NHS
Portsmouth
Clinical Commissioning Group

Portsmouth
CITY COUNCIL

Joint Strategic Needs Assessment Briefing Note

Autism-spectrum conditions

1 Introduction

1.1 This report provides details of Portsmouth's adult population with autism-spectrum conditions (ASC), current care pathways and services provided as well as identifying gaps and future needs. The findings will inform the implementation of the Autism Act 2009 and Fulfilling and rewarding lives: a strategy for adults with autism in England 2010. The government's vision is that:

All adults with autism are able to live fulfilling and 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.[1]

1.2 The term ASC will be used throughout this report.

2 Definition of ASC

2.1 ASC is:

"A lifelong condition that affects how a person communicates with and relates to other people. ASC 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 that affects adults with autism, and the way they present in different people."[2]

2.2 There are three main areas of difficulty - known as the "triad of impairments":

- Social communication (e.g. problems using and understanding verbal and non- verbal language)
- Social interaction (e.g. problems in recognising and understanding other people's feelings and managing their own)
- Social imagination (e.g. problems in understanding and predicting other people's intentions and behaviours).[3]

2.3 Many people with ASC have no obvious disability but may find their actions or words are misunderstood by others. Many do not want to be diagnosed or indeed be recognised

[1] Towards 'Fulfilling and rewarding lives' the first year delivery plan. Department of Health, 2010. www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_115121.pdf Accessed 16 September 2011.
[2] Fulfilling and rewarding lives: the strategy for adults with autism in England, 2010. Department of Health. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369 Accessed 16 September 2011.
[3] Department of Health, 2010. Ibid.

as having autism and any support that is required falls to parents, relatives or friends. The person may also fall between services and not get the right support and this can lead to further problems (including but not limited to anxiety, depression, mental health issues etc).

3 Inequalities

Gender: ASC is more commonly diagnosed in males than females. The prevalence for males is 2.0% compared with a female prevalence of 0.3%.[4] Some professionals involved in the diagnosis of autism believe that the condition is more difficult to observe in females and consequently the prevalence amongst women is underestimated.

Employment: adults with autism are "significantly under-represented in the labour market".[5] Only 15% of adults with autism are in full-time paid employment.[6]

Housing: only 14% live in their own flat or house with support but 37% would like to live in their own flat or house with support; 49% of adults with autism live at home with their parents.[7]

Access to services:

- 63% of adults with autism do not have enough support to met their needs, of those, 82% say that with more support they would be less isolated
- Of those who do not have enough support, 79% say that with more support they would be able to do the things they want to do and 70% say that with more support they would be more independent
- 92% of parents are either very worried or quite worried about their son's or daughter's future when they are no longer able to support them
- Over 69% of people with Asperger Syndrome or high functioning autism say that they have experienced problems in accessing health and social care services.[8]

4 National and local estimates of prevalence

4.1 The National Autistic Society estimates that there are 500,000 people in the United Kingdom with ASC. However, it is difficult to get an accurate picture as there is no central record, and there are few epidemiological studies. The most recent estimate is that 1.1% of the population (ie including people living in private households and in communal establishments) has ASC.[9]

[4] Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey. Department of Health. January 2012. www.ic.nhs.uk/statistics-and-data-collections/mental-health/mental-health-surveys/estimating-the-prevalence-of-autism-spectrum-conditions-in-adults-extending-the-2007-adult-psychiatric-morbidity-survey Accessed 22 May 2012.
[5] Towards 'Fulfilling and rewarding lives the first year delivery plan. Department of Health, 2010. Ibid
[6] I exist: the message from adults with autism. The National Autistic Society. www.autism.org.uk/iexist Accessed 16 September 2011.
[7] I exist: the message from adults with autism. Ibid.
[8] I exist: the message from adults with autism. Ibid.
[9] Department of Health. January 2012. Ibid

Estimates of prevalence have increased over the last 40 years due to:

- Improved recognition and detection
- Changes in study methodology
- Increase in available diagnostic services
- Increased awareness among professionals and parents
- Growing acceptance that autism can coexist with a range of other conditions
- Widening of diagnostic criteria.[10]

4.2 A local estimate of the prevalence of ASC in children and adults in Portsmouth was produced using prevalence estimates derived from the extended Adult Psychiatric Morbidity Survey.[11] The extended survey estimated prevalence in residents of private households as well as communal establishments. The extended Survey found 2.0% of males and 0.3% of females are estimated to have ASC. It is estimated that in 2012 about 2,300 people in Portsmouth have ASC and that by 2035 this will increase to about 2,550 people (or about 50 additional people every five years).

Table 1

Estimated number of people with autism-spectrum conditions
Portsmouth, 2012 to 2035

Age band	2012	2015	2020	2025	2030	2035
0-14	384	405	432	435	421	415
15-19	160	153	148	167	183	181
20-64	1,483	1,482	1,476	1,461	1,472	1,499
65+	302	319	343	377	419	455
Total	**2,331**	**2,359**	**2,397**	**2,440**	**2,495**	**2,551**

Sources (1) Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey. Department of Health. January 2012. (2) 2010-based subnational population projections by sex and quinary age. ONS. Published March 2012

4.3 Males have a higher prevalence of ASC. Of the estimated 2,300 people in Portsmouth with such a condition, about 2,000 (rising to 2,200 by 2035) are predicted to be male.

4.4 The National Autistic Society states that estimates of the proportion of people with ASC who have a learning disability, (IQ less than 70) vary considerably, and it is not possible to give an accurate figure. It is likely that over 50% of those with ASC have an IQ in the average to high range, and a proportion of these will be very able intellectually. Applying prevalence estimates to the local population, predicts that about 80 children with ASC aged 0-17 years have an IQ of less than 70, and about 290 children with ASC aged 0-17 years have an IQ of more than 70. The model predicts that 320 adults with ASC aged 18+ years will have an IQ of

[10] Baron-Cohen S, Scott FJ, Williams J, Bolton P, Matthews FE and Brayne C (2009). Prevalence of autism-spectrum conditions: UK school-based population study. British Journal of Psychiatry, 194: 500-509
[11] Department of Health. January 2012. Ibid.

less than 70, and about 1,130 adults with ASC aged 18+ years will have an IQ of more than 70.[12]

4.5 The Department of Health commissioned a follow-up prevalence study which looked at the prevalence of autism amongst adults with learning disabilities living in private households whose learning disability was sufficiently severe that they could not have taken part in the first Adult Psychiatric Morbidity Survey 2007. Summary findings:

- The prevalence of autism increased with greater severity of learning disability/lower verbal IQ
- Amongst adults living in private households, the prevalence of autism was 35.4% (95% confidence interval 24.7& to 46.2%)
- The prevalence of autism in the general population (taking into account prevalence that might be higher in some communal establishments) was estimated at between 1.1% and 1.2%.[13]

5 Recorded prevalence: Children and young people

5.1 The Community Paediatrics Service was unable to provide statistics of children and young people on their caseload with ASC. In April 2011, the Child and Adolescent Mental Health Service (CAMHS) reported 43 children aged between 6-19 years had a diagnosis of autism. It is possible that children accessing Community Paediatric Services also receive support from CAMHS. Twenty-one of the 43 children (49%) with ASC accessing CAMHS in April 2011 had a learning disability.

5.2 From current caseload data, 11 children will leave CAMHS over the next five years.

5.3 In Education, children who have a statement are categorised by their primary area need. At March 2011, 104 children had a statement with autistic spectrum condition as their primary need (This figure may include children who have not received a medical diagnosis). One statement was also confirmed as having 'other' as the primary need but with a medical diagnosis of autistic spectrum condition.

5.4 It has been suggested that children with ASC condition may not have a statement as their parents have chosen not to accept or acknowledge their diagnosis. Some parents choose not to seek a medical diagnosis as it can be perceived as being 'negative' or they fear a diagnosis will have negative consequences for the child. Other parents may be at the beginning of their journey of understanding their child's additional needs and may not be ready to accept a formal diagnosis. There are also parents who are meeting their child's needs and feel a formal diagnosis will not make a difference to the care and support they and their child receive.

[12] Wing, L. and Gould, J. (1979) 'Severe impairments of social interaction: and associated abnormalities in children: epidemiology and classification.' Journal of Autism and Developmental Disorders, 9 (1), pp. 11-29. Small Area Population Forecasts, Hampshire County Council, March 2011.
[13] Department of Health. January 2012. Ibid.

5.5 It is important to note however, that many parents have told commissioners of their frustration at being unable to access a diagnostic procedure for autism for their child. A common view expressed by parents attending voluntary sector groups in Portsmouth, is that GPs are unlikely to refer for a diagnosis of autism.

6 Primary Care

6.1 In 2010 and 2011 Portsmouth GP Practices were asked to provide data of the number of registered patients with ASC. Twenty-three GP Practices responded in each year but they were a different set of Practices each time.

6.2 The absolute number of ASC diagnoses recorded in Primary Care increased from 103 in 2010 to 361 in 2011. These figures reflect diagnoses rather than individuals as some people may have more than one diagnosis of ASCs.

6.3 The difference between years may be due to:

- More Practices with a larger list size may have responded in 2011
- More complete identification and recording of patients with ASC in Practices
- Differences in the 'diagnostic codes' used by each Practice to identify people with ASC.

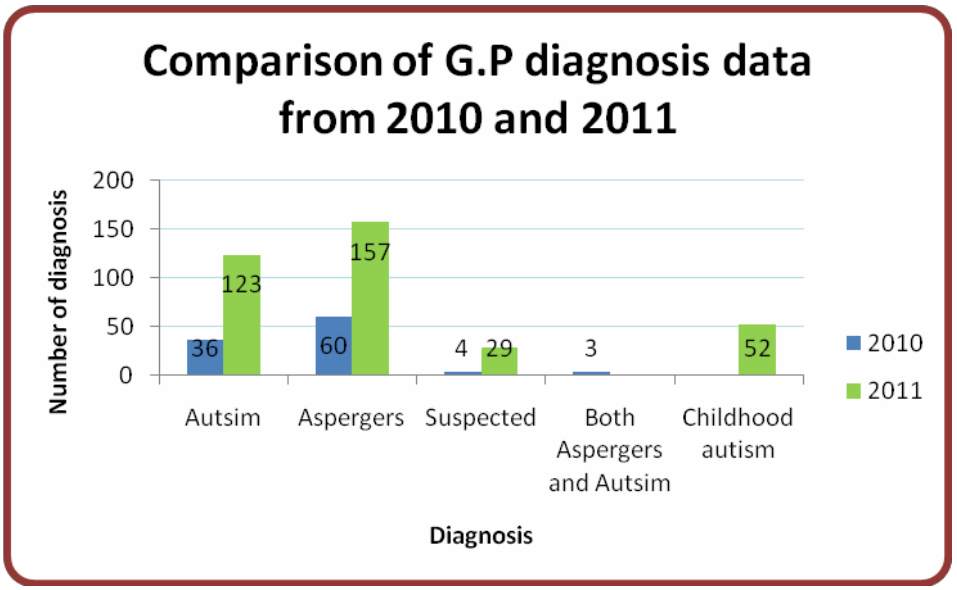
In 2011, codes used by Practices were:

- Autism
- Active infantile autism
- Residual infantile autism
- Infantile autism NOS
- [X]Atypical autism
- [X]Childhood autism
- Suspected autism
- [X]Asperger syndrome

6.4 Next year's data collection will ask for the following data for people aged under-18 years and over-18 years. This will ensure more complete data is collected and can be used to further develop any work by the Integrated Commissioning Unit.

a) Diagnosis of autism
b) Diagnosis of Asperger syndrome
c) Diagnosis of both autism and Asperger syndrome
d) Suspected diagnosis of autism
e) Suspected diagnosis of Asperger syndrome
f) Suspected diagnosis of both autism and Aspergers

Figure 1



6.5 Assuming that very few people have more than one of the above diagnoses, there is a difference of about 2,000 people who are predicted to have ASC but who have not been recorded as such. Explanations include:

- Some people with ASC may never come to the attention of services because they have learned strategies to overcome any difficulties with communication and social interaction, found fulfilling employment etc
- People who would like a diagnosis but who do not know how to obtain one or who feel that the process is too complicated
- It has also been suggested that some parents may resist a formal diagnosis if they suspect their child has autism.
- Difference in data collection methods which may have impacted on the actual data collected.

7 Services - Health and Social Care

The responsibility for services to support people with ASC lies within the NHS and national and local government.

7.1 NHS

- Assessment
- Diagnosis
- Follow-up support
- Annual health checks
- Support to access health services (dental, optician, doctors)
- Help for reasonable adjustments

- Awareness

7.2 Portsmouth City Council

- Social care
- Education
- Leisure
- Employment (Also Dept for Work and Pensions)
- Awareness
- Support with Housing
- Support with Benefits and Finances.

The following services are available within Portsmouth and are currently commissioned by either NHS Portsmouth or Portsmouth City Council or both.

7.3 Learning Disability (Healthcare) Service

a) Portsmouth's Learning Disability (LD) Healthcare Service comprises a multidisciplinary community healthcare team, an assessment and treatment service and residential healthcare services. The service is made up of a range of professionals including Community Nurses, Healthcare Support Workers, a Consultant Psychiatrist, an Occupational Therapist, a Speech and Language Therapist and a Clinical Psychologist. The LD Service provide services to adults in Portsmouth with a learning disability and a healthcare need, which together create problems in the provision of care, treatment and/ or management. The support required, being beyond that which is reasonably available from generic services. Clients supported may present with co-morbid diagnoses (formal or suspected) including ASC.

b) The LD Healthcare Service only provides services to adults who have a learning disability and ASC. While the service does have knowledge and skills around supporting people with ASC, it is not felt to be appropriate for people with average, or above average level of intellectual functioning to access services that are designed for, and provide a service to, people with significant impairments in intellectual functioning.

c) The team provides a range of person-centred assessment, support and interventions to meet the needs of clients who have a diagnosis of a LD and ASC. Support and interventions provided may include:

- Assessment and diagnosis of ASC. This may be provided to clients in the service by the Consultant Psychiatrist in the team. The Clinical Psychologist in the team is currently being trained to carry out assessments using the Diagnostic Interview for Social and Communications Disorders (DISCO) for diagnosis and assessment. Support can be provided to clients, carers and their families throughout the diagnostic process
- Teaching/ training/ information around ASC to staff teams, carers and services
- Clinical assessment and intervention aimed at addressing eg communication, emotional, psychological, occupational and sensory needs.

7.4 Speech and Language Therapy (SLT)

Support for ASC clients can be obtained from SLT through a referral to services. The services provided include:

- Language assessments
- Behavioural guidelines with communication focus
- Delivery of communication social groups
- Work on accessible information
- Provision of structured timetables
- Education and training for families, carers, health, social care, education etc.

7.5 Occupational Therapy within LD services

The OT team provides complementary activities to SLT but particularly focus on sensory integration/activities and environment as well as providing structured timetables.

7.6 Adult Mental Health (AMH)

We do not know at present how many people using AMH services have ASC. There are no clinicians specialising in diagnosis and therefore it is likely that more service users have ASC than are diagnosed. Psychotic illness can be masked or be masking an ASC diagnosis. No services are currently commissioned via AMH for ASC services.

7.7 Headspace - Early Intervention in Psychosis Service.

a) Headspace is a dedicated team of professionals who work with young people aged 14-35 yrs, who are experiencing psychosis, or may be at risk of developing psychosis. They work to deliver support quickly to young people and their families.

b) Within Headspace fewer than five out of 80 clients have a diagnosis of ASC, but there are several more with suspected ASC. For someone with ASC to access AMH there must be a co-morbid mental health problem. People with ASC are less likely to access services and there are an unknown number of people with ASC and undiagnosed mental health problems. There are also no clinicians trained in any ASC diagnostic tools. Over the last year, staff have attended training to aid development.

7.8 Substance Misuse

a) Baytrees, a residential service for detoxification of drugs and alcohol, is aware of only (*number suppressed as fewer than five)* client admitted with a firm diagnosis within the past year. They were able to participate in the therapeutic programme with additional 1:1 support sessions. There is no clear pathway for service users at present within Baytrees.

b) Kingsway House (a community resource centre for drug and alcohol services) has not had any service users with a diagnosis and there is no clear pathway within the service. Staff were unclear about how they would identify characteristics of clients with ASC. Awareness

training may help with this issue.

7.9 Community Paediatrics

The Community Paediatrics service provides:

- Diagnosis
- Referral for a specialist assessment if there is any doubt in the diagnosis
- Referral to specialist services for example occupational therapy or SLT
- Follow-up by a Paediatrician in clinic if appropriate.

7.10 Child and Adolescent Mental Health Services

a) Depending on individual needs, a child with autism and a learning disability can transition into the learning disability service at the age of 16 years. If the young person does not have a learning disability, there is no specific service for them to move on to once they have reached 18 years. If they have other needs (e.g. a mental health condition), other services are available if they meet the necessary criteria.

b) CAMHS has recently reviewed its practice against national guidelines and is developing a care pathway within the service for children and young people with autism. Twelve additional staff members have also received training in diagnostic assessment tools.

c) The average waiting time from referral to first appointment for the CAMHS service varies across the different teams. If the teams are appropriately staffed, the general waiting time is approximately eight weeks.

d) The average waiting time for a diagnostic appointment is around four months. During this time the child will have received an assessment and any necessary initial intervention.

7.11 Services – Education

a) Highbury College

Highbury College always completes an “Assessment of Needs” before taking on any students during the interview phase. Highbury reports many (not quantified) students with ASC and they are supported through learning assistants within tutor groups and classes. The college has no resources to offer 1:1 support for students. If a student requires 1:1 support, they are not offered a place at Highbury and the college does not offer a signposting service (ie to other colleges who may be able to offer 1:1 or to local LD service within the NHS) if a student is not offered a place. If students meet the entry requirements, Highbury may offer a place to ASC students who need 1:1 support if a carer/support assistant is paid for by external providers. The student would apply in the normal way and the carer would attend the interview/ assessment of needs and commit to supporting the student during the term of the course. Highbury also provides ASC awareness training for its staff.

b) Portsmouth College

Portsmouth College currently has seven students diagnosed with ASC – five with Asperger syndrome. The support given to the students varies a great deal. Some request no support; some come into FOCUS (a private work room) as a refuge and a place to talk through any issues. Others have intensive support in lessons eg a learning support assistant to help concentration, to give guided responses and to monitor inappropriate behaviour. The College's aim is to foster independence as a number of the students will go on to University.

c) Portsmouth University

The students within Portsmouth University with ASC generally have Asperger diagnoses. Direct support is provided to 37 of the 48 these students (2010), with the remainder being in their third or fourth year and no longer requesting support as they feel they can cope on their own, and some declining support, although the university will always help if they reconsider.

The Additional Support and Disability Advice Centre (ASDAC) is the University's support service which identifies the specific needs of all students declaring a disability. There are many support mechanisms in place, including specialist tuition.

Students can apply for Disability Student Allowance (DSA).[14] This is not direct funding but pays for any extra academic related costs as a direct result of ASC. There is no standard format of support for any student with ASD. A student who is eligible for DSA will be referred to National Network of Assessment Centres (www.nnac.org) where they will be assessed and recommendations made for support. The student will use the DSA funding to put these in place, with assistance from ASDAC.

Portsmouth University work closely with Hampshire Autistic Society to provide support and an emphasis is made on independent learning.

New staff are given information on ASD at induction, and awareness training is ongoing within the university for academic and support staff.

8 Employment - JobCentrePlus

There are several options in place for people trying to get into employment if they have autism. These are fairly new services and are not all necessarily ASC specific.

Work Prep – This service is tailored to suit the needs of the individual. It involves short periods (usually 6–13 weeks) of unpaid work experience with local employers. At the end of the programme the provider will write a report with is discussed by the Disability Employment Advisor (DEA) and the individual. An action plan is agreed for the future which may include looking for employment, further education or training.

Prospects – This service is specifically for people with ASC who are able to travel and is

[14] www.direct.gov.uk/en/EducationAndLearning/UniversityAndHigherEducation/StudentFinance/index.htm Accessed 24 May 2012.

offered by the National Autistic Society with the support of JobCentrePlus. The service works with employers to aid recruitment, training and retention of ASC staff. It also works with ASC individuals via Work Prep or by direct referrals. “Prospects” provide help with job applications, interviews, and support within the workplace.

Access to Work – Once a person has found employment but needs adjustments made in order for them to take up the offer, Access to Work (ATW) can be applied for via JobCentrePlus. A ATW adviser discusses needs with the individual.

There is also a fully qualified Work Psychologist within Jobcentre Plus who has experience in ASD.

9 Other local autism specific services

9.1 In Portsmouth there are specific autistic services: Pirates are Cooler than Ninjas and PASN (Portsmouth Autism Support Network) are two services available.

9.2 Pirates are Cooler than Ninjas offer support to individuals with autism, carers and professionals working with people with autism. Services include:

- **Two drop in support groups (14-19 years and an adult group)** – to enable individuals to have the opportunity to talk to others, use activities to express feelings, develop social skills and have fun
- **Outreach** Support can be provided to individuals on a one-to-one basis to enable them to have a better understanding of autism, to gain confidence and to boost self esteem. (This service is chargeable.)
- **Carers group** Allows carers to meet up and to share experiences
- **Training and consultancy** Can be provided to professionals working with people with autism or who are thinking about it. (This service is chargeable.)

About 55 adults with ASC attend. Referrals to any of these services can be made directly to Pirates are Cooler than Ninjas. The group is funded from LDDF (Learning Disability Development Fund) money.

9.3 PASN is a group of parents of children with autism who provide each other with a support network. In May 2011 there were 300 families members but it was not known how many of these were active (a new coordinator has recently started in post so these details were unclear). Parents can become members by contacting the group directly. This is free.

PASN provides a number of organised activities and one off events for families affected by autism. Activities include:

- Support meetings
- Social activities
- Seasonal events
- Organised outings
- Outreach

9.4 Hampshire Autistic Society offers a wide range of services and facilities for children and adults within the autistic spectrum. Services and facilities are available across Hampshire, including residents of Portsmouth:

- School
- Further education units
- Residential, domiciliary and day services
- Outreach services
- Parent support network

HAS have been involved with Hampshire Police and Fire brigade to launch Autism Alert cards and Autism car stickers to alert services to the person having ASC so they can be supported appropriately.

Referrals to the Hampshire Autistic Society can be made directly to the service. Once a referral has been made, an assessment of need will be carried out and, if appropriate, costings of providing support will be given.

10 Out of Area Services (Commissioning optional)

10.1 There are no local diagnostic services within Portsmouth. An adult requiring diagnosis is referred to a service out of the area funded from the Extra Contractual Referral (ECR) budget for AMH or LD depending on the referring service. There have been nine requests for referral funding (age range 22 to 47 years) and fewer than five long term placements for adults with ASC (age range 28 to 38 years) in the past 18 months, although the people on long term placements do have other clinical needs. The cost implications of the assessment referrals on the ECR budget total approximately £29,655.

10.2 The following are services that could be used for diagnosis or follow-up care, although the Horsham's LANC would not assess a service user with ASC as a primary need, only as secondary to ADHD or other neurological disorders.

a) Autism Diagnostic Research Centre Southampton (ADRC)

This is the most commonly used diagnostic centre for ECR clients. The service was set up in September 2007 and is a non-profit organisation owned by Southampton University. The service provides three types of assessment catered for each individual's need: Diagnostic Assessment, Neuropsychological Assessment and Psychiatric Assessment. The cost for assessment is £3,295.

b) Learning Assessment and Neurocare Centre (Horsham) (LANC)

The LANC currently see people of all ages, but generally concentrate on clients with neurological disorders such as ADHD. The clinic does see people with ASC but only if they present with another neurological disorder. Unlike Southampton, they are not seen as specialists in ASC and they have a more clinical approach with their clients.

Initial assessments cost between £895 and £1,785 depending on requirements. The average

cost is £1,435 with follow-ups costing £235.

c) Rookery Hove – The Priory

Rookery Hove is a new service which, if used, would have to be funded out of the ECR budget on a case by case basis. The service is provided by The Priory and caters for people with Asperger syndrome between 18 to 35 years. The unit provides ongoing independence, social development and specialist care, including developing educational needs which can lead to qualifications for service users. The service develops strategies for dealing with anxiety and challenging behaviours. Placements last between 18 months to 5 years depending on the Individual's needs. Placements cost in the region of £1,700 to £2,500 per week.

d) Worthing Diagnostic Services

Sussex Partnership Trust do offer diagnostic and support services for ASC. At present no further information is available, but Worthing are willing to meet to discuss the services offered.

11 Evidence

NICE has published clinical guidance, Autism: recognition, referral, diagnosis and management of adults on the autism spectrum (http://publications.nice.org.uk/autism-recognition-referral-diagnosis-and-management-of-adults-on-the-autism-spectrum-cg142) in June 2012.

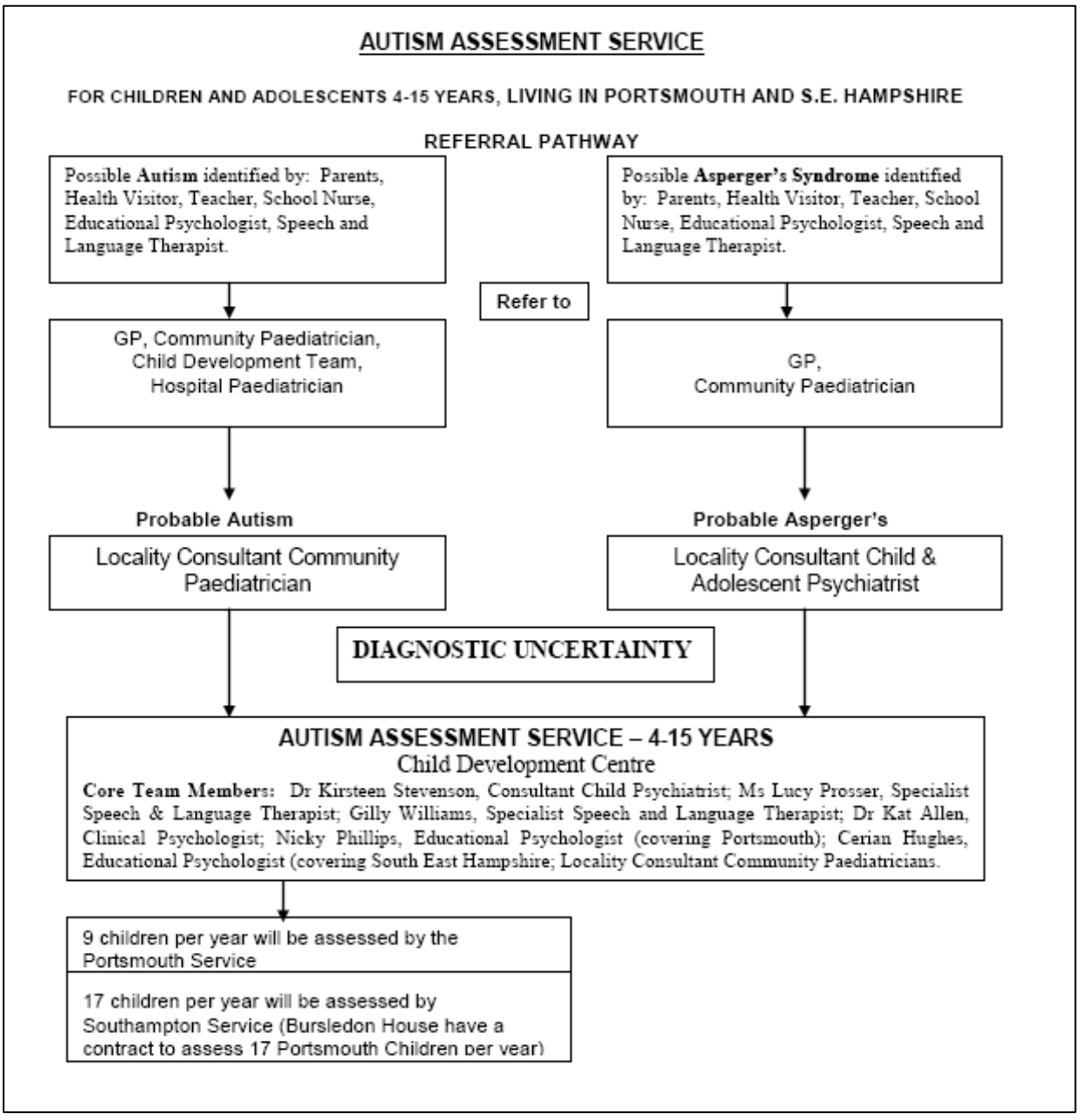
NHS Evidence provides topic information on autism at www.evidence.nhs.uk/topic/autism, including guidance, commissioning advice, information for the public, and evidence uncertainty.

12 Care pathways

NICE provides a pathway overview for autism (http://pathways.nice.org.uk/pathways/autism).

Currently there are no adult care pathways within any of the locally commissioned services or any transitional pathways for young people to enter adult services. Shown below is an example of a care pathway used in the Child Development Centre for children aged between 4 and 5 years from referral to assessment.

After assessment has taken place, children are then offered services according to need e.g. if there is a behavioural need, a child may access CAHMS; if there is a language need, the child may be seen by SLT; some children will be seen by special education needs for assessment for a statement if required. Parents will be sign posted to support groups and/or educational groups. The costs for each assessment are £2600. Other costs for the autism service are tied up within each service's own SLA e.g. Community Paediatrics, CAHMS etc.


AUTISM ASSESSMENT SERVICE
FOR CHILDREN AND ADOLESCENTS 4-15 YEARS, LIVING IN PORTSMOUTH AND S.E. HAMPSHIRE
REFERRAL PATHWAY
Possible Autism identified by: Parents, Health Visitor, Teacher, School Nurse, Educational Psychologist, Speech and Language Therapist.
Possible Asperger's Syndrome identified by: Parents, Health Visitor, Teacher, School Nurse, Educational Psychologist, Speech and Language Therapist.
Refer to
GP, Community Paediatrician, Child Development Team, Hospital Paediatrician
GP, Community Paediatrician
Probable Autism
Probable Asperger's
Locality Consultant Community Paediatrician
Locality Consultant Child & Adolescent Psychiatrist
DIAGNOSTIC UNCERTAINTY
AUTISM ASSESSMENT SERVICE – 4-15 YEARS
Child Development Centre
Core Team Members: Dr Kirsteen Stevenson, Consultant Child Psychiatrist; Ms Lucy Prosser, Specialist Speech & Language Therapist; Gilly Williams, Specialist Speech and Language Therapist; Dr Kat Allen, Clinical Psychologist; Nicky Phillips, Educational Psychologist (covering Portsmouth); Cerian Hughes, Educational Psychologist (covering South East Hampshire; Locality Consultant Community Paediatricians.
9 children per year will be assessed by the Portsmouth Service
17 children per year will be assessed by Southampton Service (Bursledon House have a contract to assess 17 Portsmouth Children per year)

12 Consultation

12.1 In August/September 2011 the Integrated Commissioning Unit consulted people living in Portsmouth who are affected by autism, and people working in services in the Portsmouth area, to obtain their views on draft objectives for the Autism Board to review, prioritise and agree to inform development of the Autism Strategy.

12.2 The survey was available from the Portsmouth City Council website with options to complete on-line or download a paper version. Respondents could also request a paper version from the Integrated Commissioning Unit. Local groups/services were made aware of the survey either by face to face contact, telephone or email. Eighty people responded.

12.3 Topics covered by the survey included:

- Education
- Employment
- Health and social care services (including assessment and diagnosis)
- Information and awareness

12.4 The main themes were:

Parents of adults with an ASC (seven responses)

- Mixed experience of education services
- Inadequate carer services available

People with an ASC (11 responses)

- Support in education services was disorganised
- Need for clearer information on diagnosis and support available
- People valued the services from the voluntary sector
- Frustrations with adjustments in employment
- Need for increased awareness amongst other people

Professionals working with people with ASC (42 responses)

- Effective training
- Lack of educational support
- Better transitional support
- Assessment and diagnosis
- Inadequate carer services available
- Unprepared criminal justice system
- The need for better awareness

Parents of children with ASC (11 responses)

- Concerns raised regarding education experiences
- Improvement of training needed
- Lack of understanding and awareness

See Appendix A for a summary of survey results.

13 Conclusion

13.1 More ASC diagnoses have been recorded by GP Practices in 2011 compared to 2010. Refining data requests next year will provide a more accurate picture of the prevalence of ASC.

13.2 The differences between estimated and recorded prevalence of people living with autism suggests that there are more people living with autism in Portsmouth than we are aware of. One priority of the Portsmouth autism strategy should be to identify people with autism.

13.3 The data for this report gives the Integrated Commissioning Unit a better understanding of the number of diagnoses in Portsmouth. However, it does not give accurate numbers of the ages of clients or if they have one or two diagnoses. It is also missing in-depth details of the needs of this client group and their experiences of services.

13.4 A young person with ASC who does not have a learning disability or a mental health illness has no specific service for them to move on to. It would be valuable for the Integrated Commissioning Unit to find out during consultation whether there is a need for continuing support or if the local autism services offer sufficient provision.

Appendix A

Summary of Key messages – Survey Results, 2011

1 Survey Results - Parents of Adults with an Autistic Spectrum Condition

1.1 Overwhelmingly, parents have found it very difficult to get support for their son or daughter, themselves or their family as a whole: "We were very lucky because we have a very supportive GP who sent us to a centre in Kent because there is nothing in the Hampshire area". For other parents "I will never forget the feeling of desperation, of loneliness, of complete helplessness. I had no one to turn to".

1.2 Families believe a son or daughter with an autistic spectrum condition dominates the whole family's life. This means "we learned to live with his lists, timetables, holidays planned up to a year in advance".

1.3 People with an autistic spectrum condition are very likely to have anxiety, depression, struggle with social situations and be socially isolated. One parent commented, "His experiences throughout his life have led to mental health problems…he still suffers from depression and anxiety". There were a substantial number of similar points made by parents.

1.4 This stress and anxiety is largely related to social contact. In one parent's opinion her son "has no understanding of the impact he has on others around him" and in another's her son "Is unable to make friends". A reluctance to initiate social contact is a recurring theme, along with a view from parents that their sons and daughter are happiest living in their own "bubble".

1.5 In one case parents were not able to be in physical contact with their son or daughter or eat the same sort of foods. The parent recounts their experience of home life "We spend hours not talking to each other" and went on to explain phrases could be taken very literally leading to difficult problems.

1.6 Parents believe people with autism have their own world view, different from other peoples. Social stories can provide an insight into this life "He has recorded his stories of these families, and the autistic young person is always getting into trouble".

1.7 The experience of education was very mixed, many people had been educated outside the city, although there was also praise for education support in the City. The key feature that emerged was the importance of detailed planning during transfers between services, "Staff at The Willows nursery and Cliffdale School were exceptionally helpful and we all made the transition to Hampshire very smoothly".

1.8 Parents did not believe opportunities to take a break from caring were anywhere near adequate. Many Carers had experienced relationship break up and said the felt "vulnerable", or "anxious and depressed". Although friends and family gave support in younger years, many parents are still unhappy with the range of support they experienced.

1.9 A very significant proportion of the people who responded felt there should a media campaign aimed at the public, employers, professional staff and families where members had an autistic spectrum condition. Many parents described their learning experience, caring for someone with an autistic spectrum condition, as a positive experience that enriched their lives - “I am extremely proud of my son and would not be doing the job I have today without him”.

2 Survey Results - People with an Autistic Spectrum Condition

2.1. Education received the greatest amount of attention amongst the responses from people with autism. Most people found the support they received in education was disorganised and not very good. One respondent suggests “somebody should be employed by the school who understands someone with autism”. Most people describe a lack of understanding and awareness about autistic spectrum conditions. More worryingly on respondent says: ‘I was bullied heavily at school for being different by pupils and teachers alike.” Almost all respondents with an autistic spectrum condition describe feeling anger and frustration because of their interaction with the education system. A proportion of people who responded did not receive their diagnosis until after they left school. However, their reported experiences do not differ significantly from those with a diagnosis suggesting there may not be widespread understanding of autism within education settings. Nevertheless, some respondents are very clear about what would help: “Someone you can talk to and speak up for you, help you solve problems with people.” And equally clear they did not get that help whilst at school or college.

2.2. Day to day life is described as “anxiety provoking” and people who responded reported they lacked confidence. Almost all people report that their experiences at school were where these feelings are established. Around half the people who responded to the survey reported difficulties in dealing with other people and socialising - this was an overwhelming concern. Voluntary sector organisations are particularly helpful in helping people to cope with day to day life one respondent says that PASN has “allowed us to go out as a family without anxiety” and Pirates “allows me to go to a place where I feel normal”. Just under half of the respondents say they have developed coping mechanisms, although this has not been easy. Many people’s special interests such as music or anime help them to cope with stress, but for some simply getting away from everyone at the weekends and evenings is what it takes.

2.3. The diagnosis of an autistic spectrum condition has been problematic for all respondents. Some respondents say they would like information about the diagnosis process and what it means. Many people said they received little help after a diagnosis. Many respondents wanted clearer information about what it means to have autism, how to deal with it and what sources of support there are. Typical responses included “Practical, structured support and guidance on living with ASD” and “Clearer ways of achieving a diagnosis. Describing what happens at a diagnosis. How to get a diagnosis, costs etc.”

2.4. Services and support: The majority of people who responded were receiving some sort of support to help them cope with the impact of autism in their lives. The respondents used voluntary sector services more than any other type. Most respondents valued their voluntary sector support very highly. However, one responded felt the service they received was not at all helpful. A common request for statutory support was psychology or psychiatry, in order to avoid taking anti-anxiety medication. Mixed experience of social care support was reported “I have had two social workers, one was easy to get on with; the other was too bossy”.

2.5. Employment: Some support in employment came from Mencap, who visited to support a work placement regularly, however the service ended after three months. Respondents express some frustration with employers around making adjustments: “I am allowed to work from home one day a month which is the same as everybody else”. The most requested adjustment was a quiet environment.

2.6. Information and awareness: Many respondents expressed frustration about their interactions with other people, “College has been difficult not the work but the other students being difficult”. Many people had difficult socialising and the ability to withdraw to a quiet environment or be away from social situation was talked about frequently. Almost all respondents valued increased awareness amongst other people. Almost all respondents had found it difficult to increase their own understanding of what autism was and how it might affect them, one respondent said “more info about support groups would have been helpful”.

3 Survey Results – Professionals working with people with Autism

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

3.1.1. It was recognised there was a considerable amount of helpful specialist training related to autism including PAATHS, IDB, TEACCH, PELICAN, PECs, graduate and post graduate education and training to use social stories and for sensory integration.

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

3.1.3. The experience of parents and people with an autistic spectrum condition as part of a training process, or to improve the effectiveness of staff was mentioned: “training in which parents and professionals work together are also very effective” and “talks from people with autism about their experience”.

3.1.4. Parents and people with autism would benefit from training on autism related issues, parents particularly ask for this sort of help.

3.1.5. Training in mainstream education was described as inadequate, a substantial number people recommended more training from mainstream teachers.

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

3.2. Many of the staff 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.

3.3. There was a substantial amount of comment on the transition of young people from school to college or work. In general the view was 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 years. There was a view that development in this area needed better user involvement, "include individuals with autism!" is the comment from one professional discussing the transition board. For one professional staff member discussing improvements they commented "I feel strongly that child and adult pathway needs to be joined"

3.4. 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 might add considerable value to the diagnostic procedure: "why they are finally relieved to know what is 'wrong' with them, they were not given any information on where to go for support".

3.5. 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.

3.6. The criminal justice system was described as "unprepared" for people with autism by one respondent and the range of comments suggest this might well be the case. It was reported that autism issues aren't high enough profile for many criminal justice sector employees to prioritise training. One respondent remarked on the usefulness of PCSOs in addressing issues that the impact of autism created.

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

audiences. Views of audiences and the impact of a campaign included "Parents should be more educated about what their children, young people are capable of because I feel a lot of them hold back because they say they can't travel alone'; 'opportunities are limited due to the lack of understanding about autism/Aspergers'; 'educate employers about the benefits of employing someone with autism'; 'placements tend to fall down when there is insufficient understanding and empathy from the general workforce.'

3.8. Families are often described as suffering anxiety and depression, despite this respondents claim they discharged mental health services, even if they have a mental heath condition, because they also have an autistic spectrum condition.

4 Survey results - Parents of children with disabilities

Two clear priorities were evident amongst the themes:

4.1. 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, and difficulties with accessing help for children in school.

4.2. A significant number also expressed concerns regarding a lack of resourced provision attached to mainstream schools at both primary and secondary, and provision for youngsters of 13+ years with complex needs. There were positive comments about accessing the current ASC resourced provision.

4.3. 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/has impacted on children's experience of school and their outcomes.

4.4 Other key issues identified were:

4.4.1 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 years practitioners and a lack of services to support families at home during their child's early years.

4.4.2 Where children and families had received Early Years support through Willows, Portage or small groups, positive comments were made. In addition some parents felt that Education professionals and Parent Partnership offered useful support.

Diagnosis and Health Care

4.5 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 information available.
- differences between services and families' experiences in each (with much greater dissatisfaction from those who were seen in Southampton).

The themes around diagnosis highlighted a need for:

a) A timely, multi-disciplinary 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.
b) 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/ providing support for the family.

4.6 In addition there were clear messages about:

a) The importance of specific therapy and health services, including Occupational Therapy, Speech and Language Therapy, Health Visitors and CAMHS services. Themes reflected mixed experiences for families, with some concerns expressed about the provision available from the OT and SLT services. A number of parents expressed clear wishes to be able to access 'Specialist' practitioners more readily i.e. from SLT, Educational Psychology etc.

b) 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.

c) A recurring theme throughout was a need for awareness-raising amongst professionals.

Family support

4.8 A highly significant 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.

4.9 A significant number of participants highlighted the positive contribution made by support groups in the city, particularly PASN, 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.

4.10 Parents commented positively on training experiences although there was a call for training for parents to be free of charge.

4.11 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.

4.12 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/ children with autism.

Training

4.13 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 the Pirates group. Concerns were raised about accessibility of training for parents, with several people suggesting that training needed to be free of charge to parents.

4.14 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, PECS, Social Stories etc.