NHS Portsmouth

Children with Autistic Spectrum Conditions

A Health Needs Assessment

FINAL

5th July 2012

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1. Introduction

This report will describe the health needs of children with autistic spectrum conditions (ASC) who live in Portsmouth City to support the development of a lifelong autism commissioning strategy for the city.

The report will have the following objectives:-

- to determine the current and future numbers of children with ASC, and to identify any associated health inequalities
- to ascertain the experiences of users of services for children with ASC, to determine their views on how services can be improved
- to determine service providers views on how services for children with ASC can be improved, alongside the recently released NICE guidance (NICE 2011)
- To bring together the information above to make sensible and achievable recommendations for future work to improve services, support and outcomes for children with ASC in Portsmouth City

1.1 What is Autism?

Autism is described as 'a lifelong condition that affects how a person communicates with and relates to other people. Autism affects how a person makes sense of the world around them….Autism is known as a spectrum condition because of both the range of difficulties ….and the way they present in different people' (DH 2010).

There are three main areas of difficulty, which all people with autism share, known as the 'triad of impairments':-

- Social communication (eg problems using and understanding verbal and non-verbal language)

- Social interaction (eg problems in recognising and understanding other people's feelings and managing their own)

- Social imagination (eg problems in understanding and predicting other people's intentions and behaviours)

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

The impact of autism will vary from person to person and family to family but will permeate every area of life including mental, emotional, social and economic health. Without the right kind of support, autism will significantly limit the individual's ability to reach their full potential and can have a strongly negative impact on the whole family's wellbeing. Studies have shown that family stresses related to the care of children with ASD are significantly greater than the care of children with other developmental disorders.

2. Epidemiology

2.1 Estimated Prevalence

A local estimate of the prevalence of ASC in children and adults in Portsmouth was produced using prevalence estimates derived from the Adult Psychiatric Morbidity Survey (Brugha et al 2007). This survey found that 1.8% of males and 0.2% of females have ASC, with an overall prevalence of 1%.

Table 1 demonstrates the estimated current and projected number of children with ASC in Portsmouth city based on these figures. As can be seen, in the next 20 years the number of children with ASC is expected to rise from 477 to 579, an increase of 21%. The highest increases are to be found in the 5-9 years age groups.

Table 1

Estimated Number of 0-19 year olds with Autistic Spectrum Conditions Portsmouth City, 2011 to 2031

Age Band	Gender	2011	2016	2021	2026	2031	% Increase 2011 to 2031
0-4	Male	115	126	135	137	137	18.8%
0-4	Female	12	13	14	15	15	17.7%
0-4	**TOTAL**	**128**	**139**	**149**	**151**	**151**	**18.7%**
5-9	Male	94	108	117	124	126	34.6%
5-9	Female	10	11	12	13	13	36.7%
5-9	**TOTAL**	**103**	**119**	**129**	**137**	**139**	**34.8%**
10-14	Male	92	90	104	112	117	27.5%
10-14	Female	9	9	11	12	12	31.9%
10-14	**TOTAL**	**101**	**99**	**115**	**123**	**129**	**27.9%**
15-19	Male	131	124	121	139	144	9.6%
15-19	Female	14	13	13	14	15	10.3%
15-19	**TOTAL**	**145**	**137**	**133**	**153**	**159**	**9.7%**
TOTAL	Male	432	448	477	511	524	21.3%
	Female	45	47	50	54	55	22.6%
	TOTAL	477	495	527	565	579	21.4%

Source: Brugha et al (2007), 2008-based sub national population projections by sex and quinary age, ONS

Notes: The above figures were calculated using rates by age and sex. This means that due to rounding issues in the calculations, the totals may be very slightly different to what is expected.

2.2 Recorded Prevalence

The Community Paediatric Medical Service was unable to provide statistics on children with ASC. In April 2011, Child and Adolescent Mental Health Services (CAMHS) reported 43 children aged 6-19 years with an ASC. Twenty-one of these children also had a learning disability. Eleven of these children will leave CAMHS caseloads over the next five years.

In education, 104 children had a statement of special educational needs with an ASC as their primary need. This is likely to be an under-representation for the following reasons:

- Some parents choose not to accept or acknowledge the diagnosis
- Some parents do not chase a medical diagnosis as this may be perceived as being negative or have negative consequences for the child
- Some parents may already be meeting their child's needs and a formal diagnosis will make little difference to the care received.

In 2010 and 2011, Portsmouth City GP practices were asked to provide data on the number of people recorded as having an ASC on their computer records. In 2011, 52 patients were recorded as having childhood autism. However, this may represent the number of diagnoses recorded rather than the number of patients as some patients may have an ASC recorded more than once in their computer record. These figures represent a significant difference to the estimated prevalence. This may be due to similar reasons to the differences in the number of children with a statement of special educational needs described above.

2.3 Incidence

One study (Powell et al 2003) has suggested that the incidence of ASC is 2.6 per 1000 live births. This would equate to approximately 8 babies born each year in Portsmouth City who will develop an ASC.

2.4 Ethnicity

The evidence base regarding ethnicity and ASC is minimal. However, one UK study by Powell et al (2000) found that there were comparable rates of ASC across all ethnic groups. **Table 2** shows the numbers of Portsmouth City residents aged 0-15 years by ethnic group and the estimated numbers with ASC based on a prevalence of 1%.

Table 2

Estimated Number of Portsmouth City Residents aged 0-15 years with ASC by Ethnic Group Portsmouth City mid-2009

Ethnic Group	Number of 0-15 year olds	Estimated Number with ASC
White	**29,800**	**298**
British	29,000	290
Irish	100	1
Other White	700	7
Mixed	**1,100**	**11**
White and Black Caribbean	200	2
White and Black African	200	2
White and Asian	300	3
Other Mixed	300	3
Asian or Asian British	**1,900**	**19**
Indian	700	7
Pakistani	300	3
Bangladeshi	600	6
Other Asian	200	2
Black or Black British	**600**	**6**
Black Caribbean	100	1
Black African	500	5
Other Black	100	1
Chinese or other ethnic group	**500**	**5**
Chinese	300	3
Other	300	3
All Persons	**33,900**	**339**

Source: ONS Experimental Statistics

Notes: The above figures were calculated using rates by ethnic group. This means that due to rounding issues in the calculations, the totals may be very slightly different to what is expected.

2.5 Education

The National Autistic Society has identified from a range of research projects that over 40% of children with autism have been bullied at school, and 20% have been excluded from school, with many more than once, and we can only assume that these figures are similar in Portsmouth City.

2.6 Deprivation

There have been no reliable studies indicating any correlation between social class, deprivation and rates of ASC in children.

2.7 Looked After Children

There is no evidence of a link between children who are looked after and ASC. However many looked after children have a severe attachment disorder which presents similarly to an ASC and may cause diagnostic confusion.

2.8 Other Conditions

A number of other conditions occur at a higher rate in children with an ASC than the general population. These include learning disabilities and difficulties, attention deficit hyperactivity disorder (ADHD), mental health problems and epilepsy.

Approximately 7.5% of those with a learning disability have an ASC and about 50% of those with an ASC have a learning disability. Of the remainder, a large proportion will have a learning difficulty such as dyslexia.

There is a suggestion that ASC can be misdiagnosed as ADHD in childhood due to similarities in presentation. Also, rates of co-occurring ADHD and ASC are reported to be high with one study stating up to 43%.

It is generally accepted that rates of mental health issues are higher in ASC than in the general population, with depression and anxiety being relatively common, and children with Asperger syndrome or high functioning autism being up to five times more likely to have obsessive-compulsive disorder. However, there may be under diagnosis of mental health issues due to individuals with ASCs inability to express emotional states.

A number of studies have examined the association between ASC and epilepsy. A lower IQ is associated with a higher risk of epilepsy, and a recent meta-analysis found the 21.5% of people with ASC and a learning disability had epilepsy with 8% of people with ASC and no disability having epilepsy. There also seems to be a higher risk of having epilepsy in females than males (Amiet 2008).

3. Service User Feedback

This section provides information from the parents of children with an ASC about their experiences of services and how they think they could be improved. This feedback was gained during a consultation which took place in September 2011 led by the Integrated Commissioning Unit for adults, via a qualitative survey.

Four main themes were highlighted from the analysis of the responses and these are detailed below:-

3.1 Education

Two clear priorities were evident amongst the themes:

- A significant number of parents and adults with autism expressed concerns regarding education experiences, particularly children not reaching their potential, children needing extra support, lack of academic progress, negative experiences in primary school, and difficulties with accessing help for children in school.
- A significant number also expressed concerns regarding a lack of resourced provision attached to both primary and secondary mainstream schools and provision for youngsters of 13+ years with complex needs.

In addition, there were many people who highlighted a need for:

- Improved training and autism awareness for staff in schools. Some people commented on a lack of understanding amongst school staff, which impacts or has impacted on children's experience of school and their outcomes.

Other key issues identified were:

- A need for "suitably trained" professionals to identify autism spectrum difficulties during the Early Years to ensure early intervention. Concerns around this issue included a perceived lack of understanding and knowledge amongst early year's practitioners and a lack of services to support families at home during their child's early years.

3.2 Diagnosis and Health Care

There were a significant number of comments about the diagnostic service in Portsmouth (and Southampton), including concerns regarding:-

- the timing/ waiting times for this service,
- the perceived levels of support involved afterwards, and
- the information available.

There are also clear concerns regarding the differences between services and families' experiences in each.

The themes around diagnosis highlighted a need for:

- A timely, multi-agency diagnostic process, which is clear and includes a detailed report. Parents feel strongly that they would welcome more support following a diagnosis for their child
- The role of the GP was also highlighted amongst the responses, with differing experiences being reflected. What was apparent from the feedback is that the role of the GP is very important in terms of them holding a 'gatekeeper role' and offering or providing support for the family.

In addition there were clear messages about:

- The importance of specific therapy and health services, including specifically Occupational therapy, Speech and Language therapy, health visitors and CAMHS services. Themes reflected mixed experiences for families, with some concerns expressed about the level of available service provision from the OT and SLT services
- Responses also reflected a need for mental health services, with a particularly significant need around managing anxiety and depression. Some concerns were raised about 'diagnostic overshadowing' e.g. not getting help for anxiety because they have autism
- A recurring theme throughout was a need for awareness-raising amongst professionals.

3.3 Family Support

- A relatively high number of respondents commented on the impact of having a child with autism on family life, including concerns about going out as a family, doing typical family activities, accessing public events, eating as a family etc. Some parents commented on how the difficulties of having a child with autism have impacted on their own mental health and emotional well-being and that of the child's siblings.
- A significant number of participants highlighted the positive contribution made by support groups in the city, particularly Portsmouth Autism Support Network, and the need to continue to have support groups for families, including some requests for more family support, with a buddying system suggested by several participants.
- Parents commented positively on training experiences although there was a call for training for parents to be free of charge.
- There were a significant number of concerns raised by parents about the 'education' process and difficulties faced by families with school placement, children's progress, obtaining additional support etc.
- Concerns were raised about a perceived lack of short break opportunities for families in the city, as well as organised social opportunities for young people and children with autism.

3.4 Training

- A significant number of respondents commented on positive experiences of training within the city, particularly specialist (autism) courses. A number of specific positive comments were also made about training delivered by Educational Psychology and Pirates are Cooler than Ninjas. Concerns were raised about accessibility of training for parents, with several people suggesting that training needed to be free of charge to parents.

- However, a very high number of people commented on a need for more training for front-line staff, e.g. school staff, police, social workers, housing officers, GPs etc, with a notable emphasis on training for staff working in mainstream schools. There were also a significant number who valued specific specialist training such as TEACCH (Treatment

and Education of Autistic and related Communication Handicapped Children), PECS (Picture Exchange Communication System) and Social Stories.

4. Childhood Autism Services

4.1 Existing Services

The responsibility for the provision of services to support children with ASC lies with the NHS and local government as below:-

NHS	**Portsmouth City Council**
Assessment Diagnosis Follow-up Support Annual Health Checks Support to Access Health Services (e.g. dentists, opticians) Help for reasonable adjustments Awareness	Social Care Education Leisure Awareness

The services currently provided in Portsmouth City for children with ASC are described below:-

4.1.1 Community Paediatric Medical Services

This service is provided by the NHS and provides the following:-

- Diagnosis in locality clinic setting (the majority of diagnoses are made here)
- Referral to specialist assessment if there is any doubt in the diagnosis
- Referral to specialist services such as speech and language therapy
- Paediatric follow-up if required

4.1.2 Child and Adolescent Mental Health Services (CAMHS)

This service is also provided by the NHS with input from educational psychology and provides the following services:-

- Diagnosis

- Assessment
- Ongoing therapy and support
- Referral to specialist services as required

4.1.3 Speech and Language Therapy

Speech and language therapy services are provided by the NHS, and are often the first service to assess children with ASC. Speech and language therapists can refer to medical services (community paediatricians or consultant child psychiatrists) for diagnosis of ASC.

4.1.4 Primary Care

Primary care services are also provided by the NHS and provide medical treatment and onward referral by acting as gatekeepers to more specialist services and support.

4.1.5 Education

Education services are provided by Portsmouth City Council. This includes provision of additional support to children with ASC at school through the provision of a statement of special educational needs. They also contribute to the assessment and diagnosis service through educational psychology.

4.1.6 Pirates are Cooler than Ninjas

This service offers support to individuals with autism, carers and professionals working with people with ASC. These services include a drop in support group for 14-19 year olds, a carers group, and training and consultancy services for professionals working with ASC.

4.1.7 Portsmouth Autism Support Network (PASN)

PASN is a group of parents of children with autism who provide each other with a support network as well as a number of organised activities and one-off events for families affected

by ASC including support meetings, social activities, seasonal events, organised outings and outreach.

4.1.8 Hampshire Autistic Society

Hampshire Autistic Society offers a wide range of services and facilities for children with ASC across Hampshire such as further education units, residential, domiciliary and day services, outreach services and a parent support network. HAS have also worked with Hampshire Fire and Police services to develop and launch Autism Alert cards and car stickers to alert emergency services to people with ASC so that they can be managed appropriately

4.2 National Guidance

Recently released NICE guidance (NICE 2011) details a set of standards in relation to services for children with ASC. This includes standards for:-

- Service organisation
- Recognising possible autism
- Referral
- Deciding on assessment
- Assessment
- Diagnosis

This report will concentrate on the service organisation section of the NICE guidance as this will be most relevant for the future commissioning of the childhood autism service at this stage.

The NICE guidance recommends the formation of two groups of professionals. The first is the local autism multi–agency strategy group and this will consist of managerial, commissioning and clinical representation from child health and mental health services, education, social care, parent and carer service users and the voluntary sector. A lead professional should be nominated to take responsibility for the autism pathway. The aims of this group should include:

- Improving early autism recognition by raising awareness of the signs and symptoms of autism through multi-agency training
- Ensuring that relevant professionals e.g. health and social care and education are aware of the local autism pathway and how to access services
- Support the smooth transition to adult services for young people with autism
- Ensure that robust data collection and regular audit of the pathway takes place.

The second group of professionals that the NICE guidance recommends is the multi-disciplinary autism team. This team should have a core membership of a paediatrician and/or a child psychiatrist, a speech and language therapist and a clinical and/or educational psychologist. The team should also be able to access other relevant professionals as needed such as specialist health visitors, nurses or social workers. The autism team should have the skills and competencies to carry out autism diagnostic assessments and to be able to communicate with children and young people and their families appropriately. The roles of the autism team should include:-

- Providing advice to professionals about whether to refer children or young people for autism diagnostic assessments
- Deciding on the assessment needs of those referred or when referral to another service is needed
- Carrying out autistic assessments
- Sharing the assessment outcomes with children and young people and their families appropriately
- With consent, sharing information from the diagnostic assessment with relevant services such as education
- Offering information to children and young people with ASC and their families about appropriate services and support.

The roles of the autism team will rely on standards for autism assessment and diagnosis that are also detailed in the NICE guidance. These standards will need to be reflected when commissioning the service to ensure that there is the knowledge and skills within the team to meet the standards described.

The last point with regard to service organisation is that there should be a single point of referral for access to the autism team, to reduce any potential confusion in accessing appropriate autism services for relevant professionals as well as parents of children with ASC and potentially children and young people with ASC.

4.3 Service Provider Feedback

This information was provided by a consultation event organised by the Integrated Commissioning Unit for adults in September 2011.

Almost a quarter of the 42 responses dealt with the need for training and how that training might be carried out:

- It was recognised there was a considerable amount of helpful specialist training related to autism including TEACCH, PECs and graduate and post graduate education and training

- Multidisciplinary training was highlighted as a useful approach, especially for front line staff and especially around awareness levels. Front line staff were considered the priority for this sort of training

- Parents and people with autism would benefit from training on autism related issues. Parents had particularly asked for this sort of help

- Training in mainstream education was described as inadequate. A substantial number of people recommended more training for mainstream teachers

- The most quoted source of useful training was from the educational psychology service. In addition many respondents believed they had expertise within their own teams which was transferred during day to day operational activity.

Many of the staff that responded identified educational support for people with autism as a problem. Professionals identified a lack of secondary school provision for people with autism

and complex needs and a lack of capacity in Portsmouth for children with complex needs in general. The lack of support for teachers in mainstream education along with resources to support children and young people with autism was highlighted. In colleges and mainstream settings, the lack of support with behavioural challenges was cited as a barrier to some people accessing an education.

There was a substantial amount of comment on the transition of young people from school to college or work. In general, the view was that this did not work particularly well. A significant number of respondents felt a specialist team to work with young people in transition would be helpful. Another substantial group of comments identified a need for better support for people from age 13. There was a view that development in this area needed better user involvement.

Many respondents believed the process for accessing a diagnosis was long-winded and stressful for people. There were particular concerns that some diagnostic assessments did not take a holistic view and there was little follow up by services outside the City. The approach to holistic assessment and multi-agency working was seen as inconsistent and confused. In particular post diagnostic review and access to support might add considerable value to the diagnostic procedure.

There was concern expressed by many respondents about a lack of short term breaks for families. The issue was highlighted particularly for people with autism and complex needs. The opportunity for socialising as part of families having breaks from each other was highlighted by some professionals.

A number of respondents indicated the need for a wider awareness campaign to address misunderstanding about autism in a wide range of target audiences.

5. Conclusions

The estimated prevalence of children with ASC shows that there will be an increase in the numbers of children with ASC over the next 20 years and commissioning plans must therefore reflect potential future increased service demand. It is also possible that the increased awareness of autism may lead to further increased numbers and service performance will need to be reviewed regularly to ensure that ongoing capacity is available, and waiting lists do not increase.

There are notable differences in the estimated and recorded prevalence of ASC in Portsmouth City, which implies that there are many children with ASC who are currently not known to services and efforts should be made to identify these children and provide any appropriate support. Data recording and retrieval systems for autism in both primary care and community services need to be improved to give more accessible and realistic figures for the number of children with ASC, so that future service planning and commissioning can be improved.

There is limited data available to be able to identify any potential health inequalities within the city, but with improved recording the more robust data may be used to identify inequalities which may lead to more efficient identification and targeting of services.

It is clear from both service and user feedback that there needs to be a number of improvements to childhood autism services in the city. The recent NICE guidance provides a set of standards which we should be working towards and the development of the new service based on these guidelines will also need to incorporate feedback from both the parents and providers.

Key points raised by both service users and providers include the lack of educational support and training for staff, children and parents, a confusing diagnostic service and a perceived lack of support post diagnosis. The split provision of autistic assessment and diagnostic services needs to be addressed appropriately to best address the health needs of Portsmouth.

It has already been decided that there will be a cradle to grave strategy in Portsmouth for ASC and it is therefore important to ensure that, where possible, the children and adult pathways share similar features to ensure that services are both clinically and cost effective.

6. Recommendations

- To incorporate potential future increased demand for autism services in commissioning plans

- To look at ways to improve the recording of autistic spectrum disorders in primary care and community services

- To continue with the multidisciplinary group work to review and map the current service pathway and develop a new pathway based on NICE guidance, incorporating a single point of access

- To look at methods to improve support to children and parents through the diagnostic process and after the diagnosis of an autistic spectrum condition

- To ensure there are robust mechanisms for the transition of children with ASC to adult services.

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