

Birmingham JSNA

Autism Spectrum

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**Learning disability and Mental Health Joint Commissioning, Birmingham
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Executive Summary and Key Findings

Autism is a neuro-developmental disorder characterised by social and language impairments and stereotyped, repetitive patterns of behaviour. There are often significant sensory differences where individuals can be over or under sensitive to sensory stimuli (e.g. sights, sounds, touch, taste) as sensory perception may be delayed or distorted. Symptoms manifest by the age of 3 years, and most children, young people and adults with autism typically require greater levels of support and supervision than their same age peers. In terms of causation, it is suggested that there are many forms of autism probably with different causations. There is now thought to be a strong genetic component causing an increased risk of having another child with autism if parents already have a child with autism. Further, in some cases, one or both of the parents might meet the criteria for diagnosis or have the broader phenotype. There is much research into other factors which might play part in causing autism but findings are often inconclusive. There are some studies that associate autism to prenatal and perinatal conditions such as birth weight and gestational period, maternal/paternal age, infections, foetal growth restrictions and hypoxia (1). However, there are many children who have such difficulties who do not develop autism.

There are possible environmental risks that affect this population. Obesity and maternal health and low birth weight may be associated with autism, but there are many children born with these risk factors that do not develop autism. However, the Birmingham population has a high prevalence of obesity and it is suggested by some who specialise in very preterm babies that low birth weight and very early births should be recorded in children's medical files as these may lead to cognitive difficulties later in life.

A recent study has found significant differences in brain development starting at the age of 6 months in some high-risk infants who later develop autism compared to high-risk infants who did not develop autism¹. There are many studies currently being conducted on babies and toddlers at increased risk of developing autism (i.e. often the siblings of a child with autism) to study the developmental path and to determine at what age a firm diagnosis of autism can be made.

It is known that children and young people with autism, irrespective of intellectual ability -(as with any other disability), do have difficulties in finding and maintaining employment, in living independently and in accessing services and leisure activities in adulthood placing them at greater risk and subsequent health inequalities. There is a need for further research about what leads to good adult outcomes and about the issue of disclosure to employers and others. The reality is that currently there are insufficient services to assess their needs and to provide support to enable many adults with autism to have a good quality of life. Some adults are late diagnosed, have a negative view of their diagnosis, have low self esteem and need help and advice on how to enter further and higher education, including work. They may be living alone or with parents and suffer from depression and anxiety disorders.

There are adults with autism who have not yet been diagnosed, particularly those of average or above average ability who might not have stood out at school. They may have good exam results but lack the social and emotional skills to apply their

¹ Caroline Institute for Developmental Disability, US.

knowledge and skills to the workplace or at University. Some of these adults may realise they have autism, following a TV or newspaper article or alternatively their families or partners may reach a stage of realisation. There is therefore a need for services to offer diagnostic assessment services for this group and to give support following diagnosis, whether or not they have autism.

The National Institute of Health and Clinical Excellence (NICE) have produced recent guidance in terms of services provision and care pathways for adults (2) and children and young people (3) with autism. The guidance focuses on the need of local pathways as defined and multiagency groups as an enabler to better outcomes.

The guidance recommends the creation of multiagency groups. A local autism multi-agency group, will be set up with managerial, commissioner and clinical representation from child health and mental health services, learning disability, primary healthcare, education, social care, the criminal justice system parent and carer service users, and the voluntary sector. It is recommended that there should be meaningful representation from people with autism and their families, partners and carers.

Adults with autism in Birmingham

Currently, in Birmingham, knowledge about the adult population with autism is poor and evidence about their needs is less than satisfactory. This is partly because past school data has not been retained with details of diagnoses and partly because they can be a hidden population – with families supporting individuals as best they can – until death or infirmity. In this report, we estimated prevalence using national prevalence and by looking at the current school population of children with autism known to the education authority. There will be children coming through the system undetected who may develop difficulties in adulthood – particularly if their needs are not identified and addressed.

The adult population of Birmingham (i.e. 16 years and over) is estimated to be approximately 809,000. The prevalence of autism is now estimated to be 1% so that we would estimate to be approximately 8,091 adults with autism living in Birmingham. Not all of these adults will require a service as the degree of their difficulties varies, but many adults will need support – including those with high IQs. It is believed that there are at least as many people with autism of average ability or above as there are with learning disabilities. Any adult with a known disability that may be considered to require help from social services is assessed². Currently in Birmingham data shows that there is a total of 267 adults with autism receiving some kind of service. This suggests that there is a potential cohort of 7,824 adults not known to social services.

There are likely to be many more individuals who need services – as the total number of children with autism -(with recognised SEN) was 826 who became adults during the 6 year period 2005 to 2011.

Table 1 gives details of the population that is known across services in Birmingham, and the difference between the expected population (at the 1% prevalence rate) and those that receive services. There is roughly a 78% gap³.

² A person eligible to be granted a service needs to meet minimum criteria

³ The Autism Attention card is not considered in the calculation.

The population of children and adults diagnosed with autism is increasing in the UK and elsewhere each year – largely due to greater autism awareness and better identification.

Table 1 Summary of children and adults diagnosed with autism across services in Birmingham

Age	Births	0-15	5-15	16+
ONS General population 2010	17,240	227,763	146,331	809,115
Autism 1% prevalence estimation⁴	172	2,278	1,463	8,091
Autism 2%⁵ prevalence estimation	344	4,555	2,927	16,182
Primary Care (tHOB)		134		148
SEN register children with autism 2011			1,959 ⁶	
Communication and Autism Team 2011			250 ⁷	
Transition 2011				133
Adult social services register 2010/11 autism				267
Adults with the Autism Attention card Autism West Midlands Up May 2012				1,350

Type of needs and support required by adults with autism

The needs and treatment of people with autism are case dependent, since the symptoms of people with autism vary depending on the severity of their autism, their intellectual ability, their level of dependence and the degree to which their family or others offer support. If their needs are not recognised and met, then they can develop mental health disorders – often depression or anxiety disorders – or they may become involved in criminal activity – often unwittingly. Meeting their needs is likely to be more costly than when services act in a proactive way to prevent crises. It is well known that having a job, having support from others and not spending a lot of time alone are very good protective factors for all adults – and the same is true for those with autism. The data however show that often they are not in employment, they have few social contacts and spend a great deal of time alone.

The type of needs many adults with autism have can be summarised as follows:

⁴ This is estimated applying prevalence to mid-year population. It differs from PANSI estimation in the Population Charter.

⁵ The children autism prevalence in the city and research suggest that Birmingham could have more than 1% of prevalence.

⁶ Gyles Glover et.al estimated 898.7 (898.3 to 899.1) number of pupils(30)

⁷ Age band has not been clarified for this group, assumption majority under 16 years old

- Access to appropriate diagnostic assessment and assessment of needs.
- Access to good health care and advice.
- Support to access and maintain employment and further or higher education.
- Support for independent and healthy living, including leisure activities.
- Access to well-trained support staff and “befrienders”.

Population

- The Autistic population is steadily increasing as the general population increases, and current prevalence is around 1% of the population. There is evidence that in some areas this could reach up to 2%. This suggests that some flexibility in commissioning services should be built into the system to allow for an increase in demand.
- Evidence shows that the current prevalence in schools for Children & Young People with autism ranges from 0.9% to 2.9%, with an average of 1.5% of the school age population.
- The estimated population⁸ for adults (18-64, working age) is 6,482 and by the year 2025 this figure will increase to 6,965. This estimation is lower than 1% of the adult population, used in the previous chapter⁹.
- The estimated population for children under 16 years old with autism is 2,314 and by the year 2025 it will reach 2,732. This estimation is around 1% of the child population.
- Better recording of data about individuals with autism and their needs would lead to better service design.
- There is some evidence implying a shift in demand in terms of requiring services to cover more complex needs¹⁰. Service providers indicated that they are dealing more frequently with individuals with autism that present other co-morbidities.
- It is now recognised that within special schools for general learning disabilities, about 30% of the children have autism. In the past, these children may not have been diagnosed as such as: their needs were seen to arise simply from a learning disability or other diagnosis. In addition, there are 5 special schools in Birmingham which specialise in teaching children with autism, where almost all the children on roll have autism. Through a policy of inclusion, the majority of children with autism attend mainstream schools, many of whom are supported by the Communication and Autism Team (CAT).
- The Birmingham prevalence of autism in pupils (SEN) is 26.2% higher than England 19.6%.

Diagnosis and Assessment

- At national level, in the Primary Care setting, there is a lack of services/expertise to assist in the diagnosis of autism in adults. This position seems to be similar on a local level in Birmingham. This is in contrast to diagnostic services for children with autism which have improved greatly in the last 10 years (hence the rise in the number of reported cases). Children are often seen at Child Development Centres by teams which are specialised in diagnosing autism. Some children and

⁸ POPPI

⁹ 1,666 difference approximately, this is due to baseline population

¹⁰ From discussions with CAT and MENCAP.

young people who develop mental health difficulties may also be referred to the CAMHS team for support.

- There is no integrated/multidisciplinary diagnostic pathway-for adults and children- in the City and there is a lack of evidence to estimate the true population requiring these services¹¹.
- Autism diagnosis in adults is not well recorded at both the Primary and Secondary Care levels.
- There are some practitioners in Birmingham who do conduct diagnostic assessments for autism with adults but they do not have the resources to deal with the demand.

Support is required after diagnosis and this is only the beginning. What is subsequently required is an assessment of their needs in terms of education, work, housing, social contacts, and level of independence. The services offered by Autism West Midlands and other local autistic societies within the 14 local authorities are necessarily limited by staffing levels and funding. Service providers can often only signpost and are unable to provide the level of support required.

Stakeholders Perspectives

For this work programme we have been consulting with the Birmingham Autism board, in which parents, services providers, and people with autism have representation; Autism West Midlands, MENCAP, CAT, CONNEXIONS, Employment Services at City Council, academics, Transition Board.

The key points made by those consulted were:

- A lack of a clear pathway to diagnostic assessment.
- A lack of support after diagnosis.
- A long process to get a diagnostic assessment.
- One problem is that adults with autism and of average ability or above are not eligible for services. These individuals do not fall within the brief of these LD teams and therefore cannot access MH services until they develop a serious problem.
- It is likely – but not certain- that adults with autism with well below average IQs receive a better service – by virtue of coming into contact within LD teams.
- A lack of clarity as to which services are best equipped, and whose remit autism should fall under regarding assessment and support.
- A lack of support for caregivers.

Birmingham City needs:

- To develop clear pathways with local multi-disciplinary teams to reflect good practice, and to follow the recent NICE guidance, and to prevent secondary health problems.
- To develop mechanisms that allow flexibility and follow up of individuals that are diagnosed with autism.
- To offer support during and after diagnosis to caregivers and parents.

¹¹ Even though commissioning is investing in the development of local pathway for children and adults, currently.

- To develop a better understanding about people with autism and their ageing process: the impact of diagnosis and what further support is needed to achieve a healthy life.

Improving access to services

- More than 50% of people living in Birmingham responding to the autism engagement survey¹² rate the services they have received as poor.
- Some of the most required services are: group support and parents support, support for living independently and accommodation, education after school, education and training, residential care, employment and support for daily tasks.
- People with autism also present other health needs reflected in admissions to hospital for mental health problems, poisoning, and respiratory conditions. Mental health problems have been identified as the major reason for admission and the literature shows that these can often be prevented.
- There were about 1,450 hospital admissions related to people with autism in the last five years, and mental health problems accounting for 20% of all admissions
- Epilepsy admission for people with autism is likely to be higher than recorded – given the national estimation of co-morbidities.
- The ratio of male to female adults with autism in Birmingham is higher (at 1.8:1 for social services) than the national prevalence which is around 4 to 1. Using SEN Census January 2012, the ratio male: female is 5:1 for Birmingham compared to 6:1 for England.
- There are fewer than expected adults with autism in Higher Education.
- There are unmet need(s) for pupils with autism finishing year 11 at the transition stage which means they are less likely to enter further or higher education or work.
- Schools often do not collect data on what happens to their school leavers.
- There is no evidence that services around the City, provide quality services that match need to demand.

Birmingham City Needs:

- Provision of services that meet needs
- Provision of well-qualified staff
- Provision of care pathways.

Employment

- At least 2% of the unemployed population in Birmingham has autism.
- Data recording is poor and makes the task of estimating the needs in employment for this population difficult.
- Data is recorded using categories such as learning disability, physical disability or mental health and does not have a separate category for autism.
- There are organisations that provide employment services for people with disability however referrals are low.

¹² Survey responses were collected from 30 January to 22 February 2012 using paper and online questionnaires. There were 112 respondents: 73 caregivers, 23 people with autism, 16 providers. The questionnaire consisted of 13 questions and not all the questions were answered by the 112 people.

- Autism West Midlands runs a small scale supported employment scheme for adults with autism to find employment and to be supported within the job. Some of these adults may have had jobs in the past but have lost their jobs due to difficulties arising from their autism. There are many more adults in Birmingham in need of this service than this service can support for. Similar schemes need to be set up to find potential employers and then to support adults with autism into work. There are many adults with autism with degrees and other high level qualifications who are out of work because their autism presents difficulties at every stage of the employment process. Once employed and supported to manage in the workplace, adults with autism can have an equal experience of employment and thrive in the workplace.

Birmingham City Needs:

- Increased awareness from employers about the difficulties facing this population and knowledge of the strengths and competency levels they can bring to a job.
- Improved data recording procedures across service providers and employers.
- Increased employment opportunities.
- Understanding of the barriers to employment and what could be done to accommodate people with autism and their needs.

Transitions

- There has been an increase of 24% yearly in average from 2005 to 2011¹³, of the number of pupils finishing year 11. Comparing 2005 (56 pupils at year 11) as baseline, by 2011 there were 175 pupils going through transition (an increase of more than 3 times). This would indicate that more people staying in education and/or more people are being diagnosed.
- Caregivers feel that there is not enough help for their children after the school years.
- There is lack of follow up after the children and young people have left school.
- If a pupil fails at the next stage or 'votes with their feet' then there may be no safety net and they may just remain at home.

Birmingham City Needs:

- Training for caregivers about preparing their children for adulthood.
- To follow up pupils when they have left school and track and evaluate the outcomes.
- Better coordination between services for children and those for adults so that children and families are not left unsupported when school ends.

Training and Awareness about the needs of adults with autism

- There are many training providers in the region and there is a need to log what support is available and to ensure that when training is given it matches and meets the needs of the staff within adult services.

¹³ SEN schools

- The Communication and Autism Team provides support and training for mainstream schools, and has experienced an increase in demand.
- Autism West Midlands also provides a training and support network across several third party organisations.
- The University of Birmingham runs accredited training courses for professionals working specifically with adults with autism on an annual basis.

Birmingham City Needs:

- To increase general awareness of autism.
- To train staff working in LD teams and MH teams and within CAMHS and Connexions about autism.
- General Practitioner training to identify the signs of autism and to know where they can refer the adults.
- Education about autism and its diagnosis for the general public and potential employers.

Focus Group and how they express their needs

In interviews with parents and people with autism¹⁴ they were asked to articulate their expectations and experience about the support and barriers to achieving a rewarding life. A summary of these interviews found:

Awareness and Education:

- The need for wider awareness of the condition, to identify the difference between diagnosis and the potential and capacity of people with autism.
- Recognition of the differences between adults with autism.
- Help to explain their disability.

Diagnosis, Assessment and Access to Mental Health services

- Services that provide care for people with autism, in psychiatric and psychological areas.
- Seamless collaboration between charities, NHS and Social services.
- Support to manage anxiety and communication problems.
- Management stress.
- Monitoring health and medications.

Access to services

- Help in managing their environment.
- Collaboration between people with autism and services commissioners to shape service design to focus in more user-centric way (personalisation).
- Support in the transition to college.
- Access to employment, education, volunteering and apprenticeship into employment.
- Access to support for living independently – making friends, adult and family life (parenting), DIY, budget and money, household activities.
- Career at work.

¹⁴ Autism West Midlands facilitated a focus group with 8 young adults of average ability and above, and one parent. Autism Transition Group parent representatives have been participating through the assessment.

- Understanding of the person's ability, space, and time
- Opportunities to do meaningful tasks and to take responsibility.
- Emotional understanding.
- Supportive and empathetic environment.

Similar needs were found through the autism engagement survey.

Case Study: Natasha's experience

Natasha, aged 36, has Asperger syndrome and depression. She currently lives in a rented flat where she has been living for approximately 9 years. This was only made possible because she received specialist autism specific support to make the transition from the parental home. She needs help to reduce her anxiety and stress levels to ensure her wellbeing. However, due to her support being delivered by support workers without knowledge of autism, she has found herself having to educate them herself. This support has significantly increased, rather than decreased, her anxiety levels.

She currently works in a supportive and understanding environment, and consequently achieves some financial independence. However she would also like to live independently, but she needs help with the following:

- Managing her finances, including owning/renting a house
- Filling in forms
- Travelling around
- Choosing clothing
- Keeping a pet
- Maintaining friendship
- She is anxious about the continuation of the support group she attends
- She would like to enjoy a holiday
- She would like to do some further study, but needs help to identify courses and she requires help to attend and complete her chosen courses.

Her parents worry about her future and how she will cope when they are not around, as they have been providing a lot of her support in recent years. Their experience has been very stressful, especially as the support given to Natasha has more recently been provided by inexperienced and unqualified staff. They have expressed their concerns that the failure to provide appropriate support to people with autism can lead to more costly support for crisis resolution in the long term and seriously affects her quality of life currently.

Further studies

1. Service analyses to understand local capacity and demand, are they fit for purpose?
2. Study of the school population to understand needs outside education.
3. Study the impact of a support network in improving the well-being of Adults with Autism.
4. Studies QOF epilepsy register and their association to Autism, and other risk factors.
5. Understanding employment environment for autism people- Career and progression.

Data Sources

There is a need of better recording and information integration across service providers.

During this research there has been information not accessible due to lack or recording, recording just initiated or access point was not identified. Data sources include:

- Police dataset
- Paediatric/child system
- Mental health services for adult and children
- Housing services
- Employment and Benefits

Autism Spectrum

Autism, sometimes referred to as Autistic Spectrum Disorder (ASD) or Autistic Spectrum Condition (ASC), is a developmental disorder. ASD may become first apparent in infancy or early childhood, in which the key diagnostic features are impaired communication, abnormal social development, and stereotyped patterns of interest and behaviour. There are often also sensory difficulties with strong reactions to light, noises, colours, touch and taste for example. In this report, we will use the term autism spectrum.

The causes of autism spectrum are not fully understood, although there is some evidence that genetic factors are involved. The term 'spectrum' is used because, while all people with autism share three main areas of difficulty (see below), their condition affects people in different ways. Some can live relatively independently – in some cases without any additional support – while others require a lifetime of specialist care.

The three main areas of difficulty experienced by all people with autism are:

- Communicating socially, particularly using and understanding facial expressions, tone of voice and abstract language.
- Recognising or understanding other peoples' emotions and feelings and expressing their own (making it more difficult to fit in socially).
- Understanding and predicting others' behaviour, making sense of abstract ideas and imagining situations outside their immediate daily routine.

Other related features can include: love of routines and rules, aversion to change and sensory sensitivity (for example, a dislike of loud noises; problems with bright lighting; inability to filter out irrelevant sensory information).

National Evidence

Autism is a lifelong developmental disability that affects the way a person communicates and relates to people around them. There is a lack of epidemiological research on adults with autism, so knowledge about the level of unmet need for services among adults with autism and their families is sparse and inhibits the planning of provision.

The Government's vision (4) for people with autism is that:

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

The Autism Act (2009) underlined the Government's commitment to achieving this vision through:

- Increasing awareness and understanding of autism, developing a clear and consistent pathway for diagnosis

- Improving access to the services and support people need to live independently within the community
- Fair employment.
- Improving training around autism for frontline staff in health, social care and employment support – which the consultation for the strategy identified as a vital first step.
- Helping adults with autism into work – an essential priority, given the low numbers of adults with autism in employment.
- Enabling local partners to develop relevant services to meet identified needs and priorities.

Using the recommended threshold score on the Autism Diagnostic Observation Schedule (ADOS), 1% of the adult population has autism. The rate is higher in men (1.8%) than women (0.2%), which fits with the profile found in childhood population studies (5).

Autism is known to be strongly associated with the presence of learning disabilities and it has been estimated that 30% of adults with a learning disability may also have autism.

Given the variability in identification rates and the general lack of data, it is difficult to quantify with certainty the number of people with autism. Recent estimates suggest that there are about half a million people with autism in England(4), of whom around 400,000 are adults(5), and that autism is three to four times more common in men than in women(6). Uncertainty about the prevalence of autism means that it is also difficult to estimate its associated costs precisely. A recent study by researchers at King's College London estimated that autism costs the UK economy around £28.2 billion per year (£25.5 billion for adults, and £2.7 billion for children). Of the £25.5 billion cost for adults, 59 per cent is accounted for by services, 36 per cent by lost employment for the individual with autism, and the remainder by family expenses(5).

The costs to society of autism in adulthood, including to diagnosed individuals and their families, has been estimated to be £90,000 per annum per adult (6).

Furthermore, National Audit Office (NAO) (7) has studied the possible impacts of providing specialised health, social care and employment support for adults with high-functioning autism. Wider implementation of such services would require additional expenditure. For example, it is estimated that £40 million per year is needed by Primary Care Trusts and Local Authorities to provide specialised health and social care teams across the whole of England. Evidence from existing specialised services does however indicate that they can improve outcomes for service users, and their model suggests that the costs could, over time, be outweighed by overall public expenditure savings.

However, local authorities across the country are still in the process of understanding how to deliver this vision and strategy.

Clinical Pathway and standards for Care: NICE Guidance & National Strategy

NICE have provided recent guidance in terms of services provision and care pathways for adults (2) and children and young people (3). The guidance focuses on local pathways defined and multiagency groups as an enabler for better outcomes.

The guidance recommends the creation of multiagency groups. A local autism multi-agency group, which should be set up with managerial, commissioner and clinical representation from child health and mental health services, learning disability, primary healthcare, education, social care, the criminal justice system parent and carer service users, and the voluntary sector. There should be meaningful representation from people with autism and their families, partners and carers.

- A lead professional is required to be responsible for the local pathway. The autism team, which should either include or have regular access to the following professionals if they are not already in the team:
 - paediatrician or paediatric neurologist
 - child and adolescent psychiatrist
 - educational psychologist
 - clinical psychologist
 - occupational therapist.

The aims of this group should be:

1. improving early recognition of autism by raising awareness of the signs and symptoms of autism
2. through multi-agency training: making sure the relevant professionals (healthcare, social care, education and voluntary sector) are aware of the local autism pathway and how to access diagnostic services
3. supporting the smooth transition to adult services for young people going through the system
4. developing a diagnostic pathway
5. ensuring data collection and audit of the pathway takes place.

Additionally, the guidance specifies treatments and interventions for Autism disorders, which are appropriate for adults and children, accordingly with co-existence disorders.

Local View

Locally, the situation is not much different in terms of the uncertainties around the population with Autism and their needs. There are services provided by public, private and charities organisations.

An Autism Joint Commissioning Board, which is working towards establishing a system to support and understand better the needs of the autistic population and their caregivers, has been created.

The "gold standard"¹⁵ approach to the assessment of autism places an emphasis on multi-professional input, but in practice this is often difficult to arrange even within established NHS services (7) (2). There is not a defined care pathway for adults and children, however there are intentions toward creating a unified approach, one for children and one for adults.

Comparing Birmingham with Hampshire in the latest self-assessment, Hampshire¹⁶ has made progress in terms of having established a network for follow up and mechanisms to involve and consult with people with autism. Birmingham still has not responded in this area, and there is uncertainty where people stand on this issue. There is evidence that creating a network of specialist services could help to follow up this population to achieve better outcomes.

Autism West Midlands has issued 1,350 Autism Attention cards to the Birmingham adult population. This is a card designed to show police (or others) that the person has autism and so may be vulnerable and need a different approach to feel supported.

Given the actual way of working and reporting, there is a lack of information, including a register that refers to people with autism and their caregiver. NHS services, social services, and other services record too little information to enable a clear understanding of the needs of this target population.

For the sake clarity, the autism prevalence is assumed to be 1% (1 in 100) for Birmingham, based on national estimation.

In the following chapters, we attend to develop a broader view of the situation in Birmingham and its autistic population; however **care should be taken regarding the data quality issues and/or lack of data**¹⁷. In some cases, we have used national estimations to attempt to ameliorate this.

¹⁵ NICE guidance for Autism referral and diagnosis

¹⁶ This authority self-assessment was accessible at the moment of writing this assessment.

¹⁷ The author(s) is not responsible for the further use or/and interpretation of the data presented.

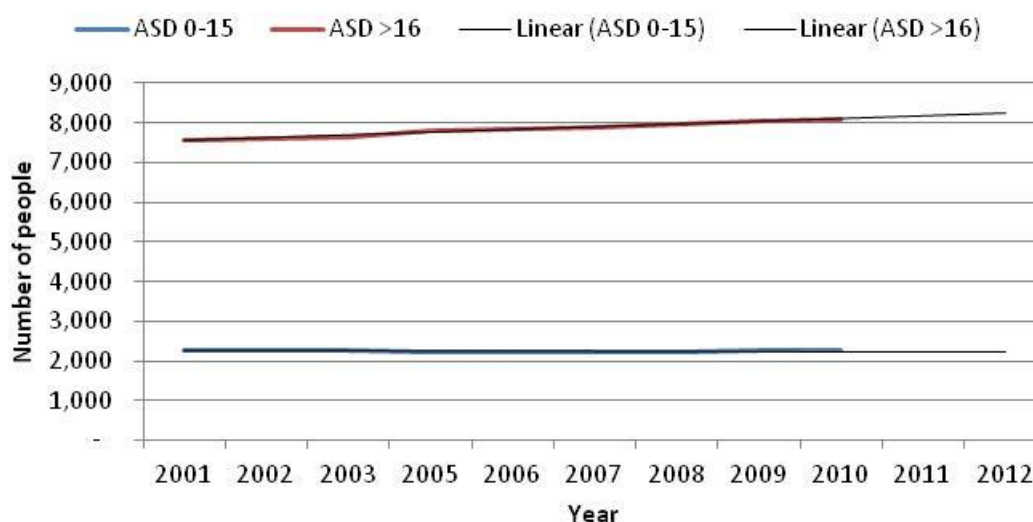
Population

The population of Birmingham is diverse and presents many challenges due to its ethnicity and age structure. The total resident population estimation (ONS Mid-Year estimation 2010) is 1,036,878 inhabitants, which is shown in Table 2. The Autistic population (ASD) is estimated to be 1 in 100 people (1%). Figure 1 shows the trends in the population with Autism that is slightly increasing as the general population increases, applying the above prevalence.

Table 2 Population estimation

	ASD	General Population
Age 0-15	2,278	227,763
Age >16	8,091	809,115
Total	10,369	1,036,878

Figure 1 ASD population trends applying 1 % prevalence



From this estimated population there is only a small proportion that is known or registered in services across the city, generating a challenge at the moment of understanding the needs of this specific population. Table 3 gives a summary of this population across the services.

Comparing the general population against the register, the children and young people population has the best register, and the adult population has the worst. This could be due to Social Services application of Fair Access to Care thresholds that include only people with critical and substantive needs.

Table 3 shows the population known to various services and the gap in adult registration is about 64% if we assume that people with higher needs and lower IQ are more likely to require more support.

Table 3 Birmingham population, autism prevalence and population known to services

Age	ONS General population 2010	Autism 1% prevalence estimation	Autism 2% prevalence estimation	SEN register children with autism 2011	Adult social services register 2010/11 autism	Autism attention card Autism West Midlands
Number of births	17,240	172	344			
0-15	227,763	2,278	4,555			
5-15	146,331	1,463	2,927	1,959 ¹⁸		
16+	809,115	8,091	16,182		267	1,350

Table 4 shows the population in special schools and the ASD population has been increasing and now represents 12% of the SEN schools population. Comparing this with 2005 a baseline, the increase is about 95%, and the prevalence by 2011 is 1.4% of the total pupils in school education. It is noticed that this prevalence is higher than national estimations and it does not include all pupils with autism in mainstream schools, who do not have a statement. A *Statement* is a document which sets out a child's SEN and any additional help that the child should receive. The aim of the Statement is to make sure that the child gets the right support to enable them to make progress in school (see page 87 for more definitions)

This suggests that the ASD population for children with autism in Birmingham is higher than 1%, as research has previously suggested.

ASD population in SEN schools represents a significant community. Within that group, there are often high health and social care needs.

Table 4 Pupils special education needs census (SEN)

Year	2005	2006	2007	2008	2009	2010	2011
Number of Pupils year 1- 11	140,716	139,916	138,984	137,575	137,368	137,771	138,673
Number of Pupils in SEN	13,430	13,770	14,692	15,440	16,018	16,467	16,584
Number pupils with autism and Action Plus	165	187	252	351	397	478	634
Number of pupils with autism and statement	839	926	1,035	1,180	1,235	1,265	1,325
Number of pupils with autism	1,004	1,113	1,287	1,531	1,632	1,743	1,959
% of Pupils with as Autism in the pupils population	0.71	0.80	0.93	1.11	1.19	1.27	1.41
% of pupils with Autism in special education needs	7.5	8.1	8.8	9.9	10.2	10.6	11.8
% Autistic pupils With Statement	83.57	83.20	80.42	77.07	75.67	72.58	67.64
% Autistic pupils with Action+	16.43	16.80	19.58	22.93	24.33	27.42	32.36

Data source: SEN Census, Education Department, Birmingham City Council

¹⁸Gyles Glover et.al estimated 898.7 (898.3 to 899.1) number of pupils(30)

Table 4 shows that since 2005 there has been a shift of 16% from children with autism with a Statement to more children being on School Action and School Action+ As the Statementing process is very costly, many local authorities have been trying to reduce the number of pupils with SEN being Statemented. In addition, the better a school is able to meet the needs of children with autism, the fewer will need a Statement. We do not have information about the outcome for these children (see page 87 for definitions).

Table 5 shows a comparison among Birmingham, England and Manchester, in which Birmingham has higher prevalence of pupils with autism spectrum in special needs schools compared against the total pupils with disabilities for England and Manchester respectively.

Table 5 Pupils with Autism as primary needs by school at January 2011¹⁹

	Primary Schools		Secondary Schools		Special Need Schools	
	Pupils		Pupils		Pupils	
	Number	% of Autism pupils among all disabilities	Number	% of Autism pupils among all disabilities	Number	% of Autism pupils among all disabilities
Birmingham	578	6.3	536	7.7	867	26.2
Manchester	146	4.7	114	5.4	188	17.7
England	22,810	6.9	20,615	7.5	18,150	19.6

Data source: Department of Education, Statistic First Release

Ethnicity

The ethnic composition of the population known to services differs between adults and children. In the latest school census (Summer 2011) 58% are from white background but in the adult population between 66% and 88% are from a white background

Services	Total individuals	White ethnicity	Other ethnicity
Social Services 2010/11	267	66%	36%
Birmingham and Solihull Mental Health Trust (BSMHFT) 2010	198	88%	12%
SEN	1959	58%	42%

Ethnicity is still not well recorded across services. The number of Children & Young people with ASD has been increasing since 2005, and those from an Asian and Mixed background have increased more than 100%, compared to 2005 figures. This is an indication of more awareness and better assessment.

¹⁹ Stated funded primary and secondary school.

% is calculated base on types of needs by Local Area

Includes maintained and non-maintained special schools. Excludes general hospital schools.

Pupils at School Action Plus and those pupils with a statement of SEN provided information on their primary need and, if appropriate, their secondary need. Information on primary need only is given here.

<http://www.education.gov.uk/researchandstatistics/datasets/a00196782/special-educational-needs>

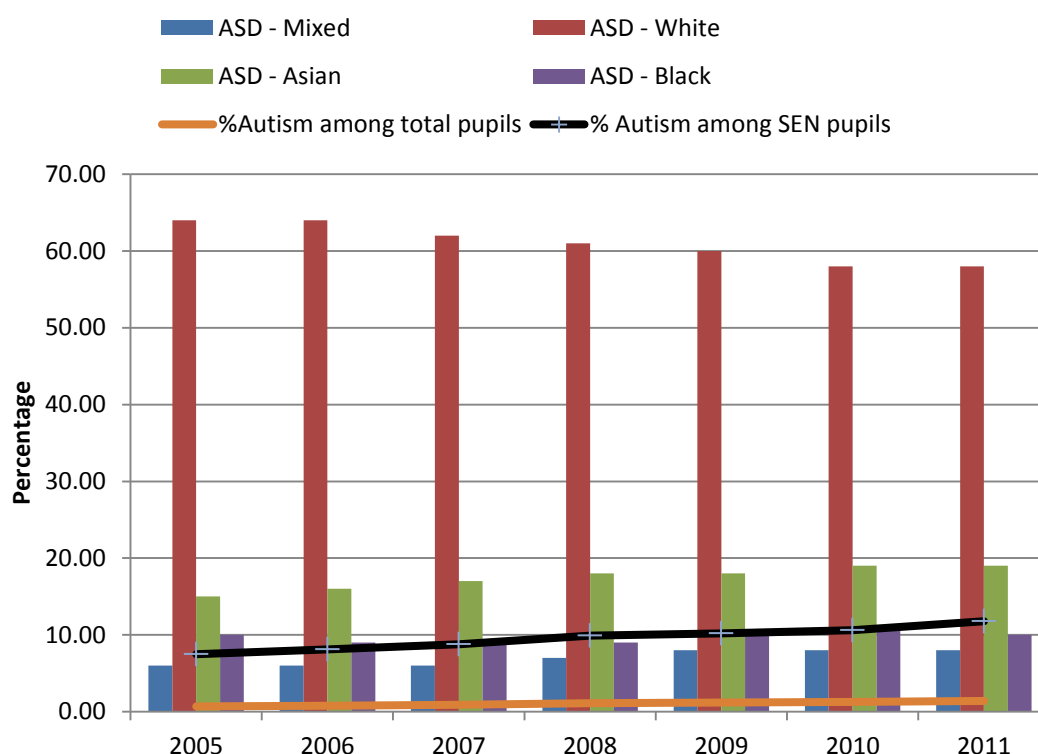
Pakistani origin pupils with ASD represent 67% of the ASD Asian pupils and White ASD represents 17% of the special school White population, see Table 6, Table 7 and Figure 2.

Table 6 Ethnicity comparison among SEN pupils with ASD, 2011

ASD and Ethnicity	Asian	Black	Mixed	Other	White
ASD SEN	19%	10%	7%	2%	58%

Data source: SEN Census, Education Department, Birmingham City Council

Figure 2 Autism pupils and ethnicity



Data source: SEN Census, Education Department, Birmingham City Council

Table 7 SEN ASD ethnicity trends

Ethnicity	2005	2006	2007	2008	2009	2010	2011
Total No ASD Pupils	1,056	1,188	1,321	1,543	1,636	1,752	1,961
No of Special Needs Pupils	3,137	3,253	3,477	3,854	4,111	4,295	4,257
%Autism among Total pupils	0.7	0.8	0.9	1.1	1.2	1.3	1.4
% Autism among SEN pupils	7.5	8.1	8.8	9.9	10.2	10.6	11.8

Ethnicity distribution reflects the population of Birmingham as a whole, and there is no evidence that ethnicity has a role in the increase in prevalence. However, cultural differences could influence disease management. Although, some studies suggest that migration status in European countries could be linked (8) to the condition.

Population Projections

The autistic population projections for Birmingham are shown in Table 8, which shows that the number of people with ASD is higher for Birmingham than in other West Midlands authorities, with an average 2.5% increase every 5 years. The working population (18-64) estimation for male is 1:54 and for female 1:500.

Table 8 Predicted adults (18-64 age group) population with autism spectrum for the West Midlands

LA	2010	2015	2020	2025	2030
Birmingham: Total males aged 18-64 predicted to have autistic spectrum disorders	5,828 ²⁰ (i.e. 1:54)	5,976	6,122	6,271	6,446
Birmingham: Total females aged 18-64 predicted to have autistic spectrum disorders	654 (i.e.1:500)	669	681	694	710
Birmingham Total 18-64	6,482	6,645	6,803	6,965	7,156
Dudley Total 18-64	1,845	1,824	1,817	1,814	1,806
Sandwell Total 18-64	1,754	1,766	1,787	1,814	1,841
Solihull Total 18-64	1,202	1,204	1,219	1,229	1,241
Staffordshire Total 18-64	5,118	5,052	5,030	5,012	4,973
Walsall Total 18-64	1,486	1,484	1,481	1,485	1,485
Warwickshire Total 18-64	3,349	3,383	3,452	3,503	3,538
Worcestershire Total 18-64	3,355	3,301	3,282	3,284	3,257

Data source: PANSI²¹

Table 9 Predicted children and young people population with autism

Age 0-15	2010	2015	2020	2025	2030
Males	116,127	124,040	132,540	137,180	139,220
Total male predicted Autistic spectrum	2,090	2,233	2,386	2,469	2,506
Female	111,636	119,040	127,020	131,520	133,580
Total female predicted Autistic spectrum	223	238	254	263	267
Total people with ASD 0-15	2,314	2,471	2,640	2,732	2,773
Age 16+	2010	2015	2020	2025	2030
Person	809,115	840,000	871,000	908,000	952,000
Total person 1% predicted Autistic spectrum	8,091	8,400	8,710	9,080	9,520

Data source: ONS Population estimation – estimated % of autism.

²⁰ Using ONS 2010 mid-population estimation

²¹ Table produced on 15/12/11 11:59 from www.pansi.org.uk version 5.0

Table 8 and Table 9 show the predicted population with Autism. The prevalence for age group 0-15 male is estimated 1:56 and for female 1:501 and for 16+ is estimated 1:100, for 2010.

In general, Birmingham's population is increasing, which implies that a steady increase in the population with autism also is expected. The increase in adults is around 2.5% every 5 years but in children decreases from 6% to 1.5% by 2030; with an average increase of 4.7%. These estimations must be taken carefully and in combination with improvements in identification and assessment, that could bring a stabilisation in prevalence, and population increase. Moreover, rate of migrations and mortality have not been considered.

Risk Factors

Evidence suggests that parental age and obstetric conditions are associated with an increased risk of autism spectrum(1): advanced maternal and paternal age, prenatal, perinatal, and postnatal infections, exposure to toxic agents, obstetric conditions like low birth weight, decreased gestation period and hypoxia during child birth are the risk factors of Autism²² (1) (9).

5%, of live births (607 babies) per year have a gestation period less than 36 weeks, and 7% of all live births have low birth weight (less than 2.5kg) (2005-2011).

19% of babies with low birth rate are from mothers²³ aged more than 35. The low birth rate for Birmingham was 8.7% compared to England 7.3%²⁴. For more details see Appendix Risk and population, page 78. In 2010, there were 17,240 live births in Birmingham.

A recent study has found an association between maternal metabolic conditions (diabetes, hypertension and obesity) during pregnancy and the chances of children having autism and developmental delays²⁵.

In general, the Birmingham population has a high rate of obesity, and maternal obesity has become an issue, with body mass index (BMI) of more than 30 in 13.3 % of mothers, compared to 12.6% in the West Midlands²⁶.

The Black Caribbean community presents the highest prevalence of obesity compared with the rest of the population, 32.7% for female. People from the Black African, Indian and Pakistani (24.5%) communities and females from the Bangladeshi community it is 13% higher than compared to the White population (10). The population attributable risk factor for females is higher than males for Type 2 diabetes 75.1%. Table 10 shows the prevalence of diabetes and learning disability, which are statistically significant and higher than the England average.

²² <http://www.scientificamerican.com/article.cfm?id=autism-maternal-age>

²³ New research indicates that father aged is a contributor rather than the mother aged <http://www.bbc.co.uk/news/health-19336438>

²⁴ Low birth weight is linked to smoking during pregnancy. Source: NHS IC Center, NCHOD

²⁵ <http://www.nhs.uk/news/2012/04april/Pages/mothers-obesity-diabetes-autism-risk.aspx>

²⁶ West Midlands Perinatal Institute, Peer Dataset 2009/10.

Table 10 Disease prevalence for adult population

	Diabetes (17+)			Epilepsy (18+)			Learning Disabilities (18+)		
	LL	Prevalence	UL	LL	Prevalence	UL	LL	Prevalence	UL
Birmingham	6.73	6.78	6.84	0.75	0.77	0.79	0.48	0.49	0.51
England	5.54	5.54	5.55	0.77	0.77	0.77	0.43	0.43	0.44

Data Source: Quality Outcome Framework 2010/11

There has been growing discussion on the co-morbidity of Down's syndrome and Autism Spectrum (11), however there is little research in this area, it is possible that people with Down's syndrome are misdiagnosed when Autism is a co-morbidity. Although Down's syndrome and the co-morbid presentation of autism spectrum is relatively uncommon compared to other psychiatric co-morbidities in Down's syndrome; the prognostic carries significant weight in valuable information for caregivers, medical professionals and educators alike in establishing appropriate early intervention programs to maximising the individuals quality of life.

Down's syndrome is uncommon in the UK. For example, from 2007 to 2008, 1,843 cases of Down's syndrome were diagnosed during pregnancy, and 743 babies were born with the condition (NHS Choice). This means that about 1 in every 1,000 live births is affected by Down's syndrome. Children with Down's syndrome are a risk of development delays and Autism. Birmingham has, on average, 10 children born each year with Down's syndrome²⁷.

Summary

The prevalence for children with autism is around 1.4% 2011; and there are areas in Birmingham that present a higher prevalence of children with autism (see Figure 12, page 48). There are electoral wards (SEN pupils autism prevalence) such as Northfield, Longbridge, Bartley Green, Selly Oak, Shard End, Stechford and Yardley North, and Sheldon which have prevalence higher than 2%.

It is expected that there will be an increase in the adult population with autism from 6,482 to 6,965 and for children from 2,314 to 2,732 by 2025²⁸. The prevalence is estimated in 1% (1:100)

The prevalence of autism among ethnic groups is shown in table below:

Table 11 Prevalence of ASD among ethnic groups

Ethnicity	ASD prevalence
White	1.14
Mixed	1.19
Asian	0.56
Pakistani	0.57
Black	0.99

²⁷ It should be noticed that HES data quality is poor in recording gestation, mother age or birth conditions, etc. In 2008/09, 50% of births recorded has unknown in some of these data fields and by 2010/11, 28% of births have not recorded data in some of these data-fields. Also home births are not recorded in HES.

²⁸ This estimation should be taken carefully, since actual prevalence is not robust.

67% of the Asian pupils with autism in SEN schools are from a Pakistani background.

The Birmingham population has a higher prevalence in risk factors associated to autism, such as low birth rate, gestation period, obesity in pregnancy, compared to the England average.

Identification, diagnosis and assessment

A diagnosis is the formal identification of autism and can be given either in childhood or in adulthood. People benefit from an understanding of their difficulties and what they can do about them, and it allows people to improve their access to services and support.

Autism can coexist with other underlying morbidities, making it difficult in some circumstances to make the appropriate diagnosis; the following figure shows some of the most common co-morbidities (Figure 3).

“Although in most individuals ASD is present from birth, the age at which symptoms become clinically evident varies greatly. In some cases of ASD, and especially when associated with developmental delay, the first signs will be evident within the first two years of life. However, very young children who do not have cognitive impairments, and particularly those who show no significant language delays (for example those with Asperger syndrome), may be able to function relatively well in one-to-one relationships at home, with sensitive, understanding adults. Recognition of their impairments may be delayed until the social demands of school and the need to interact with their peer group become too difficult for them to cope with.

The problems associated with ASD may also be compensated for, at least partially, by higher intellectual ability, especially if this is accompanied by special skills in certain areas. Many individuals with Asperger syndrome, for example, succeed well in technical fields such as engineering or computer technology, and may simply be considered as somewhat eccentric for much of their lives. In such cases the diagnosis may only be recognised if the individual later has a child with ASD and that assessment reveals similar problems in the parent as well. Alternatively, symptoms may become more apparent when marital problems arise, due to the inability of the person with Asperger syndrome to cope with the “normal” demands for intimacy and companionship (12)²⁹.

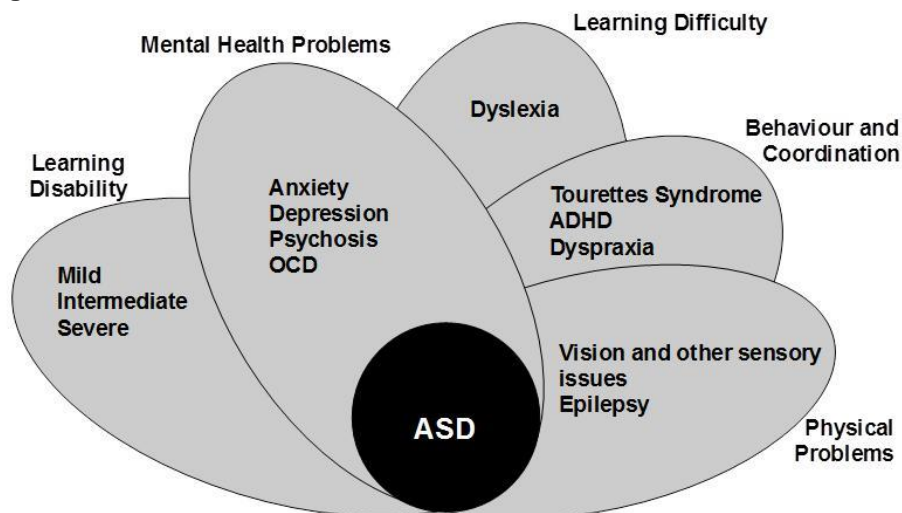
There is an increased recognition for better causal pathway modelling, integrating developmental, environmental and societal factors along with genetic, neurobiological and neuropsychological data leading to improve diagnosis (1) (2).

NICE guidance emphasises the need for local multidisciplinary pathways, with a clear path for referral and assessment taking into consideration co-morbidities and other factors associated with Autism (2).

It is recognised that the complex nature of these disorders and the change over time of clinical definitions make follow up difficult, but the important role of primary care in early intervention and as cornerstone for recognise early signs is also emphasised. However, awareness of the disorder is not well integrated in Primary and Social Care, which could put barriers in getting the right assessments and diagnosis.

²⁹ Clinical classification is under review DSM IV and ICD-10, this could implies more clinical recognition for these disorders.

Figure 3 Autism and Co-morbidities



Source: Scottish Autism

The National Autism Society and NHS Choice provide advice about Children's diagnosis and Adult's diagnosis routes. Diagnosing autism requires training and expertise, particularly in mental health settings where it may be difficult to distinguish from mental illness or learning disability. Primary care clinicians, such as General Practitioners, are generally not confident (7) in identifying and diagnosing adults with autism, hence specialised diagnostic services are required, ideally leading to a full multi-disciplinary assessment of the person's needs.

The latest national audit shows only 29 percent of Local Authorities and NHS bodies responding to the survey reported having commissioned specialised autism diagnostic services in 2007-08. In the survey of GPs, 64 per cent said that they referred adults with suspected high-functioning autism to adult mental health services, and 19 per cent to learning disability services. Twelve per cent were not sure where they should refer such patients, and only ten per cent reported that they would refer individuals to a specialised autism diagnostic service (7).

This shows the variability across the country and the lack of implementation of NICE guidance.

Primary Care

At a national level in Primary Care settings there is a lack of services/expertise to help in the diagnosis of ASD. In terms of referral of patients who had undiagnosed ASD, the latest national General Practitioner survey (7) indicates the following results:

- Children with undiagnosed 'low-functioning' autism are generally referred to Child and Adolescent Mental Health Services (51%) or Paediatric Services (50%).

- Children with undiagnosed 'high-functioning' autism or Asperger's Syndrome are generally referred to Child and Adolescent Mental Health Services (54%).
- Adults with undiagnosed 'low-functioning' autism are generally referred to Adult Mental Health Services (54%).
- Adults with undiagnosed 'high-functioning' autism or Asperger's Syndrome are also generally referred to Adult Mental Health Services (64%).
- Older people with undiagnosed 'high-functioning' autism or Asperger's Syndrome are mainly referred to Older People's Mental Health Services (73%).
- The majority of respondents (80%) don't keep a register of patients diagnosed with autism. Among the GPs who do keep a register, patients diagnosed with 'low-functioning' autism account for, on average, 4% of caseload, and those diagnosed with 'high-functioning' autism or Asperger's Syndrome account for, on average, 5% of caseload.
- Seven out of ten GPs (71%) do not provide specific ongoing support, monitoring or condition management for patients diagnosed with autism.
- Most respondents said in either type of autism diagnosis they were not very confident that patients are receiving appropriate and adequate care
 - 'Low-functioning' autism - 54% of respondents selected 'not very confident'
 - 'High-functioning' autism or Asperger's Syndrome – 52% of respondents selected 'not very confident'.

This clearly shows lack of understanding of these disorders nationally across primary care and the need for multi-profession teams integrated from primary through secondary-tertiary and community services in general.

Moreover, primary care settings are the focal point for prevention initiatives, thus improving awareness and understanding autism spectrum in this service tier is paramount, that will be reflected in better health outcomes for people with autism.

Local Evidence

There is no an integrated diagnostic pathway in the City and there is a lack of evidence to estimate the population who access the diagnostic services that do exist and data on their experience and the quality of their diagnosis. The gold standard (NICE) points out there is a need of having multidisciplinary and integrated team and pathway for managing autism.

Children and Young People are referred to CAMHS services for diagnosis and assessment, and a local pathway is being created with the integration of CAF (see appendix page 66). However data is not available at this moment to estimate which route is used for diagnosis and the population affected.

Plans to improve the adult's diagnosis and assessment pathway are being developed alongside a proposal for a Centre for Adult Autism Diagnostic Assessment³⁰.

³⁰ Birmingham Autism Partnership Board

In the Heart of Birmingham Teaching Primary Care Trust (HOBt), there are 282 people with Autism recorded as shown in table below and the rate per 1,000 population is less than 1 % for 60 % of the practices, meaning under recording is likely compared to the expected autism population. Currently, data from the other PCTs is not available.

Table 12 Rate and age distribution of people with Autism in Heart of Birmingham tPCT(HOBt)³¹

Rate per 1,000	Numbers GPs in HOB tPCT	Age Group	Numbers of people HOB tPCT
0 - <0.5	13	0-16	134
0.5 - < 1.0	23	17-25	84
0.1 - < 1.5	12	26+	64
1.5 - < 2.0	7	Total	282
2.0 - < 2.5	6	Expected Birmingham GP register population with Autism	11,107

There are local organisations that provide assessment of needs in the region such as Autism West Midlands, Communication and Autism Team (CAT). This service evaluates the needs of the individual in terms of their need to cope with everyday tasks. CAT will also ensure that communications issues are managed.

Birmingham and Solihull Mental Health Foundation Trust (BSMHFT), our major mental health provider, does not have specialised services for this population and it is difficult from records to identify people with autism. However, from the inpatient data it is estimated that people with psychological development disorders have been accessing their services due to mental health diagnosis (see appendix page 71).

The Communication and Autism Team³² (CAT) in Birmingham offers services for assessment of needs of children and young people, in main stream schools that could or could not have autism statements. CAT state that referrals have been increasing from 155 (2009) to 250 (2011), for the autumn term, an increase of 61%. Additionally, there is a continued need for awareness and training about autism in main stream schools and services for people with challenging behaviours.

Caregivers and parents views are that, locally, there is not a clear pathway for diagnosis and assessment, and there is a general lack of support. Additionally, there is a concern that IQ tests could discriminate Autistic people from receiving support³³.

Caregivers³⁴ views about the appropriateness and quality of the services during diagnoses showed:

- around 50% of the participants rate the service received as poor,
 - It takes too long to get an appropriate diagnosis.

³¹Source HOBt Business Intelligence. Re-Code used E140. Infantile autism, E1400 Infantile autism – active, E1401 Infantile autism – residual, E140z Infantile autism NOS, Eu840 [X]Childhood autism, Eu841 [X]Atypical autism

³² Lesley Baker, CAT

³³ Parents transition group, Engagement survey

³⁴ ASD engagement survey conducted by Rob Benson, Birmingham and Solihull Engagement, Feb 2012, 99 participant, 70% average response by question. Electronic base-Survey Monkey.

- The process is too long and cumbersome.
- There is not appropriate support after diagnosis.
- Of 100 responses to the survey 19% have Asperger Syndrome and 23% Autism diagnosis, also they present learning disability and Attention Deficit Hyperactivity Disorder (ADHD) as co-morbidity³⁵. Only 2 people said that their diagnosis was High functioning autism.

Small levels of support for people with Autism could make a huge difference in their quality of life³⁶.

Criminal Justice

St. Andrews Hospital provides secure specialised services for people with ASD who have been in contact with Criminal Justice Systems. This is a secure residential institution for male population; there are not secure services for females at national level.

Dr. H. Thomas at St. Andrews Hospital³⁷ has been monitoring patients (12 people, 80% white, average age 32) and has found an overall aggregate reduction in HoNOS scores of 123 (26%) since first admission and HoNOS³⁸ assessment. 50% of these patients were discharged to other Secure Units and 50% to community/home base accommodation. 41% of these patients were forensic and civic sanctioned with a history of violence and harassment.

The average length of stay is around 14 months, and patients are not necessarily from Birmingham. Moreover, he has found a reduction in use of medication in 13 patients (around 70% of the patients). This finding is linked to better health checks after being in this hospital. Given that Autism could be presented with other Mental Health conditions, then the use of medication could be a factor for further considerations in the development of integrated treatment package that could include alternative therapies to drugs.

Summary

It is clear at local level there are needs related to:

- *better diagnosis and assessments with integrated responsibilities across services*
- *better autism recognition at primary and social care*
- *better understanding of the health needs with proper registration at primary care level*
- *satisfying caregivers and patients in terms of timely assessment and follow-up support*
- *continuing support for schools to deal with CYP with autism, given the increase in prevalence reported.*

³⁵ For 56 respondents the question does not apply.

³⁶ Transition Support Group --- Birmingham Autism Board

³⁷ Dr. Huw Thomas, St. Andrews Hospital, Birmingham

³⁸ HoNOS is the most widely used routine clinical outcome measure used by English mental health services

Additionally, there is a need to understand the increase of ASD in mainstream schools and the route for diagnosis of those that have been in contact with the Justice Services.

ASD is an important public health concern, and ongoing surveillance in the US reported that prevalence estimates of ASD continue to increase in the majority of Autism and Developmental Disabilities Monitoring (ADDM) Network communities³⁹ (12).

It is important for Birmingham to establish ongoing public health surveillance to quantify and understand these changes over time. Further work is needed to evaluate multiple factors affecting ASD prevalence over time.

³⁹Centers for Disease Control and Prevention <http://www.cdc.gov/ncbddd/autism/data.html>

Improving access to services

Department of Health guidance to Local Authorities emphasises the need to focus on early support rather than later crisis management, stating that 'Councils should make changes in their practice to take a longer term preventative view of individuals' needs and circumstances' (4). It is known that the way services in social care are being designed traditionally set some barriers for people with autism due to considerations in IQ (if IQ is more than 70 they will be excluded). Similarly, people with high-functioning autism struggle to access existing mental health services unless they have a diagnosable mental illness.

With appropriate support, there is the potential for people with autism to live relatively independently in the community, requiring low-intensity services such as monitoring by a trained caseworker. Without such support, there is an increased risk of social exclusion and health problems, particularly mental illness. People may then engage with services only when their health has deteriorated, when they require 'acute' interventions such as Crisis Resolution Home Treatment or psychiatric inpatient care. Beside the negative impact of such crises on a person's life, acute services are also expensive, with inpatient mental health care costing between £200 and £300 per day(4).

In the latest self-assessment resource 'Fulfilling and rewarding lives: Evaluating Progress' from the Department of Health, local authorities should monitor progress in terms of:

- whether there is increased access to services;
- if more adults with autism have received a personal budget;
- whether there is increased satisfaction with local services;
- whether adults with autism, their family and carers have greater involvement in service planning;
- if there is increased confidence in the accuracy of diagnostic services; and
- whether healthcare professionals are able to identify signs of autism.

Locally, based in the latest Birmingham self-assessment there is no evidence of improving in those outcomes. However, steps towards better pathway and assessment are being shaped with established Birmingham Autism Board⁴⁰.

There is evidence (13) (14) that services provided for people with autism and their staff need further knowledge about Autism and its characteristics. Social care staff needs to improve their awareness of autism, to help them identify when someone may have it, and properly support someone who does. Training in how to identify autism, and how to make adjustments to accommodate the needs of people with autism, is key to addressing this. There are some barriers that constrain the success on delivering the appropriate services:

- a lack of awareness about autism, among some social care staff, other professions and society generally

40

- the 'invisibility' of autism as a condition. People with autism do not have obvious physical signs, and are sometimes therefore thought to interact in ways that are simply odd, ill-mannered or alarming
- disability and benefits legislation, which sometimes seems shaped by a sense that a disability must have a physical manifestation. It also relies heavily on good social communication and social interaction skills when completing forms or taking part in assessments
- the degree to which some people with autism can be talented and, particularly if they have no learning disability, very articulate. This can lead professionals to assume that they do not need social care or support
- the blocking of people with high-functioning autism or Asperger's Syndrome from social care and health learning disability services because they do not have an IQ of 70 or below, the cut-off point for most learning disability services, or a severe and enduring mental illness, which excludes them from mental health services
- many services, such as drug and alcohol services, not feeling confident in offering a service and trying to refer people with autism to specialised services. These specialised services are scarce, and can be geographically or financially difficult to access
- many social services having introduced generic teams, which have separate teams for initial assessment and for ongoing care. This lack of consistency in staffing can be difficult for people with autism.

Personalising services

“Personalisation means thinking about care and support services in an entirely different way. This means starting with the person as an individual with strengths, preferences and aspirations and putting them at the centre of the process of identifying their needs and making choices about how and when they are supported to live their lives. It requires a significant transformation of adult social care so that all systems, processes, staff and services are geared up to put people first” (14).

There are potential benefits of personalisation for people with autism; however there are barriers to enjoying these benefits. Personalisation works as a route to choice and control. Personalisation in services needs to overcome the barriers at an organisational and frontline level to be successful for people with Autism⁴¹.

Locally, people rate this service as very poor but also would like more opportunities and support for living independently (76% (16/21))⁴². People with ASD, require help such as management of their budget and shopping, etc; however personalisation and direct budget allows them to manage what services to buy that will fit the individual needs but impose full responsibility that in many cases people with autism spectrum cannot cope with. There are still gaps into the reality of management a budget and getting the full individual benefit.

It seems that personalisation services for people with autism need a variant to allow narrowing the gap on receiving this services and management it. In Birmingham, 24

⁴¹ BBC March 13 2012, Documentary “Let it go”

⁴² ASD Engagement Survey 2012, Birmingham and Solihull Cluster Communication and Engagement.

people of 267 registered with social services receive direct payment, compared to Hampshire 0 of 286 people⁴³.

Early intervention and prevention

Providing prompt, preventative services can work for people at different points on the autistic spectrum. It can benefit people with high-functioning autism or Asperger's Syndrome, who may find that support with social skills can prevent social isolation and attendant mental health difficulties. It can also help people with autism and complex learning disabilities or challenging behaviour, for whom intensive support within the home, coupled with decent respite care, can prevent placement in expensive residential care. In summary, early interventions could provide benefits such as:

- Getting a diagnosis easier.
- Leading more independent lives.
- Being more likely to work.
- Being less likely to have mental health difficulties.
- Increased likelihood of caregivers who are in work.

There is no evidence that services provided in Birmingham function by using a prevention philosophy associated to living with Autism.

Housing

In the latest NAO's survey (6) Birmingham does not respond to housing related questions in order to understand:

- Relative difficulty of finding appropriate supported housing locally to meet the needs of people with autism.
- Relative difficulty of finding appropriate residential accommodation locally to meet the needs of people with autism.

Figure 4 shows the services provided for people with Autism across Local Authorities in England. Care management and social groups are the largest, and housing has not been considered as a generic service. Figure 4 shows that less than 10% of generic services are autistic-specific preventative services. However, we do not have way of comparing this allocation.

According to some practitioners, people with Autism will require some adaptations to their properties, and rented accommodation is not always accessible and presents an obstacle to independent living.

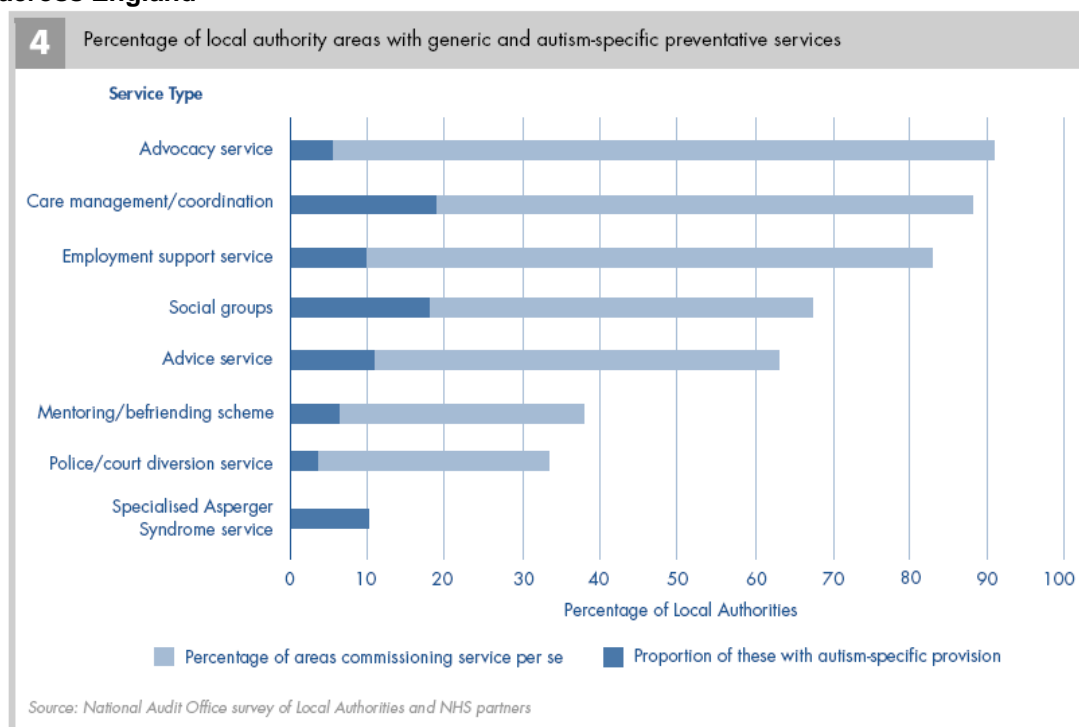
From focus groups with parents and adults with autism, and the ASD engagement survey that we have carried out, people with autism find it difficult to access housing services and some of their aspirations are being able to afford their own home, but also get some support to manage household tasks.

Based on the response from the ASD engagement survey more than 76% (16/21 people) of people rated as poor the support from housing services and living independently⁴⁴.

⁴³ Hampshire Self-assessment was available, at the moment of writing the this report.

From the provider survey, 17 people with autism 12 (70%) live in rented accommodation, one in residential care, and four in their parents' home, all of them with help of a caregiver⁴⁵.

Figure 4 Services provision for people with autism spectrum in Local Authorities across England



Data Source: NAO, 2009

Adult Social Services

It is known that social services are designed to cope with people with well defined disabilities and there are specifications to meet to be eligible for benefits. An IQ of more than 70 will be a barrier for those with autism, especially high functioning autism. There are 267 adults registered and receiving social services, and male gender is the most represented. The working population is 5:1 compared to the 65+ population receiving services. White background represents 61% of this group. See tables below.

Table 13 Population with diagnosis of autism in social care receiving service by gender, 2010/11

Gender	Critical	Substantial	Moderate	Not recorded
Female	59	18	5	16
Male	109	27	2	31
Total	168	45	7	47
Ratio male to female	1.8:1			

Data source: Birmingham City Council, Adults and Community, Business Intelligence

⁴⁴ The sample and response rate of this survey is small, hence and these results should take it carefully.

⁴⁵ The response rate of this survey was poor 12 of 300.

Table 14 Population with diagnosed with autism on the register in social care receiving services, by age group, 2010/11

Age	Critical	Substantial	Moderate	Not recorded
18-64	141	37	6	44
65+	27	8	1	3
Total	168	45	7	47
Ratio 18-64 to 65+				
5:1				

Data source: Birmingham City Council, Adults and Community, Business Intelligence

Table 15 Population with diagnosed autism on the register in social care receiving services, by ethnicity, 2010/11

	Critical	Substantial	Moderate	Not recorded
Asian background	26	9	1	9
Black background	27	8	0	5
Mixed and others	12	0	0	5
White background	103	28	6	28
Total	168	45	7	47

Data source: Birmingham City Council, Adults and Community, Business Intelligence

It is noticeable that number of people with autism receiving services from social services is low, 267 compared to the estimated population which it is between 6,483 and 8,091 for adults aged 16 years old and over.

It is assumed that the population receiving social services is small due to the disability threshold that limits those who can qualify to receive services. Based on the response from the ASD engagement survey more than 80% (41/46 people) of people rated as poor services and support from social services.

Table 16 shows that Care and Professional support are the services most received by people with Autism; 67% of the people have received these services. There is no information about refusals or a waiting list.

Table 16 Social Care by service component 2010/11

Service component	Age 18 - 64	Age 65 plus	Grand Total	%
Home/day care	71	20	91	34%
Accommodation	32	6	38	14%
Direct Payments	22	2	24	9%
Professional Support	87	1	88	33%
Other	16	10	26	10%
Total	228	39	267	100%

Data source: Birmingham City Council, Adults and Community, Business Intelligence

At this moment, we do not have comparative data from other local authorities, and we cannot compare with the rest of the population receiving services since the threshold for Autism in Social Care, and the Local Authority returns do not specify autism as a category for reporting.

There is a population supported by charity organisations that some of them are commissioned by City Council to provide specific services. Autism West Midlands has provided residential support and family support to 227 individual (2011/12), see more details in appendix page 83.

This year the local authority were asked by the Department of Health to report in advances in the implementation of the Autism Act (self- assessment). Comparing Birmingham to Hampshire⁴⁶ autism self-assessment 2012, we can see that in terms of total numbers of people with autism diagnosed and registered there is no some much different but in terms of population, the crude rate for Birmingham is higher 34 per 100,000 and for Hampshire is 20 per 100,000. Additionally, Hampshire has able to answer the questions of the self-assessment about the ASD population and Birmingham could not.

Table 17 Results of the survey to services providers

	White	Asian	Female	Male	Critical needs	Moderate needs	Low needs	Long term condition	LD/MH	Have a carer	Have GCSE	Rented Acc.	Parent home	Residential care	Obesity	Smoking	Total
Number of people	12	5	8	9	10	6	1	17	16	16	1	12	4	1	2	4	17
Percentage %	71	29	47	53	59	35	6	100	94	94	6	71	24	6	12	24	

The service provider's survey was sent to 300 providers of services in Birmingham aiming to gather information about their population. The response was too low; only 13 providers returned the questionnaires. Table 17 shows the result, 17 people with autism among 13 providers, 100% per cent of those people have a long term condition, besides learning disability (LD) and mental health (MH), smoking has similar prevalence of as Birmingham general population (25%) but obesity is lower- (26.20% for 2006/08 for Birmingham⁴⁷). Gender (1.13:1 male-female ratio) does not reflect the pattern of the autism prevalence but ethnicity follow similar pattern. The care needs follow the same pattern that those register in social care, 59% are classified as critical, 35% moderate, and 6% low. In terms of accommodation 71% live in rented accommodation and 100% need help of caregiver⁴⁸.

This survey is not conclusive but shows the lack of provider engagement. Moreover, ratio of male: female in the population known to social services is higher than the expected 9:1 approximately.

⁴⁶ Data available in Hampshire website

⁴⁷ National Obesity Observatory

⁴⁸ Only one person live in residential care were specialised care is provided.

Secondary and Specialised Care

Birmingham and Solihull Mental Health Foundation Trust (BSMHFT), which is the primary mental health services provider in the region, does not provide specific services for people with Autism. However, it provides general mental health services that people with Autism can have access. In 2009/10 there were 198 patients⁴⁹ that have used services related to Disorders of psychological development (ICD-10, F80-89).

In general, in mainstream hospitals the number of people with Autism using secondary care is small compared to the entire population. However, summarising the number of admissions from 2005/06 to 2010/11 there were a total of 1450 episodes. Table 18 shows the distribution of admissions depending of the first diagnosis code for the specific episode. Mental health disorder represents 20% of the admissions; followed by unspecific diagnosis, digestive system, respiratory system and poisoning.

It should be noted that data is poorly recorded for people with autism condition, and perhaps that is one of the reasons that number of admissions shown is low. In comparison with England and Manchester, Birmingham presents a higher percentage, for mental health and for abnormal clinical findings (further investigation).

Table 18 Total hospital admissions for people with Autism from 2005/2011

	England	Birmingham	Manchester
ICD -10 Chapters	Percentage		
XXI Factors influencing health status	22	4	7
XI Diseases of the digestive system	15	10	28
V Mental and behavioural disorders	14	20	3
XVIII Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	9	13	16
VI Diseases of the nervous system	9	8	10
XIX Injury, poisoning	8	9	10
X Diseases of the respiratory system	5	7	5
Other	18	26	22
Total Episodes	55,365	1,450	397

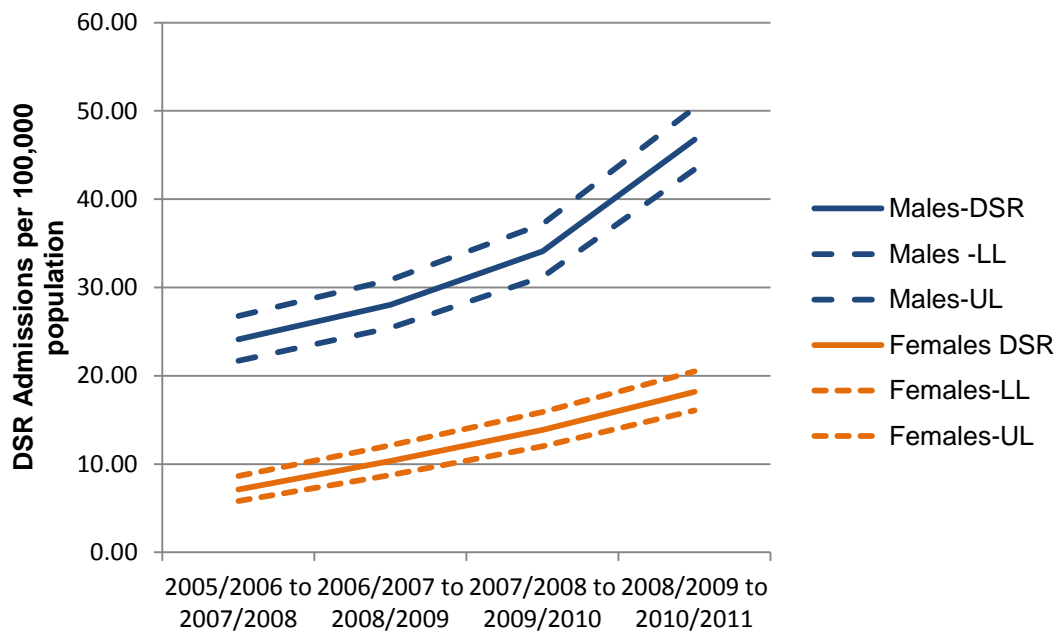
Data Source: Hospital Episodes Statistics (HES)

Figure 5 shows the trends for hospital admissions for people with recorded autism in one of the recorded diagnoses. Males and females hospital admission rate (per 100,000) have been increasing, and the electoral ward Shard End (136.9 male, and 72.2 person) has the highest admission in the last three years periods, compared to Birmingham (46.76 male, and 32.56 person); but also Shard End has the high mental health admission rate in comparison to Birmingham (Birmingham MH JSNA, 2011). The maps below show the electoral wards with highest and significant rate of hospital admissions compared to Birmingham average. However, for males Shard End, Nechells and Hall Green, and for females Stechford and Yardley are the electoral

⁴⁹ Total number of patients aged 18+ were estimated 35,148.

wards that seem to have real significance considering the control chart and the effect of small numbers, as shown for males in Figure 7.

Figure 5 Hospital admissions when autism is recorded as the diagnosis

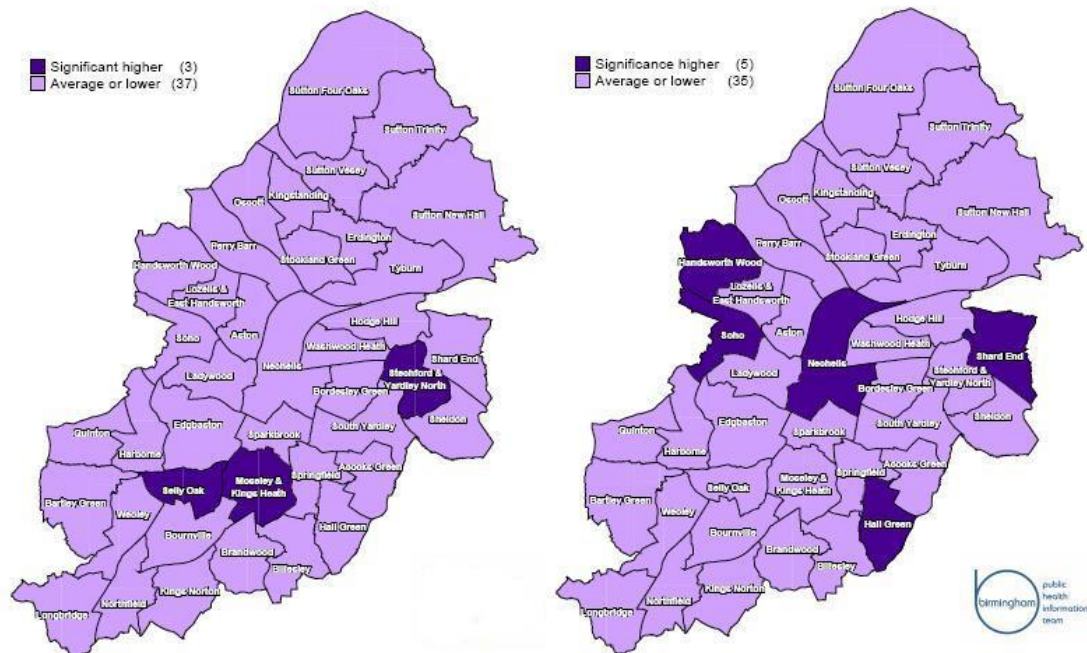


Data source: Hospital Episodes Statistics (HES)

Figure 6 Hospital inpatient admission rates for autism as recorded condition

Admission rates for females, 2008/2010

Admission rates for males, 2008/2010



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Data source: Hospital Episodes Statistics (HES)

Considering epilepsy and autism admissions⁵⁰ at the same time, then the number of admissions increase, from 3,414 (2005) to 5,483 (2010). 57% of these admissions

⁵⁰ Both, or any of the condition appear recorded at any time

are related to diseases of nervous systems, diseases related to childbirth and pregnancy, injury and poisoning, and respiratory diseases. It is recognised that people with Autism often have epilepsy⁵¹ as co-morbidity and this prevalence varies according to presence of other nervous system conditions and their age (15; 16). The rate of co-morbidity varies, depending upon the age and type of disorder, and currently the conservative estimate of co-morbidity cases is 20–25% for epilepsy for the whole spectrum (15).

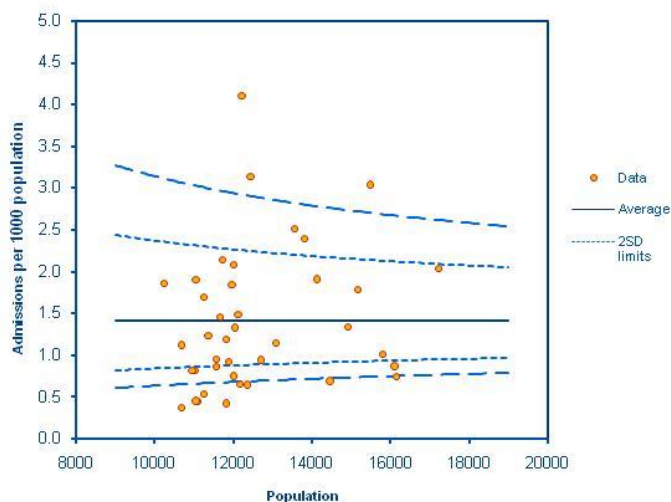
If we assume that 23% of people with epilepsy also have autism then 1,261 of the total admissions for epilepsy were from people with Autism, against 704 episodes which are the actual recorded number for autism admissions as co-morbidity.

QOF prevalence for epilepsy in Birmingham for population aged 18+ is 0.6% (6,705 people) compared to England 0.8% 2010/11, and 16% of adult with autism will still present epilepsy during adulthood compared with 5-38% in childhood. The epilepsy prevalence has changed from 0.5% to 0.6% approximately in the last 5 years, 2004/05 to 2010/11.

People with autism commonly have associated feeding difficulties that impact on growth and nutrition. A recent study identified an increase in food selectivity behaviours (24.5% vs 16.1%) (17) and constipation (33.9% vs 17.6%).⁵²

There is no local evidence that people with autism use health check services in Birmingham, and we do not have data to explain these co-morbidities. It would be of interest to assess people with epilepsy that are already in the QOF register to estimate the prevalence of autism and epilepsy in Birmingham.

Figure 7 Funnel Plot for rate of admissions by electoral wards 2008-2011

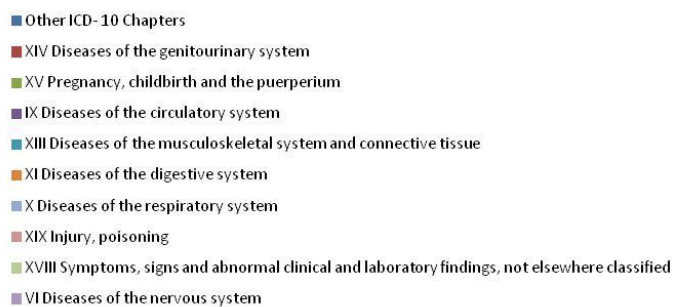


Data source: Hospital Episodes Statistics (HES)

⁵¹ “The prevalence of epilepsy in children with autism is striking—5–38% of children with autism have co-morbid epilepsy. (Rossi et al., 1995; Tuchman & Rapin, 2002; Danielsson et al., 2005). There appears to be bimodal incidence of epilepsy with onset during infancy to age 5 years and a second peak in adolescence (>10 years) (Volkmar & Nelson, 1990). In children with autism without mental retardation or cerebral palsy, the risk of epilepsy is low with a cumulative probability of 2% by 5 years and 8% at 10 years. If there is comorbid severe mental retardation, the probability is 7% at 1 year, 16% at 5 years, and 27% at 10 years. In the presence of both mental retardation and cerebral palsy, the risk rises to 20% at 1 year, 35% by 5 years, and 67% at 10 years (Tuchmann & Rapin, 2002). Epilepsy persists in the majority of patients into adult life with remission in only 16% of adults with autism and epilepsy (Danielsson et al., 2005)”.

⁵² Children with Autism and age and gender matched to control subjects

Figure 8 Autism and epilepsy hospital admissions 2005/2010 both or one condition recorded at any time



Data Source: Hospital Episodes Statistics (HES)

The rate for admission for autism and epilepsy⁵³, recorded at admission, is shown in table below. Geographically, the electoral wards Handsworth Wood and Stechford and Yardley have the highest rate for male and female admissions, 61.42 and 34.5, per 100,000 population, respectively. See appendix for other related conditions, page 78.

Table 19 Admission rate per 100,000 population for autism and epilepsy as they appears as diagnosis in the admission at the same time, for 2008/2009 to 2010/2011.

DSR	Males		Females			Persons		
	LL	UL	DSR	LL	UL	DSR	LL	UL
10.50	8.92	12.28	3.73	2.81	4.86	7.14	6.21	8.17

Data Source: Hospital Episodes Statistics (HES)

⁵³ICD 10 F840,F841, G40,G41

Children and adolescent mental health services (CAMHS)

Currently, a specific and integrated pathway across Birmingham is being developed under the umbrella of the Children Assessment Framework (CAF) that provides diagnosis and support services for children up to 18 years old. CAMHS services offer interventions for:

- Children with significant mental health issues which are impacting on their level of functioning, or those at risk of such;
- Children with severe ASD where parenting interventions are not working (e.g. provide more individualised parenting work);
- Children with a dual diagnosis of learning disability and ASD (input from CAMHS LD Team).

However, there is no specific information on the needs of these populations or an estimation of the population that access the service at the time of writing this assessment.

Based on the Engagement survey, the service provided is categorised as poor by 58% (27/46 people), additional to the diagnosis which can take years to make.

During this process the lack of support is noticed:

"I was given no support or advice from CAHMS once diagnosed we were immediately discharged"⁵⁴.

There is no local evidence that consistent support during and after the diagnosis process is in place.

Special Education Needs (SEN)

In Birmingham there are 138,673⁵⁵ pupils from of which there are 16,584 pupils in Special Education Needs (SEN) schools⁵⁶. There are 1,959 pupils with special education needs that are registered as autistic. Figure 9 shows the trends of the number of pupils with special needs and the pupils with autism. An increase in the school population with special needs and with autism was noted, but this could be associated with an improvement on pupil's assessments. Also, this increase might indicate that the ASD pupil population has become a significant population for SEN schools as SEN pupil population is significant for the entire education population.

Table 20 shows that pupils with ASD are been identified at early age, and from the total statemeted pupils 346, 23% (80) have ASD, and from the total in Action Plus 1,622, 6.5% (105) have ASD. In general, 1% of the under five children are indentified with ASD.

⁵⁴ Comments from parents, Engagement Survey 2012

⁵⁵ ONS projection for school aged 5-15 for Birmingham is 131,512

⁵⁶ 2011 School Census, Birmingham City Council

Figure 9 Trends of pupils in special needs education

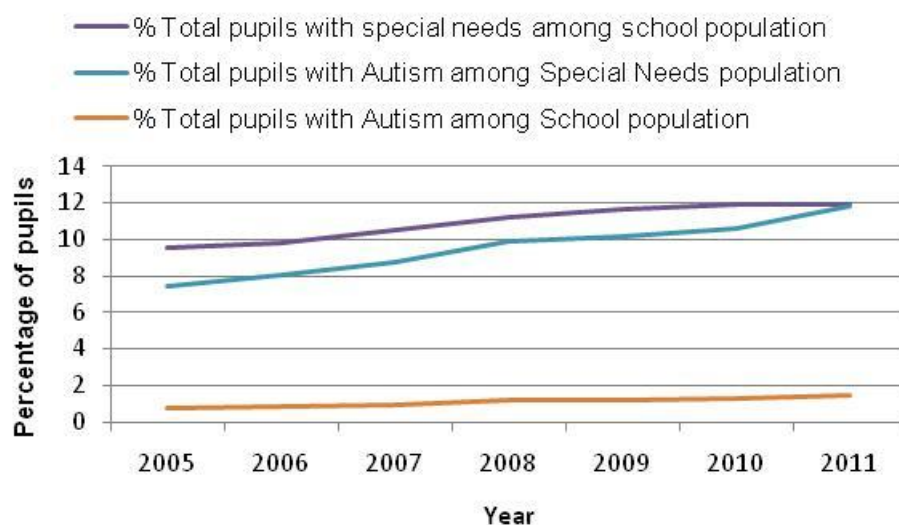


Table 20 Pupils under 5 with statement or Action Plus

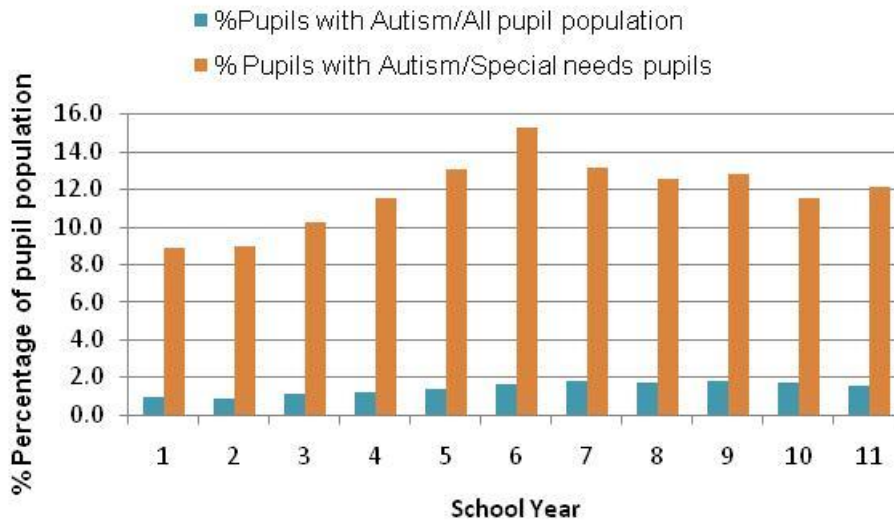
Under 5 children	Total	Under 5 Statement			Under 5 Action Plus		
		Other	Primary need ASD	Secondary need ASD	Other	Primary need ASD	Secondary need ASD
		267	75	5	1517	96	9
Total ASD	185		80			105	
Total Statement	346		23.1%				
Total Action Plus	1622				93.5%	6.5 %	
		Under 5 Statement			Under 5 Action plus		
Total Under 5	25370	1.4%			6.4%		
		Other	ASD		Other	ASD	
		99.68%	0.32%		99.59%	0.41%	

Data source: Birmingham City Council, Children Directorate, School Census 2012

The average prevalence for Birmingham pupils aged 5-15 with Autism is 1.4%, which varies across the city from 0.9% to 2.9%. Figure 10 shows that from year 1 to year 11, the percentage of people with Autism in Special Education Needs varies from 8.8% to 11.8%. White, Pakistani and Black Caribbean present the large proportion, 75% of the pupils with Autism (Figure 11).

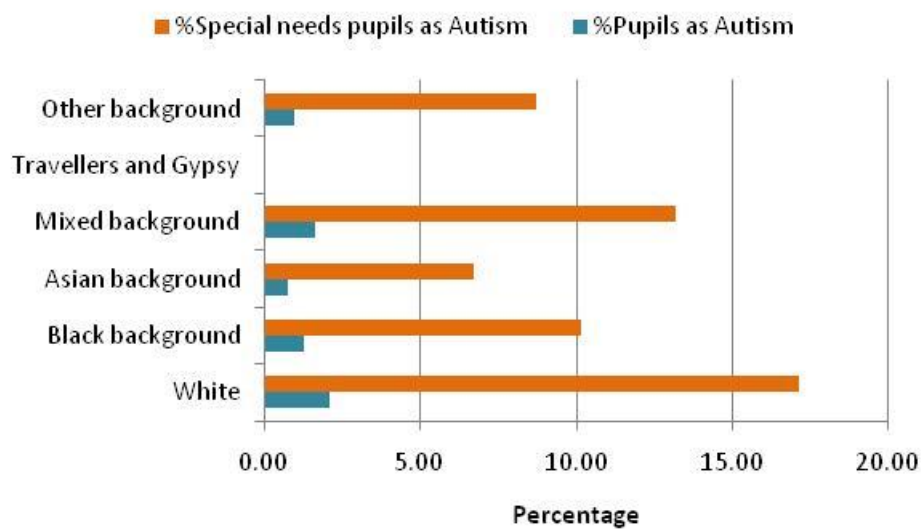
Figure 12 shows the prevalence of pupils with Autism across Birmingham, and how there are some areas with prevalence higher than 2%. These could be associated with the geographic location of the special needs schools.

Figure 10 Comparison of pupils with Autism against pupils in Special Education Needs, 2011



Data Source: Birmingham City Council, Children, Young People and Families, School Census 2011

Figure 11 Pupils with Autism in Special Needs Education, by ethnicity

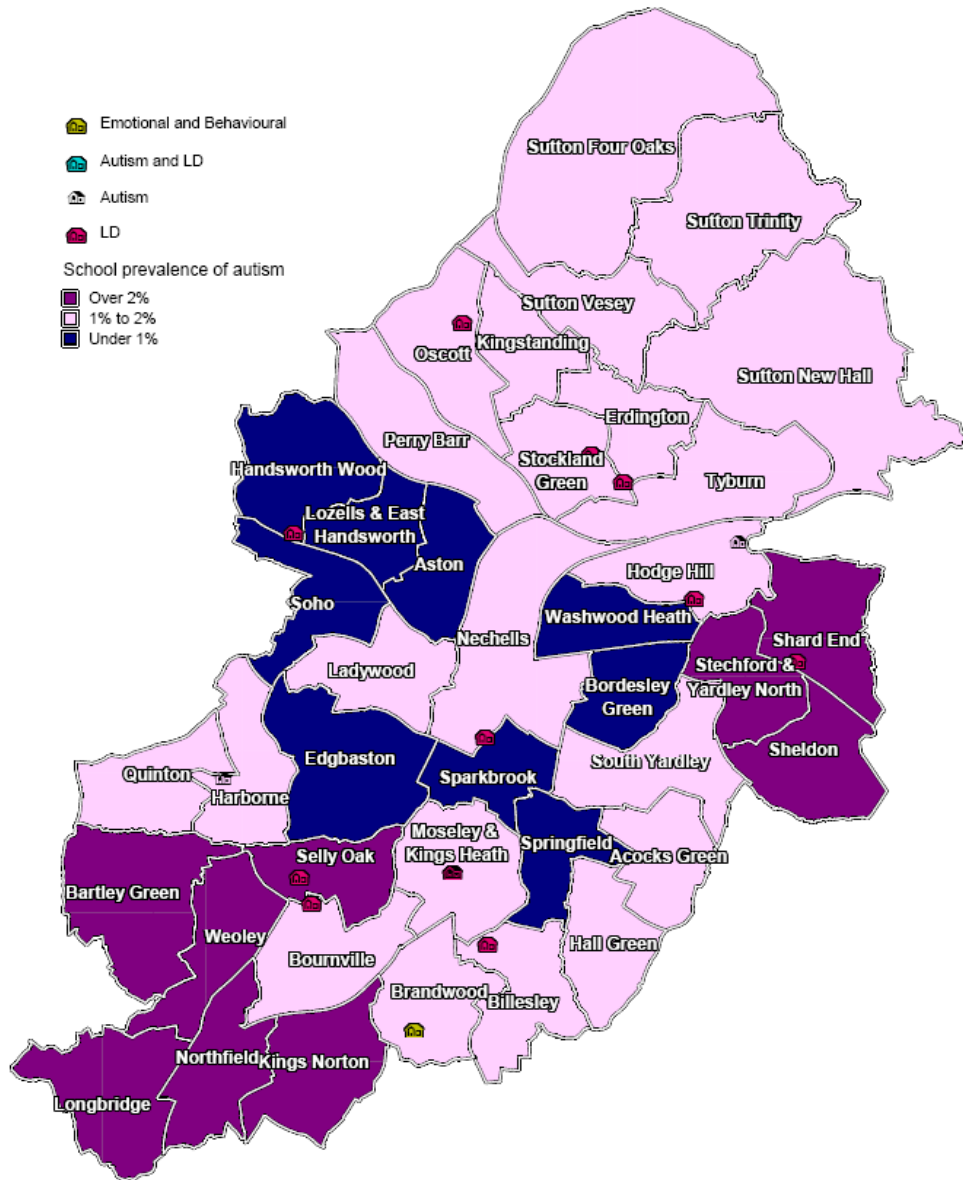


Data Source: Birmingham City Council, Children, Young People and Families, School Census 2011

Comments from practitioners in this area suggest that pupils who enter to SEN schools will continue in this type of school because of assumptions that the needs of these pupils will not be fulfilled in mainstream education, and changes of environment could undermine the child's outcomes. This implies that having the correct assessment and proper support earlier in life could determine if a child with ASD attends mainstream or SEN schools.

The map below shows SEN schools that are classified as a provider of Autism or related services. It is illustrated that some children with autism are in schools outside Birmingham.

Figure 12 Distribution of school pupils with autism across Birmingham



Main stream schools, further education and higher education

The Communication and Autism Team (CAT) provides assessment and services for pupils in mainstream schools when schools required some help and support in dealing with pupils with Autism. In the past years, demand and the complexity of the needs have been increasing. By autumn 2011, 250 pupils were assessed compared to 197 pupils (2010) and 155 pupils (2009). There is no evidence indicating an increase of prevalence⁵⁷ or relation to better awareness or services offer. However, CAT is providing a great support to cover with demand of services for autism.

Those people that receive assessments in mainstream schools are being presenting with co-morbidities rather than just Autism, and their needs seem to be more complex. Some of this population present challenging behaviour that sometimes will result in exclusion from schools because of the lack of resources in these schools to manage those cases⁵⁸. There is research evidence that there is a shift in demand in terms of the need for services to cover more complex needs (17).

Higher education data

In higher education, the number of people with Autism in the UK is 2,520⁵⁹ (0.12%) and 1.4% of all students with a declared disability, 2009/10. If this percentage is distributed across local authorities, it gives us an idea of the difficulties that face this population in adulthood for future professional development.

Table 21 Expected population in higher education in Birmingham⁶⁰

	Birmingham	West Midlands	UK
Estimated people with Autism in Higher Education	169 (140,662 population 16-23 year old)	234 (193,920 population in higher education)	2,520 (0.12%)

According to the 2010/11 HESA⁶¹ Student Records, the number of students domiciled from Birmingham declared as having autism was 10.

According to the 2010/11 HESA Student Record, the number of students at Birmingham Universities declared as having Autistic Spectrum was 5. These are wildly inaccurate as the University of Birmingham alone – has 70 students with autism known to Student Support. There will be many others who have not declared their diagnosis or made themselves known to Student support. This population will have health needs similar to the typical population – and so will make demands on services within Birmingham. Some with autism are not sure how to access services and may wait until their health has deteriorated before others suggest they seek help. They may therefore present with greater health needs than other students. They also

⁵⁷ There is not a routine assessment in mainstream schools, and the population have been done well defined to assume increase of prevalence

⁵⁸ Lesley Baker, CAT

⁵⁹ HESA, UK domiciled HE students and disability status 2009/10

⁶⁰ Estimation using ONS estimated population 2010

⁶¹ Source: HESA Student Record

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need support in knowing when to seek help and support in knowing how to find and access the relevant services.

Summary Local Evidence for Services

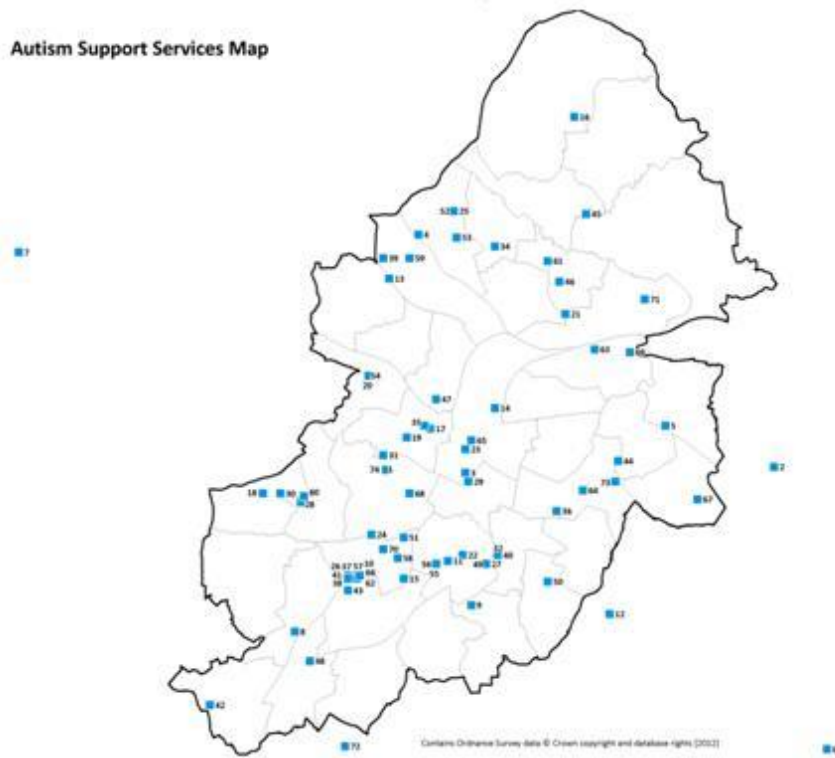
- *More than 50% of people responding to the ASD engagement survey rate poor the service received in general.*
 - *Some of the most wanted services are: group support and parents support, support for living independently and accommodation, education after school, education and training, residential care, employment support and support for daily tasks.*
 - *The main causes for people with autism to be admitted in hospital are for mental health, poisoning, respiratory conditions; mental health being the main cause.*
 - *There were at least 1,450 hospital admissions related to people with Autism in the last five years, and mental health problems represented 20% of the episodes*
 - *Admissions for epilepsy for people with autism are likely to be higher than it is recorded.*
 - *The ratio of male: female for people with autism is higher compared to male female expected prevalence in receiving social services.*
 - *There are few people register in Higher Education compared with the expected registration. Moreover, there are inaccuracies in the data register.*
 - *People with autism represents around 10% of the SEN population*
 - *Schools with services for children with autism are outside areas of high prevalence*
 - *CAMHS provide assessment services and are normally accessed if mental health co-morbidity is diagnosed.*
 - *There are unmet need(s) between pupils finishing year 11 and transition stage and their likelihood of continuing to higher education and/or employment.*
- There is no follow up for schools leavers.*

- *Figure 13 below indicates that there are a high number of services around the city, but quality of the services and match of demand to need are unknown.*

Locally, there is no or little evidence:

- *That people with autism have any wider participation in planning/developing services.*
- *That services available to caregivers provide re-assurance and quality time.*
- *Support practice in early interventions.*
- *That services are ready when people most need them.*
- *That people with autism are taking advantage of health checks or screening.*
- *That support services during and after diagnosis and assessment are available.*
- *That services around the city are appropriate and/or qualified to meet the needs of the population.*

Figure 13 Third sector services for autism around Birmingham area⁶²



⁶² See appendix for legend

Autism and Employment

Nationally, 85% of adults with autism are classified as unable to work or unemployed⁶³.

There is not enough data available on people with Autism in full employment or receiving incapacity benefits⁶⁴ for Birmingham.

If we assumed that 15% of adults of working age (16-64) with Autism are in employment and the population aged 16-64 is 672,498 (ONS, 2010) then we can expect:

Table 22 Unemployment estimation among expected population with autism spectrum in the general population in Birmingham

<i>Autism prevalence</i>	1%	2%
Estimated population with autism	6,725	13,450
Expected number unemployed or unable to work	5,716	11,343

The number of autistic people in the working age group 16-64 that are unemployed range from 5,716 to 11,343 people (Table 22); however we know that not all autistic people are able to work and there is not a national estimation either.

Many would be able to work full or part-time if they were supported to do so and money could be saved as mental and physical health would improve and they would not need benefits.

Locally, CONNEXIONS provide services for people in transition. In 2010/11, 378 people with ASD or emotional disorders (EBD) were in transition from children to adult for this period (leaving school-year 11 in summer 2011). From this cohort: the number of people with ASD was 133, only one of whom was in employment, and 5 of which were seeking for employment or training; people with EBD numbered 243, from which 41 were seeking for further employment or training.

There is no evidence that people with ASD and emotional behaviour are in employment after finishing year 11 or 6th form schools, there is a gap in services for following up this population.

Recently study in South Thames, with a total population cohort of 56,946 children aged 9—10 years (2006) (18), has found that 55% of those people with ASD have an IQ below 70. If we assume that people with ASD and an IQ less than 70⁶⁵ (19) could

⁶³ The National Autistic Society, <http://www.autism.org.uk/employment>

⁶⁴ There are 38,730 people receiving incapacity benefits in Birmingham, DWP May 2011.

⁶⁵ People with ASD and IQ > 70 are unlikely to receive social care benefits, and ASD people with also have other co-morbidities that could prevent them from getting into employment, because difficulty on cognitive and communicative functioning, social and personal functioning and concentration, persistence, and pace.

not hold a stable job, then from Table 22 using an estimated prevalence of 1%, the expected unemployment ASD population is:

Table 23 Expected unemployment, assuming constraint in IQ and functioning difficulties due to ASD

	Adult ASD Population	Adult ASD population with IQ < 70	ASD Population which could be employable	15% ASD population in employment	ASD population in Unemployment
	6,725	3,699	3,026	454	2572

This is empiric estimation indicates that at least 2,572 people with autism are unemployed, compared to the unemployed population of Birmingham 121,960⁶⁶ (18%); this represents 2% of Birmingham unemployed.

IQ does not indicate the likelihood of employment and job sustainability for people with autism. Some people even with degrees will find their condition-autism- presents a barrier to sustaining employment unless support is given. A revision of the provision of resources is required to help people with autism, to secure and maintain employment due to the specificity of this condition.

It is essential that the provision of employment is not the only support provided within the Charities Organisation but that practical help and experience is provided to assist autistic people become engaged in a wide variety of organisations and industry sectors that area able to utilise the skills and capabilities while providing the required environment and support.

Disability, Employment Service⁶⁷

Forward 4 Work provides a bespoke training and employment support service for disabled people in Birmingham. Each individual has a support package developed to meet their individual needs following an initial assessment and Information Advice and Guidance (IAG). They undertake a skills audit and a programme of training and development, including (vocational study in business administration, grounds maintenance, horticulture, catering floristry, skills for life and skills for working life), pre-employment support (confidence building, CV preparation, volunteering and work experience placements), in work support (job coaching and training) and support for the employer.

Traditionally, funding bodies like the Department of Work and Pension (DWP), Job CentrePlus (JCP) and the Skills Funding agency etc., have determined the datasets used to record the outcomes on programmes and projects. Services have not been required to provide data at the level required to capture the number of clients with Autism who are engaged within a service. Clients self-determine the category on the referrals forms, unless we are advised of a clear diagnosis of Autism it is safe to say that most clients would categorises themselves as either having a learning disability/difficulty or mental ill health.

There is a similar picture amongst third sector providers. Having liaised with BITA Pathways, Midland MENCAP and the Disability Resource Centre, who also provide

⁶⁶ Source BCC/ONS/NOMIS, November 2011 worklessness

⁶⁷ Judy Thomas, Birmingham City Council, Disability, Employment Services

employment support services in Birmingham, the number of referrals identified are very low.

Autism West Midlands through Aspire Project has been providing work related support to 65 people (2011/12) (see Appendix page 69).

In general, official bodies' record statistics about disability and employment at a high level and clinical diagnoses are omitted; in this case Autism cannot be reported.

Summary

- There is little evidence to estimate the population of adult with autism are in employment.
- It is estimated 15% (454) of people with autism are in employment
- It is estimated that around 2% of the unemployment population could be autistic.
- There is no specific support to help people with autism into employment.
- There are 65 people of 1,350 known to Autism West Midlands that are supported in employment.
- There is no evidence that after transition period people with autism get into employment.

Transitions

Transition is a process that covers three age periods 14-16, 17-19, 20-25 and it is intended to help young people through their planning about what to do after leaving school. Transition for any teenager is a challenge and more difficult if he/she has complex needs or disabilities and may need a coordinated response from a range of agencies.

“From the age of 14 (Year 9), all young people are supported by their school to consider their career choices / options in adult life and the post 16/19 education and training opportunities that will help them achieve their goals.

For young people with a Statement of Special Educational Needs the transition process starts at the Annual Review in Year 9. While the young person remains in school, annual reviews will continue until their 19th birthday. For young people who choose post 16 to attend a college of Further or Higher Education or a Training Provision, the arrangements for funding and support will change, supported by a S139A Learning Difficulties Assessment, also known as the ‘Moving on Plan’.

The Year 12 review marks another key stage in transition, as this will link to the move in social services, at age 18, from Children’s to Adult Services. Transition is a process, and not a single event, which can take place over a period of up to several years”⁶⁸.

Connexions

CONNEXIONS⁶⁹ support pupils finishing schools that required further education or help to find employment. There is a legal duty of providing and assessing young people during their transition period who have a disability statement.

By 2005 there were 56 pupils finishing year 11 (SEN) and since then the number has been increasing. By 2011 there were 175 pupils; this is an increase of two fold, with an average increase of 24%, indicating pupils staying in SEN education. Table 24 shows the pupils in contact with Connexions, the mismatch between the 133 reported by Connexions and 175 from the Census, could be due to time period.

Table 24 Population known to transition services, Year 11: Connexions

Connexions known population	In employment	Education and Training	Higher Education	NEET	Other	Total
Autism Young People 2009/10	2	76		7	5	90
Autism Young People 20010/11	1	119	4	4	5	133

By 2009/10, 15% of the population supported by CONNEXIONS had an ASD statement.

⁶⁸ Transition Handbook, <http://www3.hants.gov.uk/transition-final-march-2011.pdf>

⁶⁹ Martin Fleet, Connexions has obligations in providing help for young people in transition to find places in employment or education.

From the latest school census (summer 2011), the number of children at year 11 was 175 who will be in Transition by 2012. If we assumed a constant increase in the population passing from Children Education Special Education to Adults Services, then we would expect as many as 165⁷⁰ people in average yearly to be new registrants in Adults Services, assuming that they will need a level of support. This number does not compare with the actual number of ASD people in social services 267.

There is evidence that indicates that if children are in schools at 6th forms that they will continue in education; however, it is noticed that when the young people reach an age threshold there is no further help available and no official organisation that will take a special interest in them.

Thus, there is a gap in understanding the journey of this Young population group from finishing year 11 or those in year 12/14 through further/ higher education and employment (see Table 25). Table 26 shows that more than 75% of pupils for ASD and EBD continue in education, but also it shows that at the end of year 12 or 14 only 3:10 pupils approximately from year 11 continue to Year 12 or 14⁷¹. This shows the lack of understanding of the journey of young adults during the transition period.

Table 25 Destination of pupils with Autism (ASD) and Emotional Behaviour Conditions (EBD) for School Action Plus (SAP) and Statement (STM), 2010/11

	<i>Destination After finishing</i>	<i>in employment</i>	<i>Education and Training</i>	<i>NEET</i>	<i>In Custody</i>	<i>Other</i>	<i>Total</i>
ASD	Year 11	1	35	3			39
SAP			92	2			94
ASD	Year 11	8	107	17	2	3	137
SAP		3	75	24	3	1	106
EBD							
STM							
Total							378
ASD	Year 12/14	1	6			1	8
SAP		2	46	1		14	63
ASD	Year 12/14	1	16	2		2	21
SAP		0	11	0		4	15
EBD							
STM							
Total							107

Data source: Connexions

⁷⁰ Three years average (2009/11).

⁷¹ Assuming that 2008/09 has similar pupils population.

Table 26 Percentage of pupils continue in education

<i>Destination finishing</i>	<i>% of pupils continue education</i>	
Year 11	95%	ASD
	75%	EBD
year 12/14	73%	ASD
	75%	EBD

Data source: Connexions

Caregiver's views are that as the child gets into adolescent and transition phases there are no services that can help them, as a caregiver, to better understand the changes and needs of the young person⁷². A study (20) has shown that caregivers of children with ASD experience significantly higher levels of stress and there is need for support services designed for caregivers in order to afford carers the opportunity to seek out activities for themselves.

An international cohort study of 12-22 year olds (17) has shown the needs in areas of occupation and recreational activities, and the needs of quality of life assessment tools for autism.

After the transition period ends, our services are unable to identify what happens to young people with autism.

Summary

Young people finishing schools should find support through Connexions to continue in further education or employment.

- *There is an increase in pupils with ASD going through transition.*
- *Pupils with ASD after finished year 11 will continue in education if they are in 6th Forms schools.*
- *Few pupils with ASD in transition will go into employment.*
- *4:10 pupils (ASD and EBD) finishing year 11 will continue to year 12 or 14.*
- *There is no local mechanism to follow up people with ASD after the transition period finished.*
- *There is local evidence that parents need help understanding the transition period of the young person with ASD.*
- *There is a mismatch between expected increase of people with ASD known to social services and the actual number of young adults finishing their transition period.*
- *National evidence shows that young people in transition experience higher level of stress, and they have needs in areas of occupation and recreational.*

⁷² Conversations with parents from the transition group, Autism partnership Birmingham

Training and Awareness

Autism spectrum disorders definitions have been changing in line with new research into the area and better understanding of the clinical development. The way that autism manifests across the population is different and requires good understanding of its symptoms and mechanisms that are available to be able to help people diagnosed with ASD. Understanding the early signs and having control of what could be expected as the condition develops could improve the management of the condition and daily life for caregivers and patients.

Understanding the symptoms and the progress of the condition could help practitioners to refer and provide better assessment leading to better support, as behaviour changes are triggered. In general, people with autism will interact daily with services and people, and knowing about the condition may help all us to accommodate and build more flexible and friendly spaces for this population.

There are national and international campaigns to raise awareness about autism, with different organisations providing information and learning Hubs⁷³.

NHS Choice provides a range of information for caregivers, practitioners and for people living with Autism that people can access via a website⁷⁴:

Locally, we have a main provider in Autism West Midlands for supporting people with autism, which provides a range of courses for organisations and people interested in learning about autism. Autism West Midlands provides training for institutions across the region. Their Programme includes:

- Understanding autism.
- Communication and autism.
- Challenging behaviour and autism.
- Mental health and autism.
- Sexuality and relationship issues and autism.
- Person-centred approaches and autism.
- Developing play and social skills in autism.
- Self help skills and autism.
- Sensory issues and autism.
- Working effectively with families of people with autism.

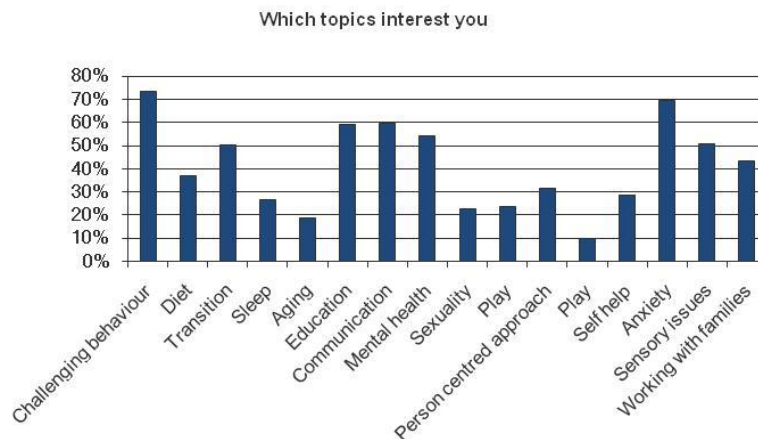
Autism West Midland (AWM) did a survey⁷⁵ to understand the need for training about the condition and Birmingham was the area with more desire for training. The subjects for training are shown in the figure below, which shows the needs in challenging behaviour, mental health education and communication. AWM has provided courses to 479 people (2011/12), and have provided 1,656 advices by telephone contact.

⁷³ <http://www.autismeurope.org/>

⁷⁴ <http://www.nhs.uk/conditions/autistic-spectrum-disorder/Pages/Introduction.aspx>

⁷⁵ 226 respondents with 16 incomplete, Autism West Midlands, 2011

Table 27 West Midlands Autism Survey on training needs from organisations and individuals



National evidence shows that there is a need for more training for GPs and awareness of this condition for employers and services providers. Birmingham Commissioners are developing a strategy to improve training and awareness. Four out of five GPs (80%) nationally indicate that they require additional guidance and training to identify and manage patients with ASD more effectively (7).

Additionally, caregivers have indicated training needs to be able to cope with changing behaviour and the overall condition in both childhood and adulthood.

People with autism from the focus group have expressed needs in

- Learning how to learn.
- Learning daily tasks.
- Learning about household tasks.
- Learning about their condition and how affect them.

Summary

There are a range of providers in the region that provide training and support for people with autism and caregivers. However, autism and understanding about the condition continues to be a low profile in Birmingham.

There are needs in areas such as:

- *Creating a network of providers and services that could strength the knowledge in Birmingham about autism.*
- *Understanding the needs of clinicians and practitioners in the area and providing tailored training.*
- *Involving local communities and industry to raise awareness of working with autism.*
- *Increasing awareness in schools about autism and declared disability.*
- *Training caregivers to understand how to cope with life-stage and autism.*
- *Training in daily life, how to learn and how autism affects an individual.*

Discussion

In general, knowledge about autism conditions and the difficulties faced by children is better understood than for adults. This condition, as any other disability, constrains this population in getting a better chance in life.

People with autism could need support through their whole life, though some of them will be fit enough to not need any/or only need minimum help. For those people that can manage their life well, sometimes the question is about “what to do after diagnosis”.

There are views from across people with Autism and their parents/carers that the services provided for this population is not adequate and the services should fit people’s needs better. The existence of a pathway that covers the whole life cycle and covers the difficulties in diagnosis, care packages and benefits is an urgent need in Birmingham.

There is considerable research which indicates that many disabled young people are not receiving the help that they need to go through pre-transition, transition and post transition, despite multi-agency services being available (21). In Birmingham, it is apparent that information is not available to understand this picture clearly. From parents in the transition group, it is noted that awareness about access to services available to parents and young people is needed, thus the services should be adaptable to cope with people with Autism. Additionally, it is noted that we do not know what happens to young adults with autism after they have finished further education.

In terms of morbidity and mortality for people with autism, more research and better data recording is needed to understand the full range of major disease groups affecting this population. However, there are a few studies suggesting a high rate of mortality and morbidity (22). In Birmingham, areas such Soho and Shard End presented a high number of admissions for epilepsy compared to Birmingham. The rate of hospital admissions for epilepsy has been increasing in the past few years, in addition to the national trends (see page 71). Birmingham has 0.6% of prevalence in epilepsy compared to England’s 0.8% (2010/11).

Given the lack of information about adults with autism in Birmingham it is difficult to understand the needs of this population, their challenge during adulthood, and the mechanisms that they have to cope with their life.

There is wide range of treatments and interventions available for families and caregivers of people with autism, but few of them have a solid research base. As well as better designed studies, it is necessary to undertake person-centred evidence based support practice in a variety of settings to take account of ability and user preferences. Although, there is not strong evidence of whether intervention early produces more long-term benefits than intervention delivered in later childhood or in adulthood, it seems logical, given children development, to provide access for young children with autism to individualised autism-friendly intervention programmes (23). Other research has found that residential programmes have a positive and indirect benefit, reducing challenging behaviours for people with autism (24).

Local pathways and assessment frameworks for Birmingham have been developed following NICE guidance, and the latest National Autism Strategy. Local practitioners recognise the need for better understanding of the local population and their needs, thus the need for a robust system that takes care of people with autism through their entire life.

However, there is evidence out there about autism and symptoms, services; there is still a barrier on getting reach this information timely and tailored. This problem is presented across to people with disability, and we have not work out through the best mechanism that influence the accessibility and appropriateness of the information accordingly with needs.

As the majority of those diagnosed with autism are likely to have needs arising from the condition, the figures of number of people register in a services suggest that there are many adults with autism in need of services in Birmingham who are not receiving these. It is known that if the needs of adults with autism are not met – they often go on to develop serious mental health problems, lost their employment and go into crisis when a family member who has given support can no longer provide this.

The way that services are delivered and the lack of an integrated network of services, and the lack of unified register it is difficult to ascertain accurately the number of people across services.

There is a need for understanding different in employment capability related to the specific disability and the support needed to enhance employment opportunities. These services need to be linked to market reality thus as employment policies.

There are opportunities to shape services and to understand disability and health needs that with a better recording of data and information processing could be made possible.

There are already a known population that could be engaged and help to design and understand the future services demand according with their current needs, however there is no evidence to show their involvement.

Key findings:

- Information and data recording across services provider does not allow us to construct a current picture of the needs of people with autism
- There is lack of integrated pathway for autism assessment or diagnosis, but there is some progress in this area.
- People with autism are at risk of being unemployed due to their conditions
- Young people with autism or emotional behaviour are not follow up after their transition stage, letting them exposed to more difficulties related their own conditions.
- People with autism have high number of admissions due to mental health.
- Parents and caregivers show needs for support during assessment/diagnosis and after it to cope and management changes around autism.
- There have been an increase in autism in special schools, but these is associated to better assessments and/or changes in schools threshold.
- There is high number of epilepsy admissions related to autisms
- The number of people with autism in social care seems to be lower than expected for this population.

- There is no specific information about mortality or health risk for this population

Next Steps

- Follow up recording data from CAMHS services, Birmingham Community Hospital.
- Understand epilepsy admissions and association with Autism
- Understand outcomes in autism in SEN schools and the changes in this population.

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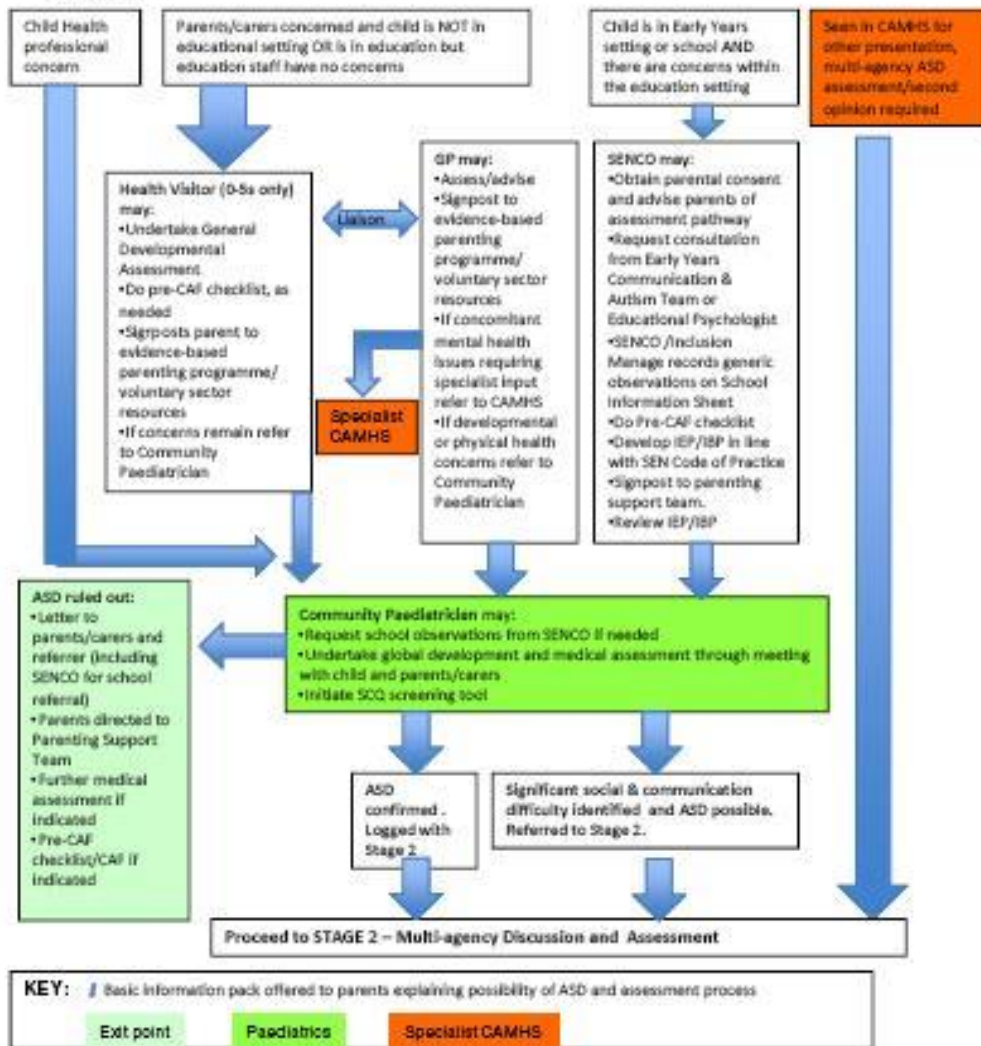
Appendix: CAMHS Proposal Pathway

Pan-Birmingham Integrated Care Pathway for Autistic Spectrum Disorders up to age 18 DRAFT 6 - 14-6-10 – PATHWAY CONFERENCE MODIFICATIONS

Promoting Early Identification
 •Ante-natal and post-natal identification where there is a family history of ASD leading to early identification of needs and initiation of support as necessary
 •ASD leaflet available for any parent/carer from multiple sources to help them recognise signs and to access advice and appropriate parenting education if necessary.

STAGE1: Initial screening and information gathering

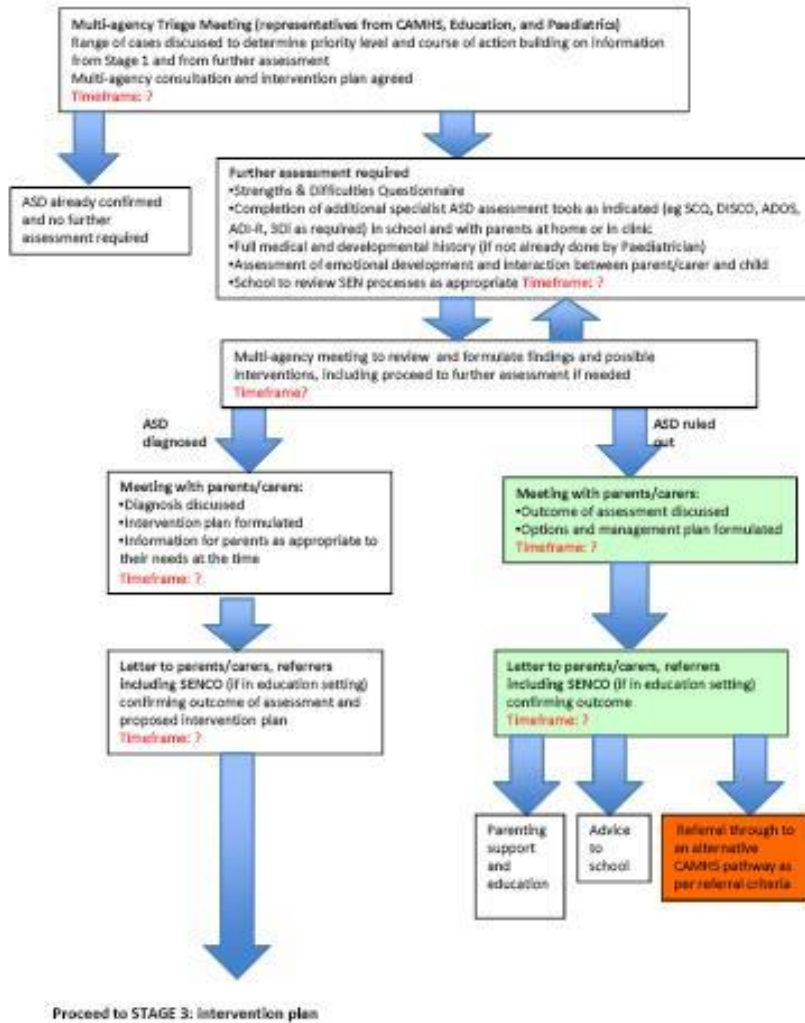
Aligned to: (a) CAF at appropriate level, (b) School Action SEN Code of Practice (c) Early Support Family Pack offered to under 5s



Stage 2: Multi-agency triage and assessment

(Undertaken in 3 teams across the city)

Aligned to (a) CAF level 3, (b) SEN Code of Practice, (c) Early Support Family Pack for under 5s offered



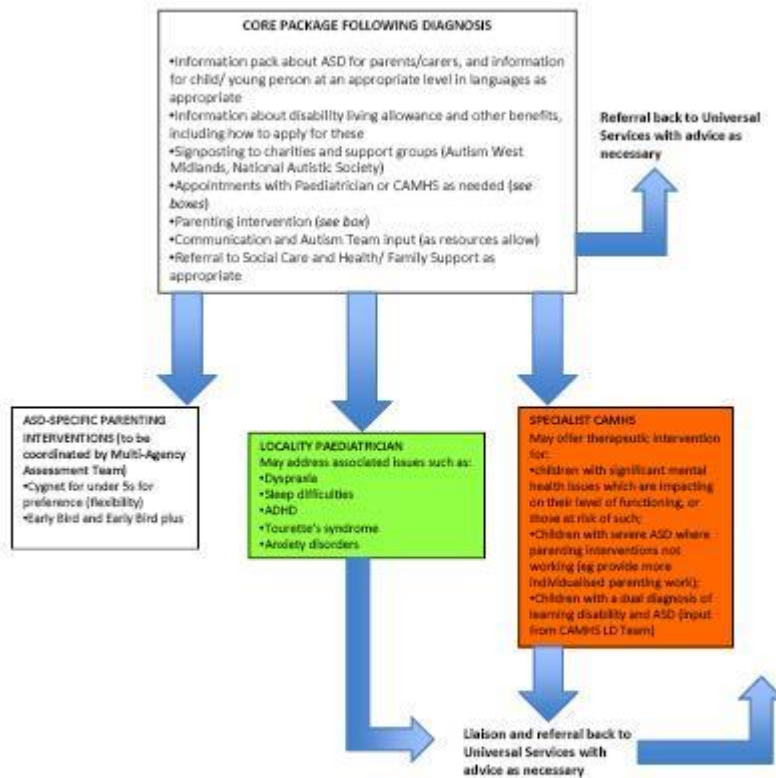
KEY: / Basic information pack offered to parents explaining possibility of ASD and assessment process

Exit point

Paediatrics

Specialist CAMHS

Stage 3: Intervention



KEY: / Back: information pack offered to parents explaining possibility of ASD and assessment process

Exit point Paediatrics Specialist CAMHS

Autism West Midlands

AWM Service	Details	Number of people from Birmingham (figures relate to people accessing our services between April 2011 and March 2012)
Residential Services	Across our 6 residential homes, number of people funded by Birmingham	26
Supported Living	We run a supported living service with 8 individual flats, but none of our residents are funded by Birmingham	0
Outreach		5
Family Services	This is the number of parents and carers from Birmingham supported through family outreach, Autism Awareness sessions, Family Days, support groups (Family outreach is where a family outreach worker goes into the family home and provides specific advice and guidance to families who are usually in crisis - under family outreach only one parent is contacted per household so the number of actual parents we support is most likely to be higher than this number)	82
Family Services	This is the number of children supported across all of our family support services.	114
Aspire	Innovation Fund/Advance Programme	8
Aspire	BEST Network NLDC programme	10
Aspire	Advance Work Choice Programme	9
Aspire	Future Possibilities	30
Aspire	Access to Work	8
Aspire	Student Support	1
Aspire	AS Support Group - Birmingham	61
	Total number of people receiving direct support (adults, children, parents, carers)	354
Family Services	Calls received from people in Birmingham by our Information Helpline	1656
Training	Approx number of people attending training courses in Birmingham	416
Training	Number of people attending seminars in Birmingham	63
	Total people receiving indirect support (information, advice, signposting, training):	2135
	Total number of people supported in Birmingham April 2011 - March 2012:	2489

Residential Support: 26 people from Birmingham

These adults live in our residential care homes and have access to support 24 hours a day. Our residential services vary in size from 4 residents to 19 residents. Some of the residents have greater support needs than others, this varies considerably. For example, some of our service users cannot speak and might require significant personal care as well as general support to carry out daily activities and go out into the community. Other service users can communicate very well and need very little personal care, and are able to go out into the community unattended.

Outreach: 5 people in Birmingham

These adults are supported in their own homes to live independently. Again, the support we deliver varies considerably. Some of these adults will need 24/7 care in their own home and will have significant personal and general support needs, and then others might only receive 4 hours a week of support from us to help them with a specific event or activity, for example helping them to feel confident travelling independently on public transport.

Support to children and families: 114 children and 82 parents/carers in Birmingham

Family outreach: This is where a family outreach worker goes into the family home and provides specific advice and guidance to families who are usually in crisis - under family outreach only one parent is contacted per household so the number of actual parents we support is most likely to be higher than this number.

Family Days: These are fun days for families and children. Training sessions and workshops are run for parents and carers, and activities are put on for children with autism and their siblings.

Support Groups: These are regular group sessions for parents/carers of children with autism. They meet up to provide peer support and share their experiences, as well as to ensure they have up-to-date knowledge of what is going on in their local area that could affect their children.

Appendix: Hospital Admissions and related conditions

Hospital Episode Statistics (HES) records information using ICD-10 diagnosis code. In this dataset information recorded about admissions for people with autism is small. This could be because of misdiagnosis/co-morbidity or coding problems. Thus, the recording of hospital admissions for people with autism across Birmingham is poor. This issue does not allow us to understand the use of secondary health services and the causes of admissions.

Despite, this limitation in this section we present admissions for some of causes that can be associated with autism. We should warning about drawing conclusions using these data.

ICD10

Epilepsy: G40, G41

Down's Syndrome: Q90

Disorders of psychological development: F80-89

Cerebral palsy: G80

Mental Health

Using 2009/10 Birmingham and Solihull Mental Health Foundation Trust (BSMHFT), there were 198 patients that have used services related to Disorders of psychological development (ICD-10, F80-89); from which 88% are from White Ethnic background.

Disorders of psychological development (F80-89)

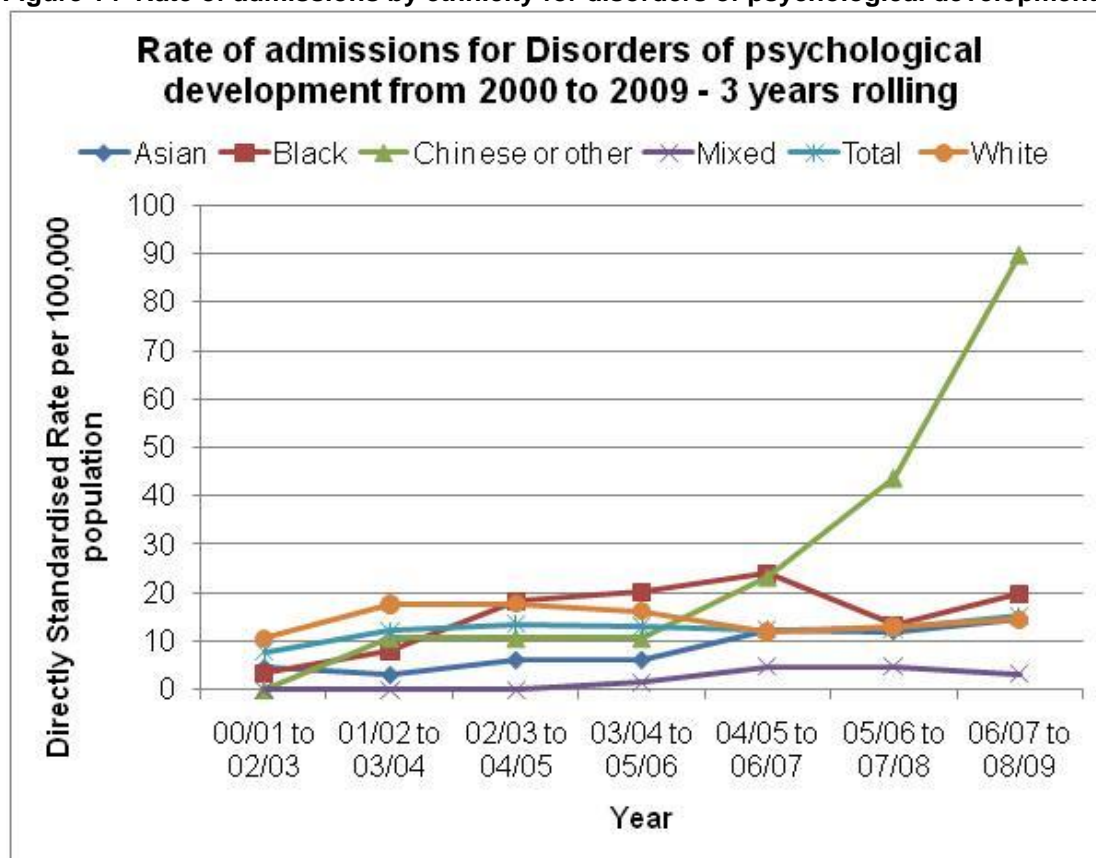
- **The data is too small to draw any conclusion**
- 1-19 age group has more number of admissions
- The rate per 100,000 population seems stable.

Table 28 ICD-10: F80-F89 Hospital Admissions, All ages

Year	Rate Per 100,000	LL	UL
00/01 to 02/03	9	7	11
01/02 to 03/04	17	15	20
02/03 to 04/05	21	18	24
03/04 to 05/06	22	19	25
04/05 to 06/07	18	15	20
05/06 to 07/08	15	13	18
06/07 to 08/09	17	15	20

Data source: HES

Figure 14 Rate of admissions by ethnicity for disorders of psychological development



Data source: HES

The spike shows for the Chinese and other population in Figure 14, might be due to data quality. However, the figure shows no difference between ethnicities, except mixed (lowest).

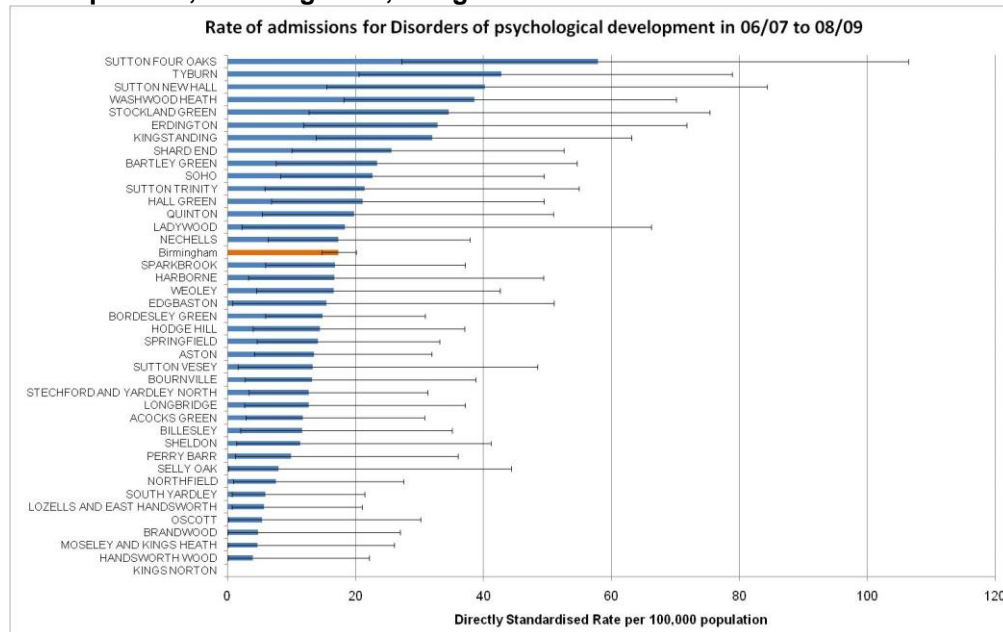
Table 29 Numbers of admissions for disorders of psychological development, three year rolling average

Age Group	Year 06/09	Year 05/08	Year 04/07	Year 03/06	Year 02/05	Year 01/04	Year 00/03
0	1	1	1	1	1	1	0
1-4	35	33	36	29	20	20	17
5-9	39	34	29	35	37	34	18
10-14	20	17	39	87	97	72	20
15-19	14	10	15	26	25	20	7
20-24	2	2	2	2	5	5	5
25-29	1	4	3	4	2	3	2
35-39	2	4	3	2	2	2	0
40-44	5	5	6	2	1	1	0
>45	18	13	10	9	6	3	4

Data Source: HES

Figure 15 shows that Sutton for Oaks and Tyburn, present the highest significant rate for admissions due to psychological development for 2006/09.

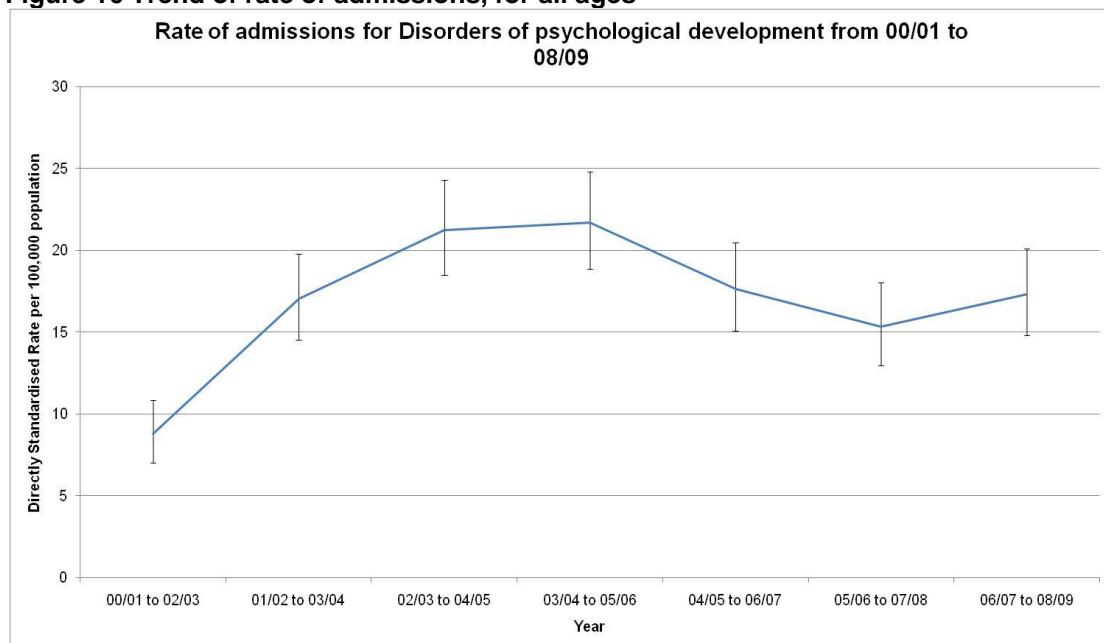
Figure 15 Admission rate by ward year 2006/09 for disorders of psychological development⁷⁶, first diagnosis, all ages



Data source: HES

Figure 16 shows the trends for admissions indicating an increase, however with a stabilising tendency in latest year.

Figure 16 Trend of rate of admissions, for all ages



Data source: HES

⁷⁶ Data is too small

Epilepsy

According to NHS Choices, around 456,000 people in the UK are affected by epilepsy. This means that about 1 in 130 people have epilepsy. Epilepsy can affect anyone at any age, finding shows (that HES data for 2009-10 supports NHS Information Centre) within the 0-4 years age group more which is more prone to attacks tends to a stay longer in hospital.

In Birmingham, areas such Soho and Shard End presented high significant number of admissions compare to Birmingham. The rate of admissions has been increasing in last past years, as well the national trends. Birmingham has 0.6% of prevalence in epilepsy compared to England 0.8% (2010/11).

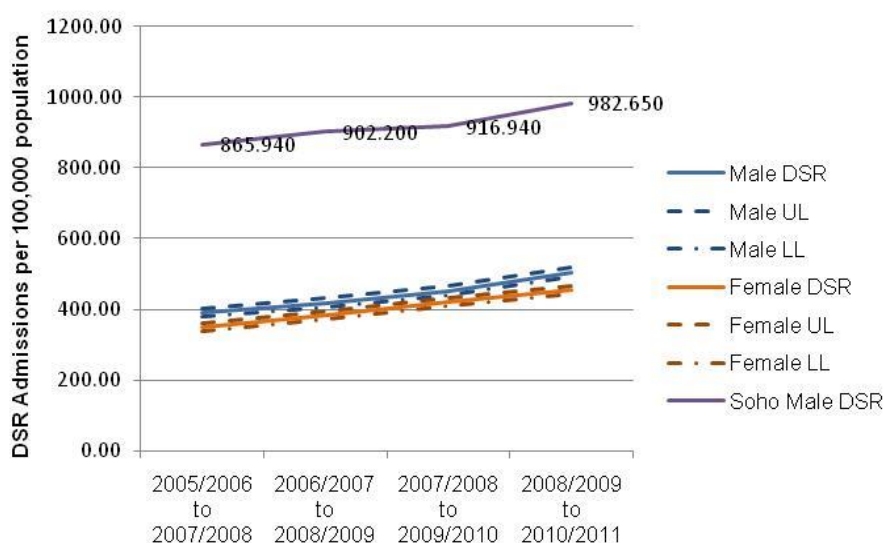
Table 30 Hospital admissions rate per 100,000 population for epilepsy, year 2008/2009 to 2010/2011, Birmingham

Age	Male			Female			Person			Significant highest DSR compare to Birmingham			
	DSR	LL	UL	DSR	LL	UL	DSR	LL	UL	Area	DSR	Area	DSR
<15	320	301	340	333	314	354	326	313	341	Ladywood	1005	Stechford and Yardley	777
15 to 24	205	187	224	285	265	307	246	232	260	Harborne	772	Brandwood	1138
>25	579	563	595	510	496	523	542	532	553	Lozells & East Handsworth	1193	Shard End	818
All ages	470	458	481	440	429	451	453	446	461	Soho	917	Shard End	731

Data Source: HES

Figure 17 shows the admissions for epilepsy and autism as one of both diagnoses appears in any position⁷⁷. Soho has the higher statistical significant male admission rate compare to Birmingham.

Figure 17 Hospital admissions for epilepsy and autism



Data Source: HES

⁷⁷HES has 20 diagnosis field.

Down's Syndrome

“Down's syndrome is uncommon in the UK. For example, from 2007 to 2008, 1,843 cases of Down's syndrome were diagnosed during pregnancy, and 743 babies were born with the condition. This means that about 1 in every 1,000 live births is affected by Down's syndrome.

Down's syndrome affects all ethnic groups equally. Boys are slightly more likely (around 15%) to be born with Down's syndrome than girls.

The cause or causes of Down's syndrome are unclear, but the single biggest risk factor for the condition seems to be the age at which a woman gives birth. The older a woman is when she has a baby, the higher the risk of her baby having Down's syndrome. The greatest risk (1 in 30) is associated with women who are 45 years of age or over.” (NHS Choice)

Figure 18 shows the admission rate trends for people with Down's syndrome, this admissions are not necessary related to other co-morbidities that this people could present. It is noticed the highest admission rate for female in the area of Shard End.

Figure 18 Admissions rate for people with recorded Down 's syndrome

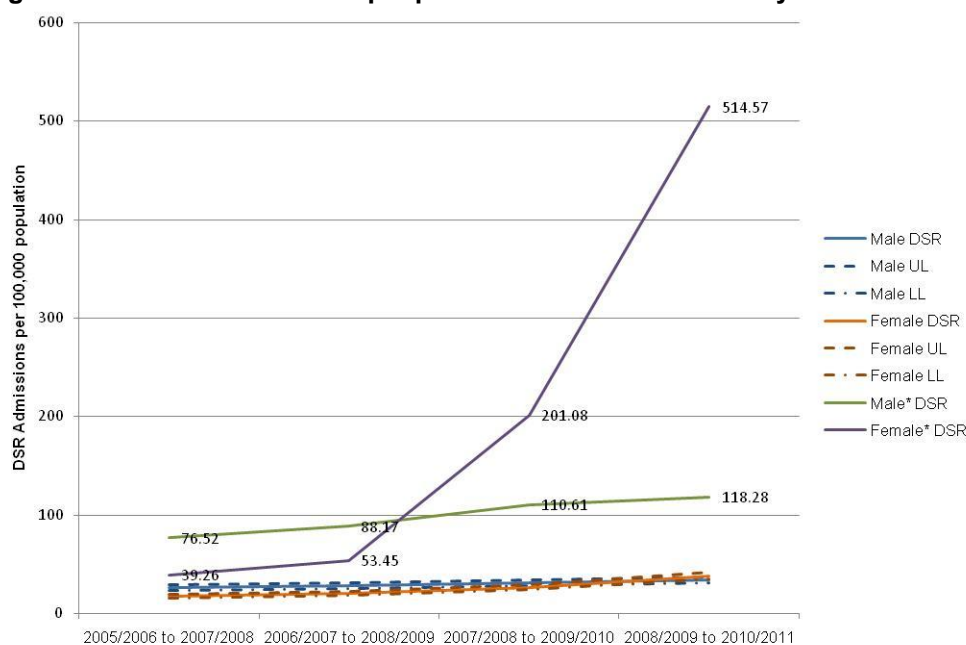


Table 31 Areas with significant highest admissions compare to Birmingham, for those people that Down's syndrome is recorded.

Year	Male*		Female*	
	Area	DSR	Area	DSR
2005/06 to 2007/08	Perry Barr	76.52	Shard End	39.26
2006/07 to 2008/09	Kingstanding	88.17	Erdington	53.45
2007/08 to 2009/10	Kingstanding	110.61	Shard End	201.08
2008/09 to 2010/11	Kingstanding	118.28	Shard End	514.57

Data source: HES

Admissions for Cerebral palsy

“Cerebral palsy is a general term used by doctors to refer to a set of neurological conditions that affect a child's movement and co-ordination. Neurological conditions affect the brain and nervous system.

Cerebral palsy is caused by damage to the brain, which normally occurs before, during or soon after birth. Known possible causes of cerebral palsy include:

- Infection in early pregnancy.
- A difficult or premature birth.
- Bleeding in the baby's brain.
- Abnormal brain development in the baby.

Children with cerebral palsy often have other related conditions or problems, including:

- epilepsy
- learning difficulties
- incontinence
- visual impairment
- hearing impairment
- difficulties speaking or understanding other people speak
- delayed growth
- curved spine (scoliosis)
- drooling.

It is estimated that 1 in every 400 children in the UK is affected by cerebral palsy. Approximately 1,800 babies are diagnosed with the condition each year.” (NHS Choice)

Figure 19 shows the trends for admissions rate in which cerebral palsy is recorded. These admissions could be related for any other conditions. There are areas in Birmingham that the admission rate is quite significant as shown in Table 32

Figure 19 Admission rate in which cerebral palsy is recorded

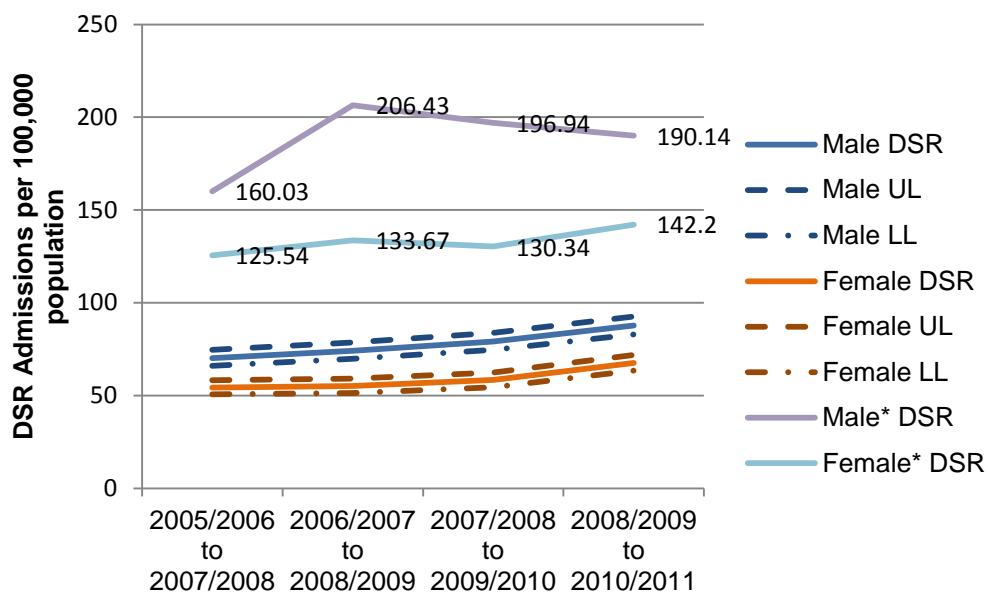


Table 32 Highest and significant admissions rate for cerebral palsy in areas of Birmingham

Year	Male*		Female*	
	Area	DSR	Area	DSR
2005/06 to 2007/08	Erdington	160.03	Ladywood	125.54
2006/07 to 2008/09	Erdington	206.43	Kingstanding	133.67
2007/08 to 2009/10	Erdington	196.94	Kingstanding	130.34
2008/09 to 2010/11	Harborne	190.14	Brandwood	142.2

Appendix: Risk and Population

Mortality by Accidents

Studies elsewhere have shown that people with Autism are a higher risk of mortality (26) (27), due to other co morbidities such as epilepsy or suffer from accidents. Table 33 and Table 34 show that Birmingham has a higher rate (double) than West Midlands for children and young people under 15s.

Table 33 Mortality due to accidents for Children under 15 year of age, 2008/10

Rate per 100,000	Male	Female	Person
Birmingham (2007/09)	4.5	2.80	3.3
West Midlands	2.19	1.39	1.80
England	2.26	1.55	1.91

Data source: NCHOD

Table 34 Mortality rate due to accidents for people age less than 75, 2008/10

Rate per 100,000	Male	Female	Person
Birmingham	17.36	5.85	11.54
West Midlands	16.22	5.59	10.89
England	15.80	5.67	10.74

Data source: NCHOD

Parental age and obstetric conditions

Evidence suggests that parental age and obstetric conditions are associated with an increased risk of autism and autism spectrum disorders is accumulating(1): advanced maternal and paternal age, prenatal, perinatal, and postnatal infections, exposure to toxic agents, obstetric conditions like low birth weight, decreased gestation period and hypoxia during child birth are the risk factors of Autism. Data quality for recording the status of the birth and mother conditions is still an issue. Table 35 shows the official numbers of births register for Birmingham population.

Table 35 Birmingham's register births

	2007	2008	2009	2010
Live Births	16,975	17,311	17,329	17,240
Still Births	123	121	120	119
Total Births	17,098	17,432	17,449	17,359

Data source: ONS

Low Birth Weight (LBW)

As women get older, pregnancy becomes a riskier enterprise. Advanced maternal age is linked to a number of developmental disorders in children, such as Down's syndrome. Birmingham has in average 10 children born each year with Down's syndrome⁷⁸. Another, study has confirmed that older mothers are more likely to give birth to a child with autism⁷⁹ (1).

In average 19% low birth rate, are from mother age 35 and over; and in average 7% of all the births have low birth weight (less than 2.5kg) (see Table 36).

Table 36 Numbers of births by mother age and baby weight

Period	Mothers 35+ age	Mothers 35 + with LBW	All Mother with LBW	% low birth weight	Total births
2007/08	2,443	147	755	4.8	15,756
2008/09	2,618	218	1156	7.1	16,240
2009/10	2,529	236	1235	8.1	15,246
2010/11	2,491	208	1121	7.7	14,632

Data source: Hospital Episode Statistics

In the latest comparison (2010) Birmingham percentage was 8.7% which is worst than England average 7.3% (NCHOD).

Gestation Period

Table 37 shows the number of babies born with gestation period, and average 5 % of live births (607 babies) per year, for those whose status is recorded. It should notice that for year 2010/11 28% of records do not have gestation period recorded.

⁷⁸It should be noticed that HES data quality is poor for recording gestation, mother age or birth conditions, etc. In 2008/09, 50% of births recorded has unknown in some of these data fields and by 2010/11, 28% of births have not recorded data in some of these data-fields. Also home births are not recorded in HES.

⁷⁹<http://www.scientificamerican.com/article.cfm?id=autism-maternal-age>

Table 37 Gestation period and mother age for delivered in Hospital for live birth between 2007 - 2011

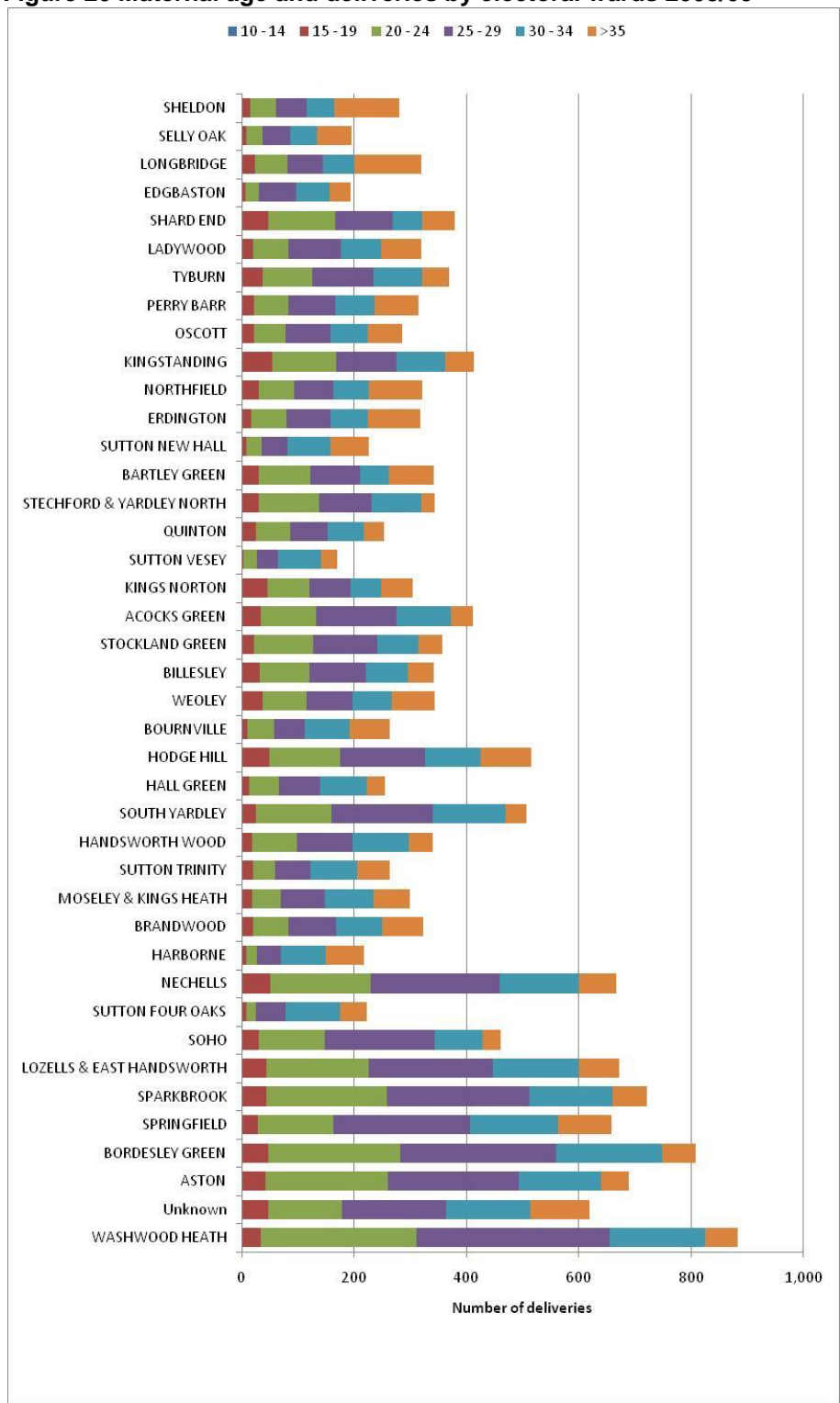
Gestation period and mother age	2007/08		2008/09		2009/10		2010/11	
< 36 weeks and mother age >35	103		152		145		179	
< 36 weeks mother age < 35	339		499		591		419	
		% of total live births		% of total live births		% of total live births		% of total live births
Total < 36 weeks gestation period	442	5%	639	5%	736	5%	598	4%
Total live births		8,454		13,956		14,608		14,719
Total births		15,756		16,240		15,246		14,632

Data source: Hospital Episode Statistics

Figure 20 and Figure 21 show the maternal ages and number of delivery by electoral wards. Wards such as Longbridge and Sheldon have the highest number of delivery for mother aged 35 and over, 118 and 116 babies for 2008/09⁸⁰, respectively. Aston has the highest number 13/213 delivery from mother age >35 and babies with low birth weight.

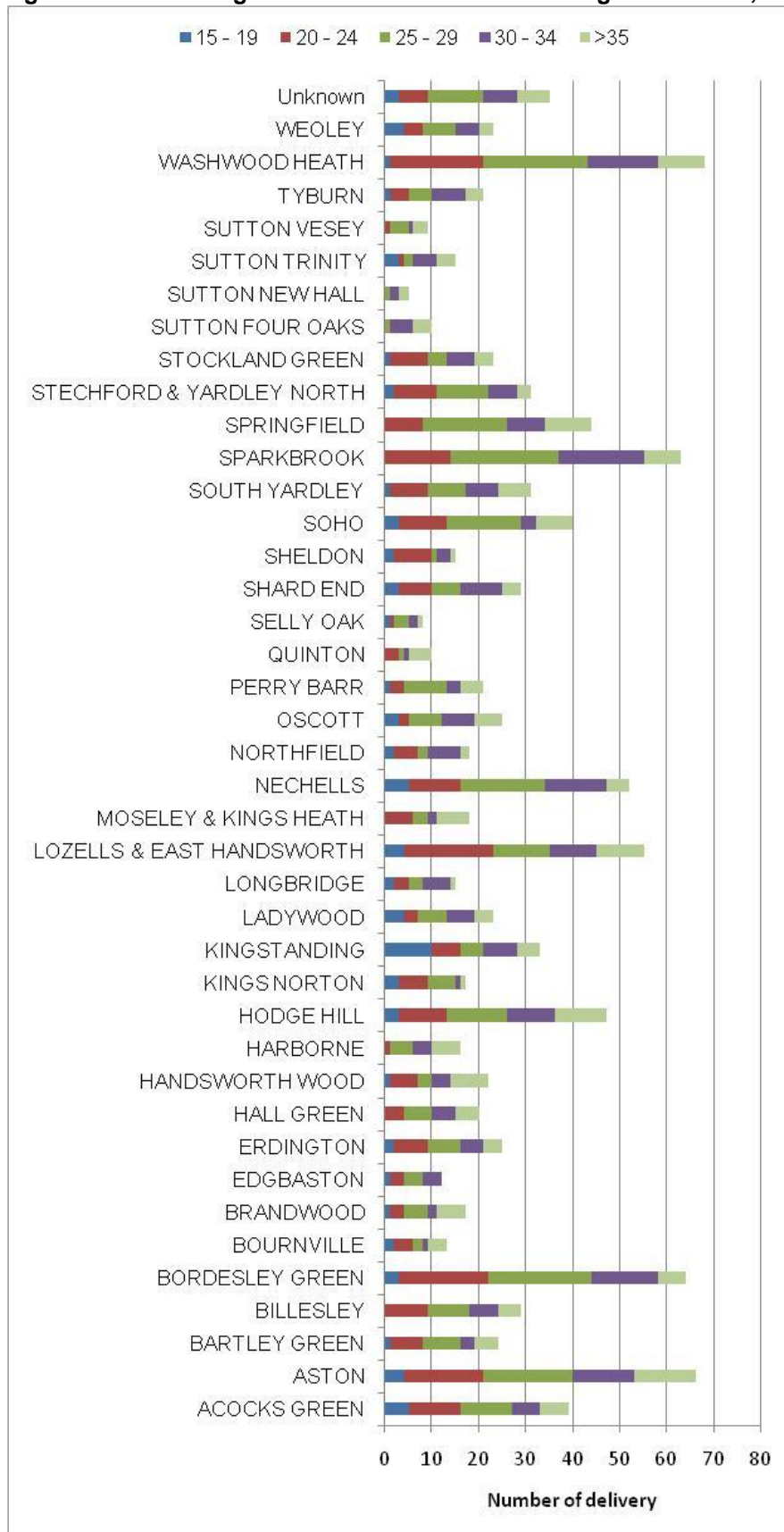
⁸⁰2008/09 and 2009/10 have better recording 0.7% only for unknown conditions.

Figure 20 Maternal age and deliveries by electoral wards 2008/09



Data source: HES

Figure 21 Maternal ages and number of low birth weight deliveries, 2008/09



Data source: HES

Birmingham Autism Needs⁸¹

It is a website designed to engage population with autism and services provider to enable them to understand the needs of this population hence provide better tailored services.

<http://bhamautismneedscom.ning.com/page/services-in-birmingham>

<http://maps.google.co.uk/maps/ms?msa=0&msid=210718691280344774678.0004b13f2d0e99a39fbe0&hl=en&ie=UTF8&t=m&vpsrc=0&ll=52.545043,-1.914368&spn=0.146151,0.291824&z=11&iwloc=0004b13f2e4f7f6acb52a&source=embed>

Summary: Engagement Survey

General public awareness is generally poor (35.7%) and very poor (21.4%). People may be more empathetic and awareness of Aspergers may be better than autism, but even then awareness is not the same as understanding how to deal with patients. Some national publicity drive may address the issue, to one respondent.

Awareness among health and social care staff is similarly poor (33.9%) or very poor (13.4%). Teachers are reported to have no understanding of ASD; other professionals would benefit from more training. Some are even dismissive about what is perceived as 'normal' behaviour. An employer has discriminated against a parent's autistic son.

Specialist staff are rated poor (32.1%) or very poor (13.4%) for awareness. GPs were no help at all and one was patronising and dismissive. No two people tell you the same thing. A speech therapist was good but expensive and too far away. A current provider (Trident) was reported for a very poor level of awareness.

One in five said that diagnosis was adequate (20.3%) for Birmingham service users; the same user said it was very poor. "Diagnosis can take years, also it is now put under the heading of ASD rather than the specific type."

Support after diagnosis was poor (25.7%) or very poor (23.0%) for Birmingham service users. Commenter's said:

"More support from professionals afterwards because at the moment the lack of support is terrible."

"Support after diagnosis is patchy at best, and you have to know where to go."

Assessment was adequate for 28.0% of Birmingham service users. But one respondent stated: "The assessment process is difficult - getting school/GP/nurse involved - many families don't understand the process or how to do it."

Support after assessment can be as patchy as support after diagnosis. One in four said such service was poor (24.3%); a similar proportion rated such support was 23.0%.

"After a person is assessed it takes too long to get the person the services they need to help them and their carer to access services in their area or any other place."

⁸¹ Author: Rob Benson, NHS Birmingham and Solihull Communication and Engagement

One commenter said: "The support [my son] has from Oakfield House is fantastic. I cannot offer him as much as Oakfield House can." Oakfield House services were praised elsewhere in other comments.

Support for parents and carers is at best variable; 45.9% of Birmingham service users rate it as poor or very poor, which is proportionately more than for all respondents (38.4%). However more such service users rate it good than for others (13.5% to 8.9%). One respondent says: "There is some support for parents but like I said we need more practical support and it needs to be free or very cheap."

Feedback on transition is relatively absent; with more than half of all respondents either leaving out this question (31.3%) or stating it does not apply (30.4%). However in Birmingham very few people rate the service good or adequate (12.2%) as opposed to poor and very poor (32.5%).

Education support is rated adequate by 29.7% of Birmingham service user respondents, the most of any rating in this area. One respondent noted: "There are special schools, which are fantastic, but mainstream schools just cannot cope, they haven't the funds or trained staff".

Employment support also does not attract a huge amount of feedback. Of Birmingham service users, 54.1% either have missed the question or says it does not apply. However more than one in three rate such support poor or very poor (33.8%). Social services support is rated very poor by more than one in four of Birmingham service users (27.0%). This is significantly higher than for all respondents (21.4%). The comment "Social Services I wouldn't involve, they are child snatchers" may appear extreme but may be the prevalent perception among service users.

CAMHS support is rated adequate by a greater proportion of Birmingham service users (23.0%) than all respondents (17.9%). One commenter said: "CAMHS: My CBT was very helpful but my psychiatrist is quite frankly a waste of time." Another highlighted what may be a typical issue: "My daughter was given a diagnosis and then I was sent to CAMHS who said because she was ASD and did not have a mental health issue all I could do would be to go on there of course which I am now waiting for."

Feedback on other mental health services was relatively low, with over half of Birmingham users and all respondents leaving out the question (57.7% and 64.3% respectively). However 20 from 74 of Birmingham service users rated such services poor or very poor.

GP support for Birmingham service users is at two extremes. More than one in five (21.6%) rated such support adequate, much more than all respondents (16.1%). However the same ratio rated such support very poor. Comments included: "GP very supportive but held back by lack of adult support for people with Aspergers." "Support from the GP was nil," and "support from GP very poor when diagnosed."

Overall, support services are poor. As one respondent noted: "I believe that people on the spectrum are let down on every level and what they do get, you have to fight for"

General support for independent living is predominantly poor or very poor for all those who answered the question with a relevant answer (although those who did not represent 60.8% of Birmingham service users).

Housing and accommodation advice was similarly not relevant to many respondents, however over a third (33.8%) of Birmingham service users rated such advice poor or very poor. One person said: "I used to receive very good support when it was provided by Autism West Midlands... Since the Supporting People contract has changed the quality of my life has deteriorated."

Although more than one in ten said travel and transport was adequate for users of services in Birmingham (10.8%), 29.8% said that the support was poor and very poor.

Relationship and sexual advice was also rated poor or very poor. One provider respondent said that a client had [been] advised to have abortions and not given after support. Specifically by Autism West Midlands. Another said: "Advisors at aspire help a little with sexuality etc but could do with more advice."

One in five rated advocacy services in Birmingham good or adequate (20.3%), compared to 14.3% of all respondents.

Almost half of respondents said anxiety and stress support was poor (21.6%) or very poor (24.3%). 'Oh please - if only' said one respondent. A parent said: "I am the sole carer for my son and at times of anxiety and stress," and praised staff at Oakfield House.

More than four in ten rated support to avoid bullying or abuse as poor (17.6%) or very poor (23.0%). This appears true in schools. One respondent said: "Avoiding bullying/abuse is nigh on impossible. Protecting typical children in schools is difficult, vulnerable children are easy pickings to the bullies. Class sizes are too big for teachers to keep a good eye on things."

Support with criminal justice was poor or very poor for 18 respondents who were Birmingham service users. "A lot of people with autism end up in jail, wrongly judged to be criminals," said one. However one respondent said: "I got in trouble with police but they handled it very well once they knew." One person said the "Autism West Midlands attention card is helpful"

Overall there appears variability in service provision, some good, some bad, some non-existent.

"Services are available through various charities but again, these are often patchy due to funding I assume. Some services you can access if you live just over the border in Sandwell like short breaks and kids clubs but because Birmingham City Council doesn't fund them we don't have them."

As for other services, group support seemed a popular service that could help, as well as education, employment, financial, and behaviour management. Respite and parental support is called for. People with direct experience can be seen to be more welcomed.

"I have started a support group for adults on the autistic spectrum in Wolverhampton so we are now the ONLY support service for adults with Aspergers in Wolverhampton and we're doing a far better job than those paid to provide support." Many respondents were answering as parents, so 15.2% of surveys were answered by those they care for aged up to 15. After that, over one in seven (14.3%) were between 35 and 44.

Almost one in four of Birmingham service users (39.2%) were male, 33.8% were female. Two thirds were White British. Six from ten (58%) were straight, the rest preferring not to answer.

Thirteen of the fifteen Birmingham service user respondents that had come from outside the area had been here over three years. Only two had come more recently. Commenter's said that services in Birmingham were better than Croydon and Poland, but not London.

Terminology

*Special School Needs (SEN)*⁸²

Special Educational Needs (SEN) is a legal term. It describes the needs of a child who has a difficulty or disability which makes learning harder for them than for other children their age. Around one in five children has SEN at some point during their school years. Some children have SEN right through their time in school.

School Action (SA) 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.

School Action Plus (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 LEA's support services, the local Health Authority or from Social Services. For example, this may be advice from a Speech and Language Therapist (SaLT), an Occupational Therapist (OT) or Specialist Advisory Services dealing with Autism, Behavioural Needs etc. SA+ may also include one-to-one support and the involvement of an Educational Psychologist. As well as the use of external services, SA+ requires more detailed planning of interventions for children whose progress has been limited. A child's progress at SA+ stage should also be reviewed regularly (i.e. at least twice a year) and an IEP should also be written to assist the child.

A Statement is a document which sets out a child's SEN and any additional help that the child should receive. The aim of the Statement is to make sure that the child gets the right support to enable them to make progress in school. A Statement is normally made when all the educational provision required to meet a child's needs cannot reasonably be met by the resources within a child's school at School Action or School Action Plus (known as Early Years Action or Early Years Action Plus in Early Years Settings).

Most children with SEN should have their needs met within a mainstream school. Before a Statement will be considered, additional help may be provided to the child at School Action. If the child still does not seem to be making enough progress then the school may seek advice from external professionals at School Action Plus. If this additional help is still not enough then the child's school or parents can apply to the LEA for a Statutory Assessment of the child's SEN in order to try and obtain a Statement of SEN.

*QOF: Quality Outcome Framework*⁸³

QOF is a system for the performance management and payment of general practitioners (GPs) in the National Health Service (NHS) in England, Wales, Scotland and Northern Ireland.

In the 2004 contract the practice could accumulate up to 1050 'QOF points' (depending on level of achievement for each of the 146 indicators). The criteria are grouped into 4 domains: clinical, organisational, patient experience and additional services. The criteria are designed around best practice and have a number of points

⁸² Taken from http://www.bbc.co.uk/schools/parents/child_development/ and <http://www.specialeducationalneeds.co.uk/UsefulInformation/SEN-EducationInfo/SchoolAction.html>

⁸³ Wikipedia

allocated for achievement. At the end of the financial year the total number of points achieved by a surgery is collated by the QMAS or other system which then converts the points total into a payment amount for the surgery. The formula includes the number of patients and in particular the numbers diagnosed with certain common chronic illnesses; the clinical element awards points for achieving specified clinical "indicators".

A typical clinical indicator would be the proportion of patients with coronary heart disease who had cholesterol measured in the financial year, or the number of patients with depression who have answered a standard questionnaire on severity. Organisational indicators include such things as the availability of practice leaflets, and practice staff education.

Services Legend

1	Autism West Midlands - Edgbaston
2	Autism West Midlands - Marston Green
3	Calthorpe School
4	Priestly Smith Specialist School
5	Hallmoor School
6	Springfield House Special School
7	Woodsetton School
8	Victoria School & Specialist Arts College
9	Dame Ellen Pinsent Special School
10	Selly Oak Trust School
11	Uffculme Special School
12	Langley Primary School
13	Care First
14	Forward 4 Work
15	St Andrews Healthcare
16	Sutton Coldfield Autism Support Group
17	Birmingham Carers' Association
18	Access Central Innovation Centre
19	Access Central Brindley Place
20	Advice & Advocacy Service, Birmingham Community Children's Centre
21	Ardenleigh Forensic CAMHS
22	Ascot Lodge & Ascot Villa
23	ASpire
24	Autism Centre for Education and Research (ACER)
25	Autism Plus
26	Autistic Spectrum Parent/ Carer Support Group
27	BASC (Birmingham AS Social Club)
28	Baskerville School
29	Birmingham Centre for Arts Therapies
30	Birmingham City SEN parent Partnership Service
31	Birmingham Disability Resource Centre
32	Birmingham Disabled Children's Register and Information Service
33	Birmingham EarlyBird Team
34	Brambles Children Centre EDEN Stay 'n' Play
35	British Dietetic Association
36	Cheap Disability Aids Ltd
37	Child and Adolescent Psychiatric Service, Birmingham (CAMHS)
38	Contact a Family West Midlands
39	Diamonds in the Rough C.I.C
40	Elm Green School
41	Freshwinds
42	Harden Housing Association
43	Birmingham Social Inclusion Project

44	Keinan Care
45	Kids West Midlands
46	Lisieux Trust
47	Maxwell Gillott Solicitors
48	Melody
49	Moseley Court Care Services Ltd
50	National Portage Association
51	Oakfield House
52	Oscott Manor School
53	Parent Support Network for Autism (PSNA)
54	Parents on the Move
55	Parkview Clinic (CAMHS)
56	Parkview Language Unit, Regional Diagnostic Service
57	Patient Information Service
58	Pinetrees
59	Platinum Care Services
60	Queen Alexandra College
61	Rowangarth Day Centre
62	Selly Oak Trust School
63	Serenity Specialist Care
64	Sinclairs Solicitors
65	Sound It Out Community Music
66	South East Birmingham Autistic Spectrum Disorder Parents and Carer Support Group
67	Spectrum Support Group
68	The Autistic Play Project (TAPP)
69	The Pines School
70	The Poplars
71	Topcliffe Primary School
72	Wast Hills Specialist Autism Services
73	Yardley ASD Parent Support Group
74	Young Person Service - Asperger Syndrome Outreach Services