

Birmingham JSNA

Autism Spectrum: Key Findings

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Learning disability and Mental Health Joint Commissioning
Birmingham Autism Partnership Board
NHS Birmingham Public Health

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Remark

This report is based on the Birmingham JSNA: Autism, July 2011. For more details please refer to the Full Report.

DRAFT

Autism: in context

Autism is a neuro-developmental disorder characterised by social and language impairments and stereotyped, repetitive patterns of behaviour. There are often significant sensory differences too where individuals can be over or under sensitive to sensory stimuli (e.g. to sights, sounds, touch, taste) and 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 in that there is a slightly increased risk of having another child with autism, if the parents already have a child with autism. In addition, 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 have a 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). But 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 who do not have 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 keeping employment, in living independently and in accessing services and leisure activities in adulthood. There is a need for more research on what leads to good adult outcomes and on 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 knowledge and skills to the workplace or at university. Some of these adults may

¹ Caroline Institute for Developmental Disability, US.
<http://news.unchealthcare.org/news/2012/february/brain-imaging-differences-evident-at-6-months-in-infants-who-develop-autism>

realise they have autism, following a TV or newspaper article or their families or partners might come to that realisation. Thus, there is a need for services to offer diagnostic assessment services for this group and to give support following diagnosis, whether or not they 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 (1), of whom around 400,000 are adults (2), and that autism is three to four times more common in men than in women (3). 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 (1).

Furthermore, National Audit Office (NAO) (1) 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.

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 (4) and children and young people (5). The guidance focuses on need local pathways defined and multiagency groups as 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 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-existing disorders.

Marmot: Reducing health inequalities is a matter of fairness and social justice

Inequalities are a matter of life and death, of health and sickness, of well-being and misery. The fact that in England today people in different social circumstances experience avoidable differences in health, well-being and length of life is, quite simply, unfair. Creating a fairer society is fundamental to improving the health of the whole population and ensuring a fairer distribution of good health. This review emphasise the importance tackled inequalities across the life course and fundamentally looking six (6) broad policies:

- Given every child the best start in life.
- Enable all children, young people and adults to maximise their capabilities and have control over their lives.
- Create fair employment and good work for all.
- Ensure a healthy standard of living for all.
- Create and develop healthy and sustainable places and communities.
- Strengthen the role and impact of ill-health prevention.

The above six policies, frame the life course approach for health and wellbeing which focus on ensuring that at each stage in life there is enough understanding of the health and social outcomes that an individual is expecting to benefit from. This guarantee successful outcome, if factors that could contribute to better results are considered early enough to have an impact in the individual's life.

Give every child the best start in life

It is recognised that given the complexity of autism spectrum, the diagnosis could be deferred until later in life given the individual characteristics and co-existent morbidities. 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 and 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.

Evidence which 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 Autism²(28).

In Birmingham, 5%, on average, of live births (607 of babies) per year has a gestation period less than 36 weeks. On average, 19% of the low birth weight rate are from mothers aged 35 and over. 7% of all the births have low birth weight (less than 2.5kg) (2005-2011). The low birth weight rate in 2010 for all mothers in Birmingham was

²<http://www.scientificamerican.com/article.cfm?id=autism-maternal-age>

8.7%, poorer than the England average of 7.3%³. Moreover, smoking in pregnancy (at delivery) is a contributor for low birth weight; although Birmingham has shown some improvement compared to 2004/2005, and its average (11.47%) is better than England average (13.2%). There are variations across city with Birmingham East and North Primary Care Trust showing the higher average (14,8%) for 2011/12⁴.

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 delays⁵. In general, Birmingham population has a high rate of obesity 25.8%⁶. Maternal obesity prevalence is about 13.3 % compared to 12.6% in the West Midlands⁷.

The MRC Determinants of Adolescent well-being and Health (DASH) study (7) found that overweight was more prevalent among Black Caribbean and Black African girls, and obesity more prevalent among Black Caribbean girls. In Birmingham, Black Caribbean presents the highest obesity prevalence 32.7% compared to the rest of the population.

Using 1% prevalence; at birth it is expected that Birmingham would have 172 babies (2010, see table below) that could potentially develop autism. Baron-Cohen (8) suggested that prevalence of autism-spectrum could as high as 2%. At present, there are areas in Birmingham with more than 2% among school pupils. The percentage of children under five years old in Special School Needs (SEN) register is around 29% of the total of children under five in Birmingham, and approximately 1% (142) have ASD as primary or secondary need. That means around 1:3 children has a type of disability.

Table 1 Under five population and autism spectrum population estimation

	Births (2010)	0-4 age group (2010 estimation)	0-4 age group (2011 estimation)
Population - ONS	17,240	81,432	81,900
Autism 1% prevalence estimation⁸	172	814	819
Autism 2% prevalence estimation	344	1,629	1,638
SEN Under five population 2010	23,843	142 (1%) ASD	

Birmingham has a large number of births; however, we are not able to estimate how many of them develop autism spectrum, due to lack of follow up data.

³ Source: NHS The Information Centre, NCHOD

⁴ Birmingham East and North Primary Care 14.8% and NHS South Birmingham Primary Care Trust 14.2% in 2011/12.

⁵ <http://www.nhs.uk/news/2012/04/april/Pages/mothers-obesity-diabetes-autism-risk.aspx>

⁶ Health Survey for England, 2005

⁷ Body mass index (BMI) of more than 30. Source: West Midlands Perinatal Institute, Peer Dataset 2009/10.

⁸ This is estimated applying prevalence to mid-year population.

Children and Young People are referred to Children and Adolescents Mental Health Service (C AMHS) for diagnosis and assessment, and a local pathway is being created with the integration of the Common Assessment Framework (CAF).

Key Findings from the needs Assessment:

- Delays in diagnosis and assessment.
- General practitioners and staff are not well trained to identify, manage and support individuals with autism and their parents.
- There is a birth cohort, given the maternal/paternal risk, that could benefit from early diagnosis and assessment.
- Parents and caregivers need support for management changes in child development, and managing their own life.
- There is a cohort of 1% of children every year that, depending on the severity of the condition and their co-morbidities, will need support to cope with transition to nursery and schools. Most of those children will be male.
- Under 5 population with ASD is approximately 1%.
- Around 1:3 children aged less than 5 have a declared a disability.

Needs

- Access to appropriate diagnostic assessment and assessment of needs.
- Clear pathways with local multi-disciplinary teams to reflect good practice, and to follow the recent NICE guidance, with well interconnected agencies
- Mechanisms that allow flexibility and follow up of individuals that are diagnosed with autism.
- Support during and after diagnosis to caregivers and parents.
- Trained staff in services such as Nurseries which offer support to children with autism spectrum
- Early identification and support for children and families.
- Better inter-agency data recording.

Enable all children, young people and adults to maximise their capabilities and have control over their lives

People with autism spectrum can experience a range of co-morbidities that limit how they interact with their environment and communicate effectively with peers.

There is a known population of children and adults with ASD within Birmingham services. However, there is a lack of data in terms of understanding what difference those services do in their lives and how they enable them to live independently.

Findings from the needs Assessment:

Currently, in Birmingham, knowledge about the adult population with autism is poor and evidence about their needs is less than satisfactory. Table 1 gives details of the population that is known across services in Birmingham, and the difference between the expected population (at 1% prevalence rate) and those that receive services.

The difference between the expected autism population 2,278 and those known to services 2,343 is 65 for the age group 0-15. This indicates that this population is likely to be known to services. However, not all primary care data is available and duplications have not been taken into account. But also, this could indicate that the prevalence is higher than 1%. The table below summarises the population across services and the gap; the adult population has the bigger unknown population with ASD.

Table 2 Summary of children and adults diagnosed with autism across services in Birmingham

Age	0-15	5-15	16+
ONS General population 2010	227,763	146,331	809,115
Autism 1% prevalence estimation ⁹	2,278	1,463	8,091
Autism 2% prevalence estimation	4,555	2,927	16,182
Primary Care (tHOB)	134		148
SEN register children with autism 2011		1,959 ¹⁰	
Communication and Autism Team 2011		250 ¹¹	
Transition - Connexions 2011			133
Higher education			10
Adult social services register 2010/11 autism			267
Adults with the Autism Attention card Autism West Midlands Up May 2012			1,350
Gap between expected 1% and know to services ¹²	-2,144	+746	-6,183

The number of children enrolled in Special Education Needs School has been increasing. By 2005 the autism population in SEN schools was 1,056 (7.9% of the register SEN pupils) compared to 1,961 (11, 8% of the register SEN pupils) in 2011.

The number of children with autism at school year 1 has been increasing; looking at the number of births in 2000, and calculating the expected number of children with ASD, 55% of those estimated children with ASD by 2005 they appear register at school year 1 with ASD; percentage that is lower compared to 79% in 2011. This means that in 2011 of 163 expected children with autism, 128 have been registered

⁹ This is estimated applying prevalence to 2010 mid-year population. It differs from PANSI estimation in the Population Charter.

¹⁰ Gyles Glover et.al estimated 898.7 (898.3 to 899.1) number of pupils(30)

¹¹ Age band has not been clarified for this group, assumption majority under 16 years old

¹² It is expected more ASD diagnosis after 3rd birthday.

with ASD in SEN school¹³ at year 1. This means that more and more young children are being diagnosed before and around their 5th birthday. Birmingham prevalence of pupils with autism (SEN) is 26.2% higher than England 19.6% average.

The prevalence of autism is now estimated to be 1%; however there is research that shows that this prevalence could reach 2% (9). In Birmingham, there are areas that have prevalence of more than 2%. Using SEN pupils autism prevalence, electoral wards such as Northfield, Longbridge, Bartley Green, Selly Oak, Shard End, Stechford and Yardley North, and Sheldon are areas with more than 2% (see Figure 1).

Local evidence shows that the current prevalence in schools for children and young people with autism ranges from 0.9% to 2.9%, with an average of 1.5% of the school age population.

The adult population of Birmingham (i.e. 16 years old and over) is estimated to be about 809,000 (2010). The estimated ASD prevalence is 1%, this means 8,091 adults with autism living in Birmingham. There is a gap between people with ASD known to services and the estimated population with ASD, 76% of the estimated adult population with ASD is not known to services.

Not all adults with autism will require a service, because this depends on the severity of their condition; however, many adults will need a type of support, including those with high IQs. It is thought 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 is thought to require help from social services is entitled to be assessed¹⁴. Currently in Birmingham data shows that there are a total of just 267 adults with autism receiving some type of social services.

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

The Communication and Autism Team (CAT) provides assessment and services for pupils in mainstream schools when schools require some help and support in dealing with pupils with autism. 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 prevalence¹⁵ or relation to better awareness or services on offer. This suggests a delay in diagnosis in the young population.

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 person¹⁶. Smith et.al. (10) have 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. The job of caring for someone with autism can act as a powerful barrier to life and employment options for caregivers. It is a situation that has led to mental health problems in caregivers (11).

¹³ This is an estimation assuming only 1% of the births with adjusted mortality develop ASD. Migration has not been considered.

¹⁴ A person eligible to be granted a service needs to meet minimum criteria

¹⁵ There is not a routine assessment in mainstream schools, and the population have been done well defined to assume increase of prevalence

¹⁶ Conversations with parents from the transition group, Autism partnership Birmingham

There are a good number of organisations that work with people with autism spectrum but it was not possible to assess how good these organisations serve this specific population. Autism West Midlands has a good understanding of their population and respondents of the engagement survey, focus group have been happy with this organisation.

There is no local evidence available to discuss or infer about healthy living. Locally, there are providers such as Dimensions in partnership with Cineworld Cinema bringing monthly Autism Friendly Screening.

Needs

- Access to appropriate diagnosis and assessment
- Clear pathways in which local multi-disciplinary teams are involved and reflect good practice, following the recent NICE guidance
- Develop mechanisms that allow flexibility and follow up of individuals that are diagnosed with autism.
- Support during and after diagnosis to caregivers and parents.
- Access to good health care and advice.
- Develop 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.
- Support for independent and healthy living, including leisure activities.
- Access to well-trained support staff and “befrienders”.
- Better data recording.

Create fair employment and good work for all

Nationally, 85% of adults with autism are classified as unable to work or unemployed¹⁷.

Findings

There is not enough data available in Birmingham on people with Autism in full employment or receiving incapacity benefits¹⁸.

It is estimated that at least 2,572 people with autism are unemployed, compared to the unemployed population of Birmingham 121,960¹⁹ (18%); this represents 2% of Birmingham unemployed.

In the transition stage, the population 16-19 age group continue in education but there is no information indicating whether they gain employment after finishing school.

Autism West Midlands²⁰ 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 have had jobs in the past but have lost them, due to difficulties arising from their autism. There are many more adults in Birmingham needing this support than this service can provide. 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 unemployed because their autism presents difficulties at every stage of the employment process.

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 form. Unless we are advised of a clear diagnosis of autism it is safe to say that most clients would categorise themselves as either having a learning disability/difficulty or mental health problem.

There is a similar picture amongst third sector providers. Having liaised with BITA Pathways, Midland MENCAP and the Disability Resource Centre, who also provide employment support services in Birmingham, the number of referrals identified are very low²¹.

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

Based on response from focus groups and engagement survey, people with autism expressed their needs for:

- Friendly work environments which share an understanding of autism and the associated limitations.
- Get equal job opportunity and meaningful task during employment.

¹⁷ The National Autistic Society, <http://www.autism.org.uk/employment>

¹⁸ There are 38,730 people receiving incapacity benefits in Birmingham, DWP May 2011.

¹⁹ Source BCC/ONS/NOMIS, November 2011 worklessness

²⁰ Correspondence from Autism West Midlands

²¹ Judy Thomas, Birmingham City Council- Work and Employment Officer

Needs

- Support to access and maintain employment and/or continuation to further or higher education.
- Increase awareness for employers about the difficulties facing this population and the strengths they can bring to the job.
- Understand the barriers to employment and what could be done to accommodate people with autism and their needs.
- Education about autism and its diagnosis for the general public and potential employers.
- Identify those that are unemployed and offer appropriate support.

The NHS should better recognise the signs and symptoms of autism in adults to improve their quality of life and employment opportunities, advises NICE (4).

NICE advises that every adult with autism who does not have a learning disability or who has a mild one should be offered an individualised support programme if they are having difficulty obtaining or maintaining employment. This programme should include:

- Help with writing CVs and job applications and preparing for interviews
- Training for the identified work role and work-related behaviours
- Carefully matching the person with autism with the job
- Advice to employers about making reasonable adjustments to the workplace. Continuing support for the person after they start work
- Support for the employer before and after the person starts work, including autism awareness training.

Ensure a healthy standard of living for all

A proportion of people with autism can work and can engage with a work routine if they are supported in the work place. In Birmingham, we do not know with exactitude how many are in employment and enjoying a good standard of living. Additionally, there is no evidence about their family conditions.

A result from a survey²² indicates that 16 of 17 people with autism have a career, in Birmingham.

Table 3 Population known to transition services: Connexions

Connexions known population	In employment	Education and Training	NEET	Other	Total
Autism Young People 2009/10	2	76	7	5	90
Autism Young People 20010/11	1	123	4	5	133

²² Birmingham Adults and Community, Autism Commissioning, 300 questionnaires to services provider were sent and 17 were returned.

By 2009/10, 15% of the population supported by CONNEXIONS had an ASD statement, in contrast with 10% at year 11 in 2009 in SEN schools.

Table 4 Expected numbers of pupils with autism going through further and higher education

Pupils leaving school 2011	Pupils expected going to HE
376	188

According to the 2010/11 HESA²³ Student Records, the number of students domiciled from Birmingham declared as having autism was 10. This is a huge difference compared to 188 expected pupils (see Table 4).

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.

However, regardless of the inaccuracy of the data it is likely that people with autism have less chance to succeed in getting into higher education. Hence their chances of future employment opportunities and better standard of living are also reduced.

Needs

- Understand standard of living of people with autism and barriers
- Increase awareness about **statutory benefits**
- Increase awareness about personal development and opportunities to improve standard of living
- Better data recording to enable understanding about autism population and their living standard.

Create and develop healthy and sustainable places and communities

Birmingham has been re-inventing itself and implementing a regeneration plan. The population is growing fast with a 9% increase between 2011 and 2001. The latest estimated population is 1,073,000.

In the latest National Audit Office (NAO)'s survey (1) shows that 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.

There has been improvement in council housing and increased the number of council homes that met - the Government's Decent Homes standard. Currently, 99.1 percent

²³Source: HESA Student Record

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HESA cannot accept responsibility for any conclusions or inferences derived from the data by third parties.

of council house met the standard -. There are 26,529 people on the waiting list at March 2011 (12), but at the moment of writing this report statistics about clients with autism and disabilities were no available. The latest Private Sector Stock conditions (2010)²⁴ found:

- 37.4% of private homes in Birmingham fail the decent homes standard (36% nationally). This equates to 117,580 homes.
- Decency rates vary by tenure. 41.6% of privately rented properties are non-decent compared with 36.7% of owner-occupied dwellings.
- There are 41,690 vulnerable households living in a non-decent home. Vulnerability is defined in terms of households in receipt of certain benefits and/or tax credits.
- Lower income households are more likely to be living in a non-decent home.

From the provider survey, 17 people with autism 12 (70%) live in rented accommodation, one in residential care, and four in their parents' homes - all with help of a caregiver²⁵. 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.

, 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. This difficulty have been reported by local focus group with parents and people with autism, and by autism engagement survey²⁶.

There are many service providers (third sector) that supply training, counselling, employment advise, etc. for people with Autism and for other agencies that work with people with autism . However, many of these services are not in areas of higher prevalence of Autism²⁷.

Be-active²⁸ is being a successful intervention in term of promoting physical activity in Birmingham but there is no evidence that this intervention is taken care or considering specific issues that people with Autism could have in terms of physical activity needs.

There exist and Autism Identification Card, to help people with Autism and others to recognise to engage properly, currently 1,350 cards have been issue. Report from services user said that the card have helped them make people aware of their condition and the card have been well accepted.

Table 5 Social care by service component 2010/11

Service component	Age 18 - 64	Age 65 plus	Total	%
Home/day care	71	20	91	34%
Accommodation	32	6	38	14%
Direct Payments	22	2	24	9%

²⁴ Housing Department, Birmingham City Council

²⁵ The response rate of this survey was poor 12 of 300.

²⁶ 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.

²⁷ SEN autism prevalence

²⁸ <http://www.birmingham.gov.uk/beactive>

Professional Support	87	1	88	33%
Other	16	10	26	10%
Total	228	39	267	100%

Data source: Birmingham City Council, Continuous Improvement Team

Table 5 shows services that are provided to adults with autism spectrum by Birmingham City Council Social Services. This shows a gap between known to services (267) and expected adult with autism (8,091). Some of the factors contributing to this gap are the assessment threshold based on Fair Access to Care Services (FACS) and service available, lack of follow up of individuals that are known to Children and Young People services.

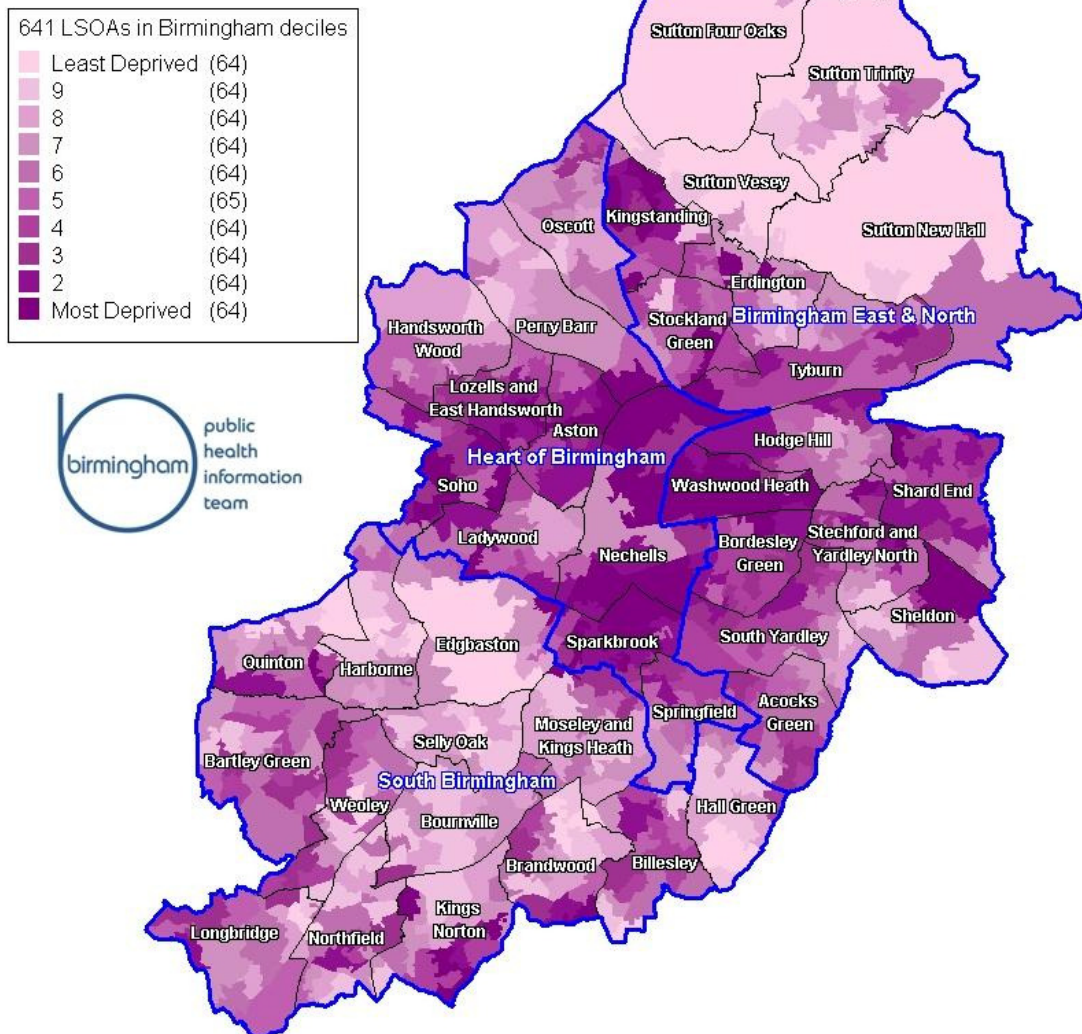
Based on the response from the ASD engagement survey more than 76% (16/21 people) of people rated as poor the support from housing services and living independently. More than 50% of people living in Birmingham responding to the autism engagement survey²⁹ rate services they have received as poor.

There are Electoral Wards in Birmingham that present higher autism prevalence, according with the SEN school census 2011. These wards and their index of multiple deprivation are Northfield (29.02), Longbridge (30.35), Bartley Green (40.44), Selly Oak (18.16), Shard End (58.50), Stechford and Yardley North (42.51) and Sheldon (35.07). The local Birmingham 2010 index of multiple deprivation (IMD) is 37.54. There is not link between deprivation and autism prevalence, however, but living in areas of high deprivation could hide specific needs of the population. Shard End, Stechford and Yardley North are areas with high IMD compared to Birmingham. The map below shows the IMD score in the area of Birmingham.

²⁹ 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.

Figure 2 Birmingham's deprivation index

Deprivation - Local View IMD 2010



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Needs

- Support for daily living.
- Create environments that are “Autism friendly”
- Understand housing issues across the Autism population
- Understand access to leisure activities and autism population

Strengthen the role and impact of ill-health prevention

It is known that people with disability and especially those with severe disability are likely to be at risk of not getting the right and timely services for reasons such as the service does not provide the suitable environment to accommodate their disability, or their own understanding of their conditions. Ensuring that people have opportunity to live a healthy life is an importance matter for the Public Health Framework (13). At local level, evidence of the health of people with autism is not well recorded. Some of the findings are as follows:

- There is no integrated/multidisciplinary diagnostic pathway in the City and there is a lack of evidence to estimate the true total population requiring health services³⁰.
- At national level, in the Primary Care setting, there is a lack of services/expertise to help in the diagnosis of autism in adults. This situation 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 cases). Children are often seen at Child Development Centres by teams which are specialised in autism. Some children and young people who develop mental health difficulties may also be referred to the CAMHS team for support.
- 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.
 - o Support is required after diagnosis and this is only the start. What is then needed 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. They can often only signpost but not provide the level of support that is required.
- 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 their 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. With the policy of inclusion, the majority of children with autism attend mainstream schools, many of whom are supported by the Communication and Autism Team (CAT)
- Mental health problems were the major reason for admission in hospital and the literature shows that these can often be prevented. There were about

³⁰ Even though commissioning is investing in the development of local pathway for children and adults, currently.

1,450 hospital admissions related to people with autism in the last five years, and mental health problems accounted for 20% of the admissions.

- Epilepsy hospital admission for people with autism is likely to be higher than recorded – given 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.
- Some of the most wanted services are group support, 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, Hospital admission statistics show that the most common admission in hospital for people with autism in Birmingham are for mental health problems, poisoning, and respiratory conditions.
- There is no local evidence about the access to health checks for people with autism.
- There is no local evidence about mortality and difference in life expectancy for this population.
- Given the provider survey, smoking has similar prevalence as Birmingham general population (25%) but obesity is lower-(26.20% for 2006/08 for Birmingham³¹).

Needs

- Promotion of health checks among people with autism.
- Awareness of the risk of obesity/alcohol/smoking among people with autism.
- Understand co-morbidities such as mental health and epilepsy and the impact in people with autism.
- Better understanding of the needs of people with autism in social care and the difference of male/female.
- Create integrated pathway, to improve diagnosis and referrals.
- Improve data collection.

³¹ National Obesity Observatory

Views of the stakeholders in Birmingham consulted for this paper

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 diagnosis or an assessment.
- A problem in that adult with autism of average ability or above is not eligible for services. They are not the brief of the LD teams and cannot access MH services until they develop a serious problem.
- It is likely – by not certain - that adults with autism with well below average IQs receive a better service – by virtue of coming within LD teams.
- A lack of clarity as to which services are the best equipped, and whose remit autism should fall under regarding assessment and support.
- A lack of support for caregivers.
- 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 then just remain at home.

Focus Group and how they express their needs

In interviews with parents and people with autism³² 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:

- Need for wider awareness of the condition, 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.
- 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.

³² 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.

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
- Having a pet
- Having friends
- 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 would need 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.
6. Understanding caregivers' needs

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 of recording or access point was not identified. Data sources such as:

- Police dataset
- Paediatric/child system

Discussion

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, in order to be able to help people.

In general, knowledge about autism conditions and the difficulties faced by children is better understood than adults with autism. Autism, as any other disability, in some cases limited this population in getting a better chance in life.

People with autism could need support throughout their life, though some will be fit enough or only need minimum help. For those people with autism that can manage their life well, sometimes the question is about “what to do after diagnosis”.

There are views across people with Autism and parents/carers that the services provided for them are not adequate; and the services should fit people’s needs better- people centre service. The development of a pathway that covers the whole life cycle and 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 they need to go through pre-transition, transition and post transition, despite multi-agency services being available (22). In Birmingham, it is apparent that information is not readily available to aid the understanding of autism.. Parents in the transition group, commented that awareness about what services are available to parents and young people is needed. 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 completed further education.

More research and better data recording is needed to understand the range of major diseases affecting morbidity and mortality among people with autism. However, there are a few studies suggesting a high rate of mortality and morbidity (23).The electoral wards 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 **Error! Bookmark not defined.** Autism JSNA report). 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 their coping mechanisms.

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 early intervention 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 (24). Other research has found that residential programmes have a positive and indirect benefit, reducing challenging behaviours for people with autism (25).

Local pathway and assessment frameworks for Birmingham are being developed, following NICE guidance, and the latest National autism Strategy. Local practitioners recognise that it is necessary better understanding of the local population with autism and their care needs, thus there is a requirement for a robust system that takes care of people with autism through their entire life.

There is evidence "out there" about autism and symptoms; however, there are still barriers on getting appropriate, timely and tailored information. This problem is across people with disability and not exclusive of autism. We have not been able to work out the best mechanism that influences the accessibility and appropriateness of the information accordingly with needs.

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

It is essential understanding the difference in employment capability related to the specific disability and the support needed to enhance employment opportunities for a person with autism. These services need to be linked to the economic market reality thus as employment policies.

Better recording of data and information processing could be made possible to shape services and to understand disability and health needs of the population with autism.

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

There are groups that could be targeted to improve understanding and improve support and follow up across life course for people with autism:

- People that are in employment benefit.
- Young People that are in Transition.
- Children from parents that are at high risk – maternal age/weight/pre-term and low birth weight.
- Children excluded at school because challenging behaviour.
- Young adults register in university support services
- People with autism in contact with Criminal Justice

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