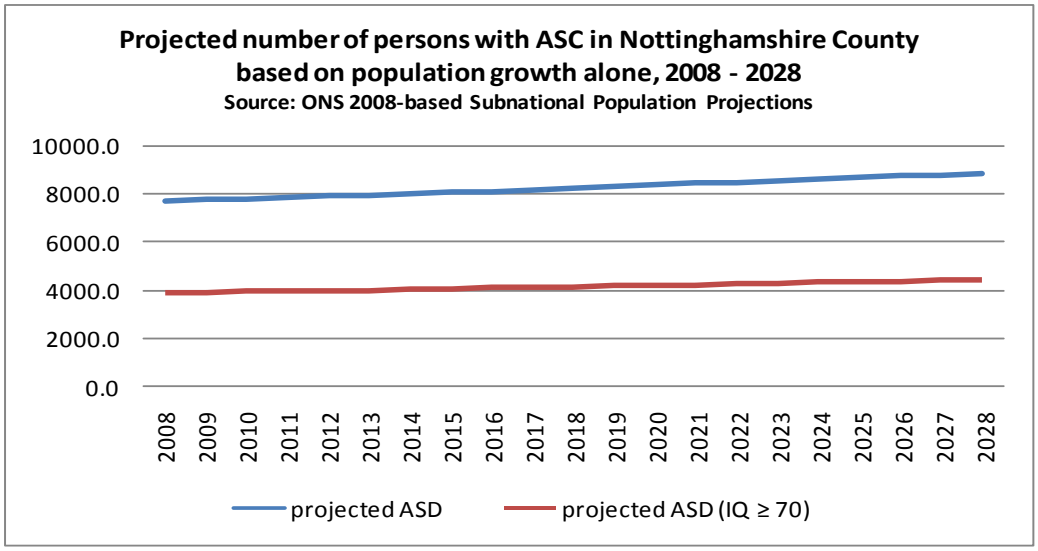


Figure 5. Yearly increase in ASC cases based on population growth

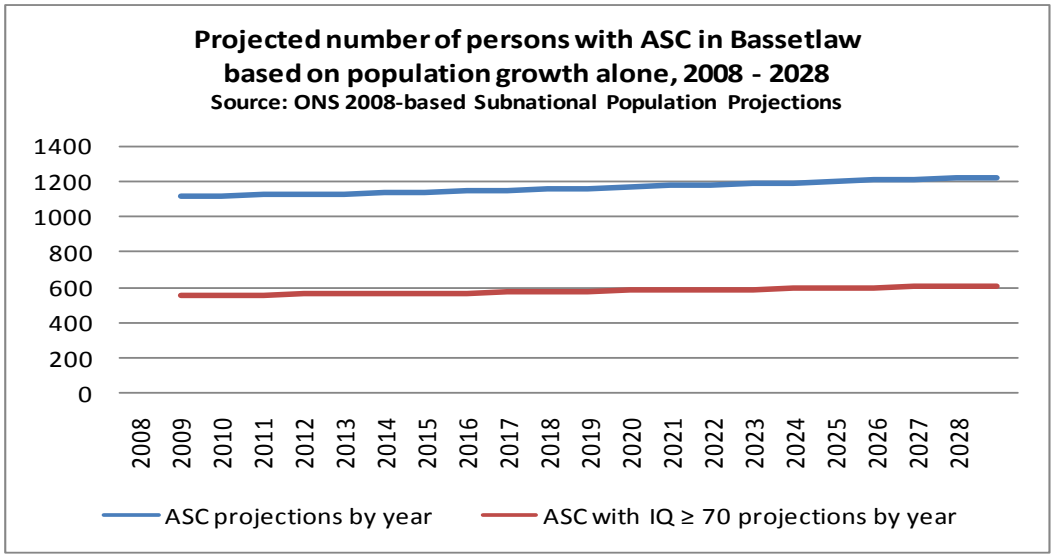
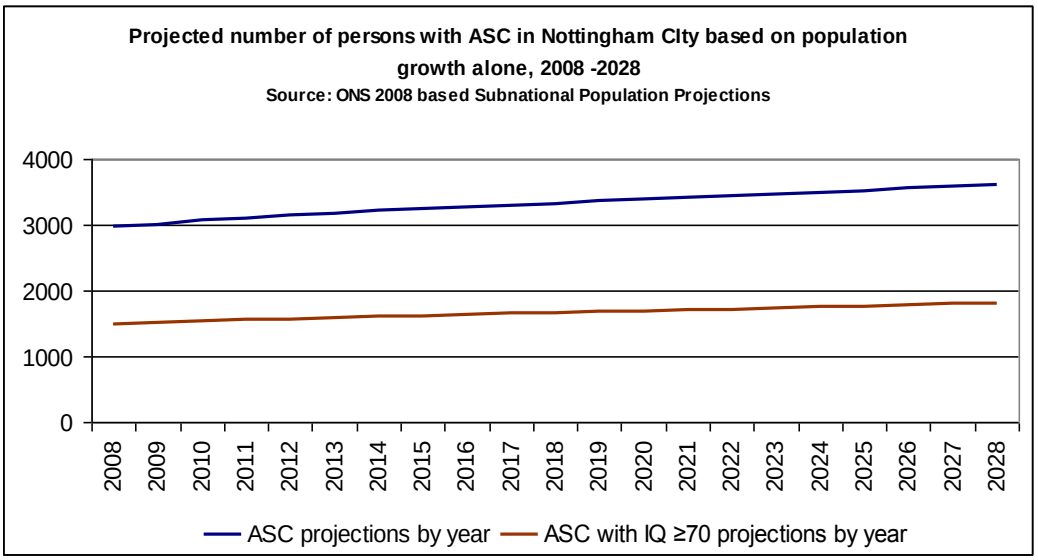


Figure 6 Yearly increase in ASC cases based on population growth



5.7. Service Utilisation

In some circumstances the number of people accessing services can be an indication of prevalence and/or need. However, data is not currently routinely collected on this client group and it has not been possible to identify how many people with ASC are accessing either health or social care services.

Nottinghamshire Healthcare Trust are unable to identify clients with ASC accessing LD or adult mental health services due to complex coding problems. Nottingham City Social Services are also unable to identify clients with ASC as their classification system does not sub categorise below the level of LD, and it is unlikely that clients with autism are identified as such.

The only organisation that holds data on clients with ASC is Nottinghamshire Social services. In 2010/11there were 343 clients accessing social care who had an ASC (including Aspergers). Of these, 49 were Bassetlaw clients.

It is highly unlikely that this represents the true prevalence of ASC in Nottinghamshire, not least because not all clients with ASC will want, need or be eligible to receive social care support. In addition there will be a significant number of adults who are not recognised as having ASC and have had no contact with either health or social care services.

5.8. Children with an ASC

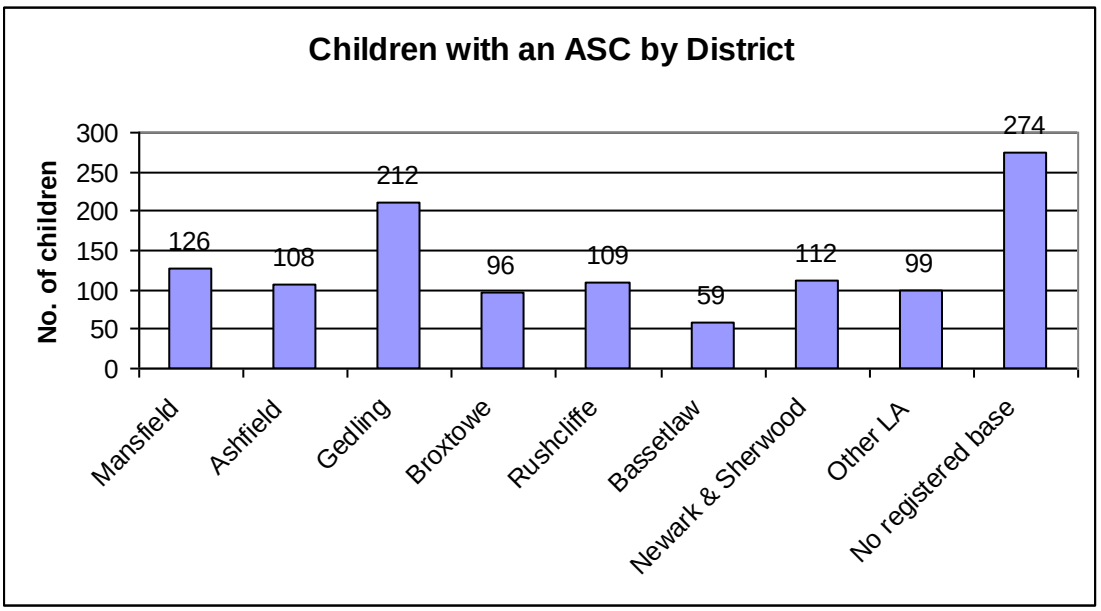
The prevalence of adults with ASC can only be estimated due to the lack of routine data, however, much better information is available in respect of the number of children with a diagnosis of ASC. Using this data facilitates a validation of the adult prevalence estimates and also provides useful information for future planning.

5.8.1. Nottinghamshire and Bassetlaw:

In 2009 the total population of children in Nottinghamshire Schools (including Bassetlaw) was 130,000. Of these 1195 had been identified as having an ASC (NCC 2009). This equates to 0.92% and supports the use of the 1% prevalence estimate used for the adult population. It also indicates that the identification of children in the county is robust. However, the ratio of males to females in Nottinghamshire children is 6:1, which is lower than the 9:1 ratio found in the NHSIC study, but higher than the 4:1 ratio quoted by the American Psychiatric Association and experienced by the Nottingham City Asperger Service.

A breakdown of the number of children with a diagnosis of ASC by district is given in figure 7.

Figure 7 Children and Young People with an ASC by District



5.8.2. Nottingham City

Data from the Spring School Census 2011 shows there are 537 children and young people with a diagnosis of ASC in Nottingham City Schools. This equates to 1.37% of the school population. The ratio of males to females is 5.4:1. This is similar to the ratio in County and not in line with findings from research. 73% of children and young people with ASC attend mainstream schools and 47% have a statement of SEN.

6. Current Services in Nottinghamshire, Nottingham and Bassetlaw

The scope of this needs assessment is limited to a focus on the pathway to adult diagnosis and social care assessment, and the transition from children's social care to adult social care services. As such the description of current services will not include the range of support services that are available to adults with ASC. Nor will it include the processes for the diagnosis of children and young people with ASC or the transition to adult health care services.

There are significant differences between Nottingham City and Nottinghamshire County and Bassetlaw in the organisation of health and social care services for people with autism. Because of this the current services will be described separately.

6.1. Nottinghamshire County and Bassetlaw

Both PCT areas are served by common health and social care providers in Nottinghamshire Healthcare Trust and Nottinghamshire County Council. However, people in Bassetlaw also access health services in Yorkshire and the Humber Region. This may in part reflect the traditional flow of patients in Bassetlaw PCT area into South Yorkshire. It may also reflect differences in the availability of services from different healthcare providers.

6.1.1. Adult Diagnosis

The process for adult diagnosis of Nottinghamshire County and Bassetlaw clients within Nottinghamshire Healthcare Trust (NHCT) is not currently formalised, although work is ongoing to address this. An adult diagnostic pathway for Asperger syndrome has recently been agreed with NHCT on behalf of County and Bassetlaw PCTs, and within the Trust, the specialist LD service is formalising the current ad hoc diagnostic process into a documented and coordinated process.

Bassetlaw PCT also contracts with The Sheffield Aspergers Syndrome Service to provide a multidisciplinary diagnostic service.

There are multiple points for the identification of potential ASC. These include employers (via occupational health), family and friends, the criminal justice system, social services, adult mental health services (AMH), learning disability services, associated clinical services (e.g. IAPT, Drug & Alcohol services) and the individual themselves. With the exception of adult MH and LD services, the most likely route from all points of identification will be via a General Practitioner referral to Nottinghamshire Healthcare Trust. Individuals

identified by AMH and LD services may be internally referred for diagnosis. Management within the Trust is dependant on whether the client has a concurrent LD or is suspected of having Asperger syndrome.

Autism with LD

It is far more likely that individuals with LD will already be known to NHCT and Nottinghamshire social services and be receiving support through the Community Learning Disability Team (CLDT) or specialist LD services. The CLDT is an integrated health and social care team providing a wide range of social care and support and any necessary health input including health promotion advice. Clients accessing LD services will be in receipt of appropriate support for their LD. However, diagnosing a concurrent ASC is useful to inform the care and support offered to the individual and is therefore still important. Diagnosis of LD clients is currently undertaken by NCHT but there is no formalised process by which this happens. The LD service at NHCT is currently addressing this and developing a formal internal pathway for the diagnosis of adult LD clients suspected of having an ASC which will bring together the necessary disciplines and professionals required to undertake the diagnostic assessment and determine the health support needs of the client.

Autism without LD (Asperger Syndrome)

Diagnosis for individuals without an LD has, in the past, been far more challenging. Bassetlaw PCT currently hold a contract with the Sheffield Aspergers Syndrome Service to provide a diagnostic service and County PCT have previously considered requests for referrals to this provider on a case by case basis. In the three years since April 2007, 2 referrals have been approved.

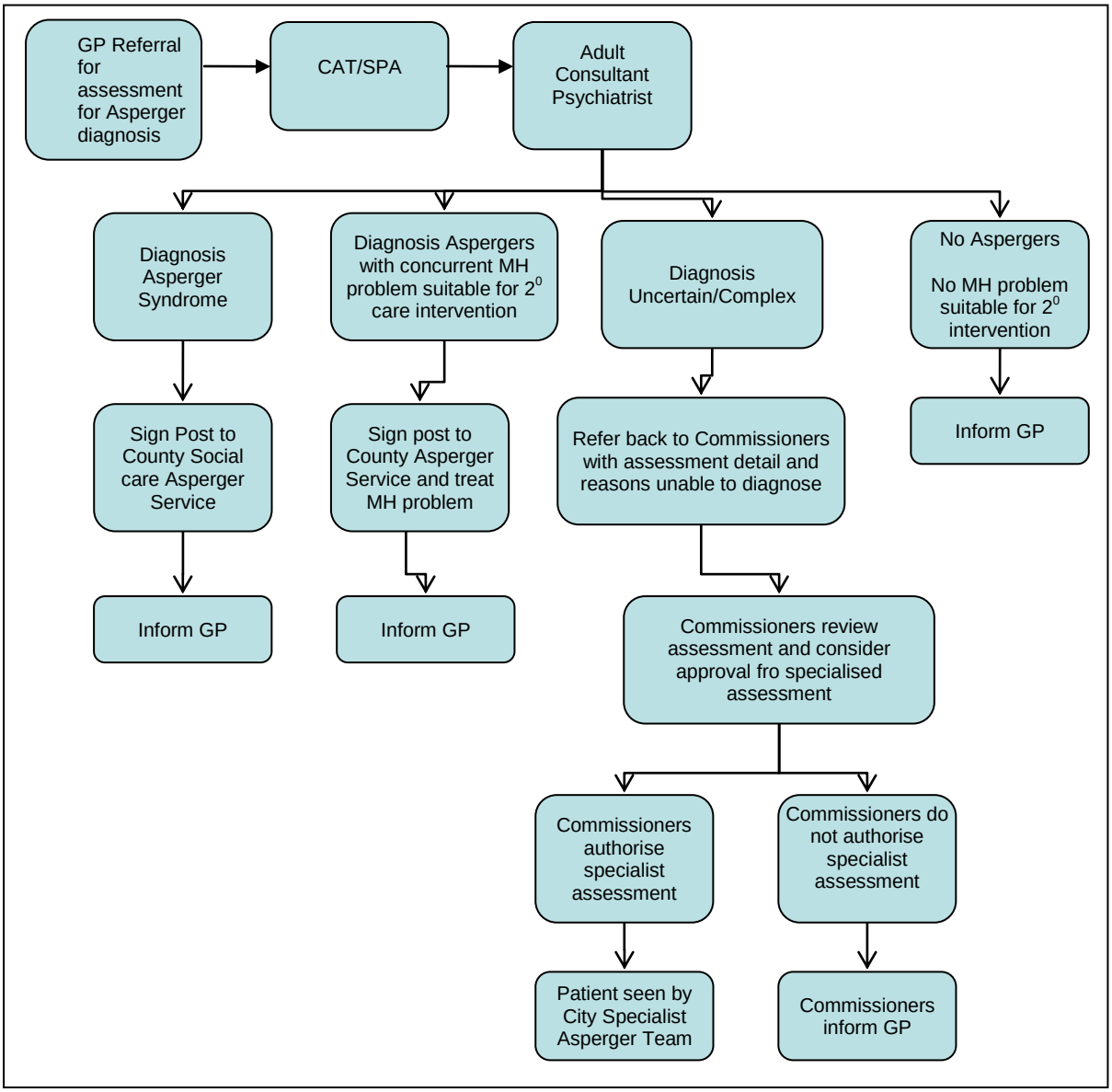
In 2009 NCHT established a multidisciplinary diagnostic and support service for patients of NHS Nottinghamshire County and NHS Bassetlaw. This was funded for one year from internal “Invest2Innov8” funding, but the service ceased in March 2010 following the decision of the PCTs not to commission from mainstream resources. A similar multidisciplinary diagnostic and support service continues to be available to Nottingham City PCT patients (see later for details).

NHS Bassetlaw and Nottinghamshire County have recently agreed an interim diagnostic pathway with NHCT which includes access to the City team in circumstances where the diagnosis is complex. The service is commissioned on a cost per case basis and requires prior approval from the PCTs. The agreed pathway is illustrated in figure 8. This pathway is currently being implemented within the Trust, but has not been widely publicised, and it is evident that not all staff involved in the diagnosis and management of ASC within the Trust are aware of it’s existence. Anecdotal evidence also suggests many GPs are unaware of this pathway.

When both the LD pathway and the Aspergers pathway have been fully implemented there will be clear processes for diagnosis for individuals suspected of having an ASC. However, where the client does not have an LD the primary process of assessment will be by a Consultant Psychiatrist. Only

in complex cases will the diagnosis be undertaken by a multidisciplinary team. As previously mentioned, the Royal College of Psychiatrists acknowledges that psychiatrists should be able to diagnose an ASC in "clear-cut" cases (RCP 2006). However, diagnosis is likely to be more difficult in adults compared to children and diagnostic rigour would be greatly enhanced through a multidisciplinary approach which enables other developmental disorders to be ruled out. For instance, input from a Speech and Language Therapist (SLT) enables the identification of language development disorders which may be misinterpreted as an ASC without the specialist skills and understanding of SLT.

Figure 8. Asperger Diagnostic pathway - County and Bassetlaw



6.1.2. Social Care Assessment

The process by which clients may access a social care assessment is also dependant on whether they have a LD as well as an ASC. Those individuals with a LD will receive a social care assessment as a result of being known to and supported by the Community Learning Disability Team which includes professionals from Adult Social Services.

For individuals without a LD and without a MH problem the County Council Adults with Aspergers Team provides support and assessment of social care needs. This specialist team offers social care assessments for the individual and their carer(s), as well as providing social support if clients meet the *Fair Access to Care* criteria. Where clients are assessed but don't meet FACs criteria (services are only available to clients in the substantial and critical categories), they will be signposted to services provided by the 3rd sector.

The Adults with Aspergers team includes social workers, and community care officers and is a resource for other professionals and agencies providing specialist expertise in the support of people with Aspergers. It also works closely with employment workers from within the County Council to support clients in finding employment. The service has been cited as an example of good practice in the National Autism Strategy for Adults in England.

There are currently no formal channels for notifying the Adults with Aspergers Team of adults newly diagnosed by NCHT. Following diagnosis clients are informed of this service and sign posted to them by clinicians at NCHT involved in the diagnosis. Some clinicians make direct written referrals to the service, but this is not an agreed and formalised process, and is not in accordance with the established process for referral to the team. The Adults with Aspergers Team does have a formal route of referral (via the Customer Services Centre), but current referral practice indicates many clinicians are unaware of this.

The team takes an average of 3 new referrals a week and provides ongoing support to over 160 clients with Aspergers.

6.1.3. Transition from Children's to Adult services

Nottinghamshire County Council's Adult Social Care, Health and Public Protection Directorate is divided into four service areas. Within the Younger Adults (under 65 client group) area, there are five groups, two of which are concerned with the provision of services. The other three have responsibility for mental health, physical disability and learning disability/ASC. It is common for young people with ASC to also have other needs such as a physical disability or learning difficulty. Therefore, the group into which they transition from children's services will be very much dependant on their individual circumstances and the primary source of their need.

Both the physical disability and the LD teams have dedicated Transition Coordinators (TCs) within the teams. The Adults with Aspergers Team does not have this support. As a result the process of transition is different for young people whose primary need for support arises from their Asperger syndrome, compared to young people with ASC who may make the transition into the Young Adults or CLD teams.

Transition into physical disabilities and/or LD Teams:
The organisation of TCs in the physical disabilities and LD teams reflects the number of clients with LD relative to physical disabilities, with a greater number of TCs covering smaller geographical areas in the LD team.

TCs in the physical disabilities team are organised across three localities;

- Broxtowe, Gedling and Rushcliffe
- Ashfield and Mansfield
- Bassetlaw and Newark

The TCs in the LD team are organised across seven localities;

- Bassetlaw
- Newark
- Ashfield
- Mansfield
- Rushcliffe
- Gedling
- Broxtowe

TCs in both teams work closely with Special Educational Needs Coordinators (SENCOs). These are staff based in special and mainstream schools who are responsible for the day to day operation of the schools' Special Educational Needs (SEN) policy; this includes SEN assessments and the coordination of additional support. TCs also have links to the SEN team in the County Council.

Different levels of support are available for children with SEN, these include School Action (SA), School Action Plus (SA+) and a Statement of SEN. School Action is used when there is evidence that a child is not making progress at school and there is a need for action to be taken to meet learning difficulties. SA can include the involvement of extra teachers and may also require the use of different learning materials, special equipment or a different teaching strategy. SA+ is used where SA has not been able to help the child make adequate progress. At SA+ the school will seek external advice from the Local Education Authority's support services, the local Health Service or from Social Services. For example, this may be advice from a Speech and Language Therapist (SLT), an Occupational Therapist (OT) or Specialist Advisory Service dealing with autism, behavioural needs etc. SA+ may also include one-to-one support and the involvement of an Educational Psychologist. Where a child is still not making adequate progress at the SA+ stage then the child's school or parents can request a Statutory Assessment, which may lead to them receiving a Statement of SEN. A Statement is a document which sets out a child's SEN and any additional help that the child should receive. All children attending a special school will have a Statement of SEN. Children in mainstream schools may be SA, SA+ or have a Statement of SEN. Of the 1195 children and young people diagnosed with an ASC in Nottinghamshire and Bassetlaw only 382 (32%) have a Statement of SEN.

A formal and detailed, multi agency transition protocol has been locally developed and agreed and is in the process of being implemented (Nottinghamshire County Council 2010). This protocol clearly sets out the stages of the transition planning process and the agencies/individuals responsible. The transition planning process includes the assessment of health and social care needs for the individual and their carer(s). Built into this is a process of review and updating to ensure the individual continues to receive the appropriate health and social care as they make the transition

from children's to adult services. It is a statutory requirement that all pupils who have a Statement of SEN have a transition plan, the development of which commences in year 9. However, in recognition of the low level of statementing in Nottinghamshire the local protocol seeks to provide person centred transition plans for more than just statemented children. It was, therefore agreed that the protocol should encompasses all children who:

- are on the roll of a special school
- are on the roll of the Nottinghamshire Learning Centre
- are in receipt of the High Level Needs funding allocation
- are a Looked After Child
- attend an independent non local authority maintained education/care setting

In reality, the capacity of the TCs and the revised threshold for access to services under *Fair Access to Care* mean that the number of pupils for whom this protocol is applied is restricted, and there is a tendency to focus only on pupils attending special schools as these pupils will most likely have the most severe and complex needs. Consequently it is possible that young people in mainstream schools with a Statement of SEN do not receive a formal transition plan from the age of 14. In addition, only 256 of the 1195 children identified with ASC attend special schools. To focus only on children in special schools will, therefore, exclude the majority of young people with an ASC who could benefit from transition planning. In 2009, of the 1195 children and young people identified as having an ASC, 660 of them were in year 9 or above; the age group for which transition planning should be available.

TCs are made aware of all young people who require transition planning by both the SEN Team and school based SENCOs when pupils enter year 9 (aged 14). Pupils who are SA, SA+ or have a Statement of SEN but do not receive transition planning support from the TCs will receive support from Connexions staff. If necessary, Connexions staff can refer pupils to the TC if they feel there is a need for more rigorous transition planning and social support in adulthood.

The involvement of TCs in the development of a transition plan is crucial to the support that will be available to the young person when they leave full time education. Access to adult social care is **only** routinely available to pupils who have a formal transition plan developed by a TC.

Transition into Adults with Aspergers Team:
Young people with Aspergers will not have a TC led transition plan as the Adults with Aspergers team does not have a TC. Transition planning for this client group does not currently take place. The Adults with Aspergers team are notified of clients requiring support three months prior to the individual's 18th birthday. This short timescale does not facilitate adequate planning for the commencement or continuation of appropriate support.

For young people who receive a TC led transition plan, the agreed protocol, if it is fully implemented to include the all young people it was intended to cover, will provide a rigorous and robust process for transition planning. However,

there are young people who have ongoing health and social care needs who do not receive a TC led transition plan and whose access to a social care assessment and support is, therefore, severely compromised.

It is worth noting that in the development of this needs assessment a half day workshop was held to bring together relevant stakeholders to process map the current arrangements for the transition of young people from children's to adult services. The conclusion of that group was that no process currently exists to support the transition of young people into adult services. This is clearly not the case and may be a reflection of a lack of clarity in the purpose of the workshop, or it may demonstrate that many of the professionals and agencies involved in the transition process are unaware of, and therefore not actively implementing, the agreed Nottinghamshire Protocol.

Not all young people with a diagnosis of ASC will require access to adult social care. However, it is important that support is available to young people making the transition from school into post 16 education or employment. During their school years many children and young people will have been in receipt of varying levels of support from the Nottinghamshire Inclusion Support Service. They will require transition support to ensure they do not face a "cliff edge" at age 16. The Inclusion Support Service has plans in place to ensure young people with an ASC who may not transition into adult social care receive transition support post 16. This includes provision of work experience placements at the Park hall Autism Centre.

6.2. Nottingham City

6.2.1. Adult diagnosis

The multiple potential points for identification of individuals with an ASC will mirror those identified in the County and Bassetlaw. However, a crucial difference in the diagnostic pathway in the City is the existence of a specialist Asperger Service. This is described more fully below.

Autism with LD

The pathway to diagnosis for clients with an LD will be the same for clients from Nottingham City as it is for Nottinghamshire County and Bassetlaw. Clients known to the CLDT will be assessed for a concurrent diagnosis of ASC. As previously mentioned this process is currently somewhat ad hoc, but is being formalised into a multi disciplinary pathway within NHCT to ensure uniformity and diagnostic rigour.

Autism without LD (Asperger syndrome)

In 2009 Nottingham City PCT commissioned a specialist diagnostic and support service for adults with, or suspected of having Asperger Syndrome. The Nottingham City Asperger Service is a multidisciplinary diagnostic and support service which undertakes formal assessment and diagnosis and develops coordinated packages of support and enablement.

The team consists of a specialist Asperger nurse, an Asperger liaison nurse, a consultant psychiatrist, clinical psychologist, speech and language therapist, occupational therapist and an inclusion support worker.

Referrals of individuals aged 18 or over are accepted from any agency, but self referrals are not accepted. In the period from April 2010 to March 2011 the service received 130 referrals. This represents an increase of 12% on the previous year. Of the 130 referrals, 95 were adults seeking initial diagnosis, with the remaining 35 referrals being adults with an existing diagnosis seeking specialist support. Referrals were received from a number of sources, with GPs being the biggest single source of referral. A full analysis of referral sources is given in figure 9.

Of the 95 referrals for diagnosis received in the first year, 33 received a diagnosis of Aspergers, 25 were considered not to be Aspergers, 6 did not engage in the diagnostic process, and 7 were inappropriate referrals (lived out of area or had an additional LD). The remaining 24 clients were pending diagnosis at the time of publication of the report from which the data is drawn (Gillott & Dziewanowska 2011).

Provision of a multi disciplinary diagnostic assessment ensures consistency and diagnostic rigour by enabling other developmental disorders, which may present with similar characteristics to Aspergers, to be identified.

Figure 9 Analysis of referral sources 2010/11

GP	65	IAPT	10
AMH*	24	Probation/forensic	5
Independent Sector**	6	CAMHS/Paediatrics	5
Adult Social Care	7	Other (Trust Personnel)	1
Learning Disability Service	7		

* CMHT, Psychiatry, inpatient wards

** Housing support, advocacy

Whilst it is outside the remit of this needs assessment, it is worth noting that the Nottingham City Asperger Service provides specialist ongoing support to clients diagnosed with Aspergers. It also develops and provides training programmes for a range of audiences including healthcare colleagues, voluntary organisations working with clients on the autistic spectrum, users and carers.

6.2.2. Social Care Assessment

The process by which clients may access a social care assessment is similar to that in the County and Bassetlaw in that it is dependant on whether the client has a LD as well as an ASC. Those individuals with a LD will receive a social care assessment as a result of being known to and supported by the Community Learning Disability Team which includes professionals from Adult Social Services.

Clients without a LD and who don't have complex mental health needs can be referred to the Social Inclusion Team within Nottingham City Adult Social Services. The gateway into all adult social care in Nottingham City is the Adult Contact Team. Any referrals from the diagnostic service for a social care assessment should be via this facility. However, there are no formal links between the Social Inclusion Team and the City Asperger Service. In addition there is a long waiting list for social care assessment by the Social Inclusion Team, and the reorganisation of adult social care in the City means that it is unclear whether this team will continue to exist. Further details of the reorganisation are given in the following section.

Adults who receive an assessment but do not meet the *Fair Access to Care* criteria will be signposted to services provided by the 3rd sector.

The City Asperger Service within NCHT includes a social inclusion worker, and cites the development of coordinated packages of support and enablement as part of their remit. It also lists support in accessing the community, welfare services, employment and housing among its activities. This suggests some level of assessment and provision of social, as well as health care need is delivered by the NCHT service. However, this would not constitute a formal assessment of social care needs. Only a formal assessment by adult social services could lead to the allocation of a personal budget and access to social support.

The nature of ASC makes it very difficult to distinguish between health and social care needs. For instance, social isolation resulting from difficulties in accessing the community is a consequence of the communication difficulties which are a fundamental aspect of ASC. While support to promote social inclusion may ordinarily be regarded as a social care function, in clients with an ASC, the appropriate intervention may be speech and language therapy to aid understanding of social situations and support the individual in managing social situations.

6.2.3. Transition from Children's to Adult services

Nottingham City Adult Social Services are currently in the process of restructuring, and it is not possible to fully describe the future structure as the consultation process has not yet ended. The timescale for completion of the reorganisation is August 2011.

Adult Social Care currently consists of two directorates; Assessment and Provision. The Assessment Directorate is sub divided into Younger Adults and Older Peoples services. Younger Adults includes the Independent Living Team, Sensory Impairment Team, Social Inclusion Team, LD Team and MH Team.

The Authority is consulting on a structure which will be based on a locality model for all clients over the age of 18. However, the LD and MH teams will remain as city wide specialisms as it is recognised that specialist knowledge and expertise is required to determine and develop care packages for these client groups. On this basis it seems the Social Inclusion Team will be subsumed into the more generic 18+ city wide service. In the new structure young people may transition into LD, MH or general adult services, depending

on the primary source of their social care needs. The transition to adult services is also dependant upon the client meeting the *Fair Access to Care* (FAC) criteria. The FACs threshold in Nottingham City is currently slightly lower than in the County, with social care provision being available to clients in the higher moderate, substantial and critical categories.

Currently there are two transitions coordinators within the LD team. These form part of a specialist multi agency transitions team that is based within the Connexions service - The Disability Transitions Team (DTT). There are no transitions coordinators in the MH team or the Social Inclusion Team.

The DTT includes specialist connexions Personal Advisors, transition social workers, a Person Centred Planner, and colleagues from adult social services. The team also works closely with transitions nurses who are part of the special schools nursing team.

The team collates information from the SEN Service and children's social care services. Obtaining data from two sources allows for the cross checking and validation of information to ensure its' completeness. Information is collated on all children who have a statement of SEN, or who are SA+ with a level ≥4 Mainstream Support Grant (MSG) from year 7 upwards. An MSG of level 4 or above equates to at least 10 hours/week of support.

In order for a young person with an ASC to receive a transition plan and transition support from the DTT they must meet the criteria for the Community LD Team. This states they must have an IQ <55, or an IQ of 55-70 and complex healthcare needs. Complex healthcare needs may include mental health needs. These criteria effectively exclude young people with Aspergers from the proactive transition planning process. The processes for transition for young people with an ASC and an LD are, therefore, more robust. The two processes are described separately below.

Transition into the LD Service

Transition planning starts at year 9 (age 14) and is lead by the specialist, multi agency DTT. A transition pathway is in the process of being developed and this will be implemented through a single policy statement across children's and adult social care services and Connexions.

The age at which a young person makes the transition into adult services will depend on whether or not they remain in education and the type of education provision. Within Nottingham City there are two special schools with post 16 provision. Young people who attend and remain in these facilities will continue to have their support provided by the Disabled Children's Team until the time they leave school. Young people who leave school post 16 to attend college, take up employment or become unemployed will transition into adult social care services at age 18.

It should be noted that the formation of the DTT is a relatively new development and the team is still in the process of developing processes and systems to proactively support the transition of young people into adult services. As such it has a substantial backlog of cases to deal with and,

therefore, not all young people will currently be in receipt of a formal transition plan from the age of 14. However, it is the aim of the team that the planned proactive approach with a robust, multi agency transition protocol can be applied to all young people with an ASC and LD in Nottingham City in the near future.

Transition into the MH or Social Inclusion Service

If a young person does not meet the criteria of the CLDT but is thought to need support in adulthood, the transition planning is less robust. It is the responsibility of the Disabled Children's Team social worker to liaise with the appropriate Adult Social Care team (e.g. MH or Social Inclusion) to facilitate transition. However, it is unlikely this will take the form of a proactive plan with inbuilt review mechanisms from age 14. No formal process currently exists to ensure the smooth transition of young people into the MH or Social Inclusion teams.

The DTT is currently looking at the arrangements that are in place for young people who don't meet CLDT criteria in order to understand how the process can be improved.

7. Evidence of effectiveness and best practice

7.1. Literature

A search of the Ovid Medline database revealed no available literature to demonstrate the most appropriate model or process for diagnosing ASC in adults. The few studies that are available focus on the validity of specific diagnostic tools, interviews and questionnaires rather than attempting to identify the most effective team structures or professionals. However, the Royal College of Psychiatrists Guidance (RCP 2006) highlights the need for clinicians undertaking diagnosis to be familiar with ASC in all its manifestations, and, in anything but clear cut cases, for there to be a multi disciplinary approach. It also acknowledges that diagnosis in adulthood is likely to be far more complex than in childhood because of the lack of information on childhood development. This would suggest that a multidisciplinary approach is likely to be frequently required.

The National Institute for Health and Clinical Excellence (NICE) is due to publish a clinical guideline for the management of autistic spectrum conditions in adults. The scoping document that underpins the development of the guideline lists the key clinical issues that will be covered as:

- Signs and symptoms that should trigger referral for specialist assessment
- Validity, specificity and reliability of the components of a diagnostic assessment
- Psychosocial interventions
- Pharmacological interventions
- Physical interventions (such as diet)
- Information and day-to-day support
- Organisation and delivery of care based on an ethos of multi professional working (NICE 2010)

It is anticipated that this guideline will provide an evidence based framework for the further development of diagnostic services.

Current national policy statements with respect to transition planning, such as Aiming High for Disabled Children (HM Treasury, Department for Education 2007) are relevant to young people with autism and can be used to determine local services.

7.2. Examples of Best practice

The national strategy undertook to provide examples of best practice and effective service models within the statutory guidance documentation. However, the statutory guidance does not provide such examples. Instead it states that examples of good practice will be made available "soon via the DH website" to provide a "living and growing resource" for health and social care bodies, as well as adults with autism and their families/carers. At the time of writing, this is not yet available.

However, there are recognised examples of good practice within the national strategy. One of the most widely cited is the Liverpool Asperger Team. This is a multidisciplinary team of ten staff providing diagnosis of Asperger syndrome as well as direct support through a managed care pathway. It works with other local services to provide advice and support as well as promoting awareness of Asperger syndrome. The Nottingham City Asperger service is based on this model of care.

In Glasgow an autism resource centre provides a range of services for adults with autism and their families or carers. This includes diagnosis, support and information about education, housing, employment and social opportunities.

In Milton Keynes Section 75 flexibilities have been used to provide fully integrated mental health and learning disability services between the PCT and local authority. The integrated nature of MH and LD provided the opportunity to create a virtual team with specialist expertise in ASC diagnosis and assessment.

Adult social care and MH teams have received training in the use of an ASC screening tool to improve identification and referral for diagnosis. The virtual team have been trained to provide diagnostic services and because the team is drawn from the mainstream MH and LD integrated teams, it is able to access and co ordinate any ongoing support through these services.

The team will be officially launched on 1/09/2011 and will provide an integrated health and social care service for assessment and diagnosis.

The virtual team also has a role in collecting better data on the ASC client group.

The London Borough of Newham has provided training to colleges, voluntary groups and other partners to help identify those who may benefit from an

assessment. Assessment has been made more accessible with specified criteria.

7.3. National Standards

The National Strategy for Adults with Autism sets out a long term vision and broadly identifies the actions that are needed to realise that vision. The subsequent Implementation Plan provides a greater level of detail in respect of the actions and services that achieve the goal of *Fulfilling and Rewarding Lives*, but still does not set out specific standards. The latest in the *Fulfilling and Rewarding Lives* suite of documents is a framework to evaluate progress (DH 2011). This explicitly states that the vision will not be achieved through centralised target-setting, and so aims to provide a quality framework with outcome indicators.

Seven outcome indicators have been developed with a recognition that achieving the vision in *Fulfilling and Rewarding Lives* will not "happen overnight". These seven outcomes are set out below.

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

In recognition of the need to have clear steps to achieve and monitor progress the framework identifies three service ambitions:

- Local Authorities and partners know how many adults with autism live in the area
- A clear and trusted diagnostic pathway is available locally that not only leads to enhanced access to diagnosis but also improves diagnostic consistency to ensure **all** parties trust the diagnostic process
- Health and social care staff make reasonable adjustments to services to meet the needs of adults with autism.

The evaluation framework goes on to set out 10 'Steps to Progress' and it is these that offer the most helpful guide to support implementation of the strategy.

1. Appoint a local autism lead
2. Include autism within key procedures
3. Collect and collate relevant data about adults with autism
4. Develop an integrated commissioning plan around services for adults with autism
5. Develop a plan to deliver appropriate levels of training to front-line staff
6. Map local employment services that support adults with autism

7. Map voluntary services and groups that support adults with autism
8. Involve adults with autism, their families and carers in service design and planning
9. Develop and implement a staff survey about working with adults with autism
10. Learn from and share best practice

8. Unmet needs

Considering the analysis of current service provision in the context of the Steps to Progress relevant to the scope of this needs assessment, it is possible to identify where Nottingham, Nottinghamshire and Bassetlaw are currently falling short of the standards required in *Fulfilling and Rewarding Lives*. From this analysis recommendations for action can be developed.

8.1. Data collection

There is no robust mechanism to identify adults with ASC across Nottinghamshire, Nottingham City and Bassetlaw. Without this information it is impossible to provide services with relevant capacity and designed to meet clients' needs. It is also difficult to assess equity in access to services and engage with a representative group of clients to understand their needs. The following Read codes are relevant to ASC and could be used to identify clients in primary care:

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

8.2. Service provision

Clients who have an autistic spectrum condition and co-occurring LD are better supported across all geographical areas than clients with Asperger syndrome. Their LD means they have access to integrated health and social care services through the Community LD teams, and the process for diagnosing a concurrent ASC is being formalised within Nottinghamshire Healthcare Trust.

For clients with Asperger syndrome there are established services within both Nottingham City and Nottinghamshire County and Bassetlaw that have been highlighted nationally as examples of best practice. However, these services are not uniformly available across all three areas.

8.2.1. Diagnosis and assessment

Clients in County and Bassetlaw benefit from a specialist adult social care service targeted at individuals with Asperger syndrome, but currently have

difficulty in accessing consistent and rigorous diagnostic services. Conversely, clients in the City benefit from the specialist, multi disciplinary diagnostic and support service for individuals with Aspergers, but have difficulty in accessing appropriate social care assessment and support services that are able to understand their specific needs.

The impact of these gaps in services is profound, both for the client, their carer(s) and for the respective services. Individuals in the County and Bassetlaw with a diagnosis of Asperger syndrome (i.e. no LD) have no access to essential support such as speech and language therapy following diagnosis. They are, therefore, inappropriately directed to the Adults with Asperger Service which is resourced to provide social care and not the health care support often needed.

Clients in the City who are diagnosed with Asperger Syndrome do not have access to an appropriately skilled and experienced adult social care service that understands, and is able to support, their specific needs. As a result they continue to access support from the Healthcare Trust's City Asperger Service. In the longer term this may not be a sustainable position as the needs of the existing client group may utilise the capacity of the service, compromising the ability to provide the specialist diagnostic support to new clients.

The current situation puts pressure on both the health and social care Asperger services and does not adequately meet the needs of the client group.

8.2.2. Transition support

Young people with Asperger Syndrome are not included in the formal transition planning processes currently in operation in County, Bassetlaw or City. They are, therefore, reliant on generic Connexions services which may not be resourced to meet their needs. This can result in crisis intervention at the point the young person leaves education. Such intervention is more resource intensive for the agencies involved and less effective in terms of the outcome for the individual. It may also lead to expensive residential placements in specialist facilities that could have been avoided with co-ordinated planning.

9. Recommendations

The scope of this needs assessment is limited to adult diagnosis leading to social care assessment, and the transition from children's to adult social care services. Therefore, not all of the 10 Steps to Progress are directly relevant. The recommendations are, therefore based on the steps that are appropriate to the remit of this assessment.

9.1. General

I. Appoint a local autism lead in the City and County – in line with DH guidance, the Director of Adult Social services should ensure there is a

senior manager who is responsible for commissioning services for adults with autism.

II. Health and Social Care organisations should complete the Self Assessment Framework to provide an assessment of current services and a benchmark against which to plan, commission and measure improvement.

III. Ensure the output from this needs assessment is included in the Joint Strategic Needs Assessments of the City and County Local Authorities, and informs the commissioning plans of the PCTs/Clinical Commissioning Groups and Social Services.

IV. Develop robust systems across health and social care organisations to collect data on all clients diagnosed with autism, promoting the use of appropriate Read codes in primary care.

V. Develop integrated working practices between health and social care partners and define the roles and responsibilities of each agency in respect to the provision of diagnostic, assessment and support services to clients with ASC.

9.2. Diagnosis

9.2.1. City, County and Bassetlaw:

I. Develop and implement training programmes for staff across health and social care, and other agencies to improve the identification of individuals with ASC and facilitate access diagnosis.

II. Ensure that all individuals who are accessing services for an LD or MH problem, and who may already be in receipt of services and support are also able to access diagnosis of ASC where this is suspected.

III. At the point of diagnosis information must be made available to the individual and their carer(s) about:
   - autism and how it affects those who have the condition
   - sources of help and support, including local voluntary groups

IV. Ensure the client and their carer(s), and all staff involved in the process of diagnosis recognise that diagnosis is a catalyst for a community care assessment or reassessment. This includes an assessment of the carer(s) needs under the Carers (Equal Opportunities) Act 2004.

9.2.2. County and Bassetlaw:

I. Ensure that all clients have access to a clear, consistent pathway for diagnosis of autism that GPs, mental health practitioners and those working in the voluntary sector are aware of and can access.

II. Ensure all clients have access to a multi disciplinary diagnostic team as standard, to ensure diagnostic rigour and consistency.

9.3. Social Care Assessment

9.3.1. City, county and Bassetlaw:

I. Develop **explicit** processes for referral from diagnosis into adult social care services to ensure that diagnosis leads to a person-centred assessment of need for the individual and their carer(s) in line with the NHS and Community Care Act 1990, and the Carers (Equal Opportunities) Act 2004.

II. Ensure all those who qualify for, and would benefit from personalised budgets, receive the offer of a personalised budget to manage their care and support.

9.3.2. City:

I. Develop and agree a robust process for social care assessment and support for individuals with Aspergers and their carers. This assessment should be delivered by appropriately qualified staff able to understand the needs of individuals with an ASC.

9.4. Transition to adult services

9.4.1. County and Bassetlaw:

I. Fully implement, resource and promote the County transition protocol to ensure the full range of young people detailed in the protocol receive active transition planning and support.

II. Extend the remit of the County Transition Protocol to include young people with Aspergers known to Education Services.

9.4.2. City:

I. Develop, agree and implement a multiagency transition protocol in the City to clearly set out how transition planning should be undertaken and define the responsibilities of all agencies involved. This transition protocol should include within its remit all young people known to have an ASC, including those with Asperger syndrome.

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