

FOI 1213 103B

Summary Issue – Autism Spectrum Disorder

This information relates to NHS Bristol

| Question | Response |
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| 1. How many adults you have with a diagnosis of autistic spectrum disorder (any, although if there are separate statistics for Asperger's, HFA, LFA, they would be appreciated) in your area; | <p>Recent epidemiological research indicates that an estimated 1% of the population have an autism spectrum condition (Brugha et al, 2009). Many adults with autism remain undiagnosed, as a result of having not been assessed during childhood; this is particularly an issue for adults with Asperger syndrome. It is therefore highly unlikely that NHS Bristol, or any other Primary Care Trust in the UK, has any good demographic information about the local prevalence of autism.</p> <p>Bristol is however one of the only areas in the country to have an established specialist autism team (the Bristol Autism Spectrum Service), providing a diagnostic service for adults with Autistic Spectrum Disorder (ASD). To date the team have diagnosed 111 individuals in Bristol with autism. This however is in no way indicative of the actual number of people with ASD in Bristol; these are merely the people who have been seen for assessment by BASS.</p> <p>BASS remains a very small service, with very limited resources in terms of meeting the current demand for diagnostic assessment.</p> |
| 2. How many children; | The Avon Longitudinal Study of Parents Children (ALSPAC) showed a local prevalence rate of autistic spectrum diagnosis as 6.2 per 1000 |

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| | <p>children up to the age of 11 years of age. A small local study of children on 5 GP registers found an averaged rate of ASC diagnosis of 5.5 per 1000 children, aged 0-18 years. These figures suggest that approximately 700 children in Bristol are likely to have ASC.</p> |
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| <p>3. What diagnostic services are available to:</p> | |
| <p>a) adults</p> | <p>Bristol Autism Spectrum Service (BASS) offers a diagnostic service to individuals from 18 years upwards. This consists of the following:</p> <ul style="list-style-type: none"> • Stage 1: Assessment 2 x 1.5 hour assessment appointments by DISCO/ADIR/ADOS qualified diagnosticians to conduct a full clinical interview in addition to the analysis of a battery of pre-assessment measures and the administration of tests of social reasoning and/or cognitive reasoning as required. • Stage 2: Feedback Individuals are offered a feedback session where the results of the assessment and the implications of this are discussed with them in detail. If they have been given a positive diagnosis, they are offered an appointment for a comprehensive needs assessment, signposted to appropriate mainstream services, and given the opportunity to attend a post-diagnostic psycho-educational group. • Stage 3: Needs assessment An individual needs assessment is undertaken by the team social worker. This meeting includes an assessment of an individual's needs in a number of different areas of life; such as housing, |

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| | <p>employment and mental health. Following this, referrals can be made for a full Community Care Assessment, and/or individuals can be signposted to relevant services as required.</p> <ul style="list-style-type: none"> • Stage 4: Report A detailed report is written to the referrer and client. Relevant referrals are also made to other agencies as appropriate. • Stage 5: Post-diagnostic psycho-education group. Individuals attend a 6 session post diagnostic psycho-education group. • Stage 6: Access to the Autism Advice Service (flyer attached). |
| b) children; | <p>Child Diagnosis and Assessment</p> <p>Parents are key observers of their child's progress and needs and when they become concerned they will often discuss their concerns with GPs or early years settings/schools.</p> <p>All children routinely receive professional assessments, eg by health visitors and teachers. Additional needs, including possible indicators of ASC, may be detected in any of these. Health visitors undertake family health and developmental assessments of all young children.</p> <p>In Early Years settings and schools, when a young child is identified as showing communication, social interaction, play and behaviour difficulties, a</p> |

plan will be developed between the pre school setting, the parents, and appropriate others (eg Speech and Language Therapists) to help the child, under Special Educational Needs School Action, School Action Plus, or, in Bristol local authority maintained schools and some academies, through School Action Plus Enhanced (SAPE) systems.

If an Early Years child's difficulties do not improve, a multi agency assessment may be offered at a child development centre, or in a community setting, health and pre school provision staff cooperating with parents to combine information about how the child is at home and at pre-school. This can lead to a diagnosis, but if the assessment is inconclusive and difficulties persist, this should always lead to further action to help the child.

A school age child who has difficulties with communication, social interaction, play and behaviour, for whom early intervention by school etc is not working, will be referred through an informed professional e.g. GP, health visitor, school nurse or teaching staff to the Childrens Community Health Partnership 'single point of entry'. Children referred will receive a general developmental assessment from at least two health professionals, (eg a paediatrician, speech and language therapist or clinical psychologist). Ultimately the NHS is the agency with responsibility for diagnosing whether or not a child has ASC (frequently described as Autism Spectrum Disorder).

If it becomes clear that, even with appropriate intervention and support, the current educational setting / school requires additional support to meet the child's needs, it may be appropriate for a statutory assessment of Special Educational Needs to be considered.

When a child is diagnosed with ASC, a meeting should be held with parents

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| | <p>to help them understand the diagnosis and a multi agency support plan should be developed. If the diagnosis is not clear, more detailed ongoing assessment and monitoring may be undertaken.</p> <p>A key worker will be identified for children up to 5 years of age following assessment.</p> |
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| <p>4. What agencies or teams you have that work with autistic people, provide support/services, strategise, etc.</p> | <p>BASS has aimed to provide a cost-effective, local solution to the lack of services for this client group. It does this by primarily helping existing services work more effectively and efficiently with adults with an ASD. It has delivered three primary functions:</p> <ul style="list-style-type: none"> • To identify/diagnose adults with Autism Spectrum Disorder in Bristol and offer a comprehensive package of post diagnostic support. • To help people with ASC to access a range of appropriate mainstream services with the aim of reducing social exclusion, promoting well being and reducing contact with secondary mental health services. • To improve the ability of those providers to met the complex needs of people with ASD through the provision of specialist training and supervision. <p>BASS has recently opened the Bristol Autism Advice Service, running each Friday, with the aim of bringing together agencies, skills and knowledge in one setting that is accessible and feels safe for service users. This is a low cost, high impact, preventative service aiming to bridge the gap for those who fall between LD and MH services and are receiving no support. The</p> |

service is currently accessible to anyone with a diagnosis of autism in Bristol, or anyone who has received support from BASS. BASS are actively pursuing alternative streams of funding to enable this to continue on a sustainable basis, The service is working in partnership with other agencies, including:

Mental Health Matters (a local supported employment provider).

- Rightsteps (the local IAPT provider for Bristol)
- Housing and Benefits agencies.

This is done with the aim of bringing together resources and expertise from a range of public, private and voluntary sector organisations to help improve health, social care and employment outcomes for adults with autism in Bristol.

Work clubs are provided at the Advice Service each Friday, with volunteers from Mental Health Matters and BASS staff. Other group interventions include: anxiety management, mindfulness, problem-solving and social skills groups. In addition, staff are available to see people on an individual basis to provide direct 1:1 support with a range of issues including: housing, benefits, further education and signposting to agencies across the care pathway.

Information on Bristol services for children, young people and their parents can be found on two websites:

<http://www.autism.org.uk/our-services/residential-community-and-social-support/parent-and-family-training-and-support/family-support/teenage-life.aspx>

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| | <p>http://www.findabilitybristol.org.uk/</p> <p>The Joint Adult/ Children Autism Strategy Group has developed a draft Autism Strategy for Bristol, which has just completed a 12 week consultation stage. See http://www.citizenspace.com/bristol/cyps/autism_strategy</p> <p>Following this consultation and finalisation of the Strategy, an implementation group will be set up.</p> |
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| 5. An email address/website for each of these agencies or teams where possible. | BASS@awp.nhs.uk |

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| 6. What the typical process should be for an adult in your area first asking their GP for an assessment for autistic spectrum disorder to receiving a diagnosis/support. | <p>GP refers to BASS for assessment and provides relevant presenting information.</p> <p>BASS Triage (gaining additional information from GP as required) and put on waiting list.</p> <p>BASS lets GP/patients know they are on a waiting list and indicates to them the time frame in which they expect to be seen.</p> <p>BASS sends the patient a list of local and national organisations where they may be able to access additional support from while they are waiting for their diagnostic appointment. This list includes contact details for various agencies such as:</p> <ul style="list-style-type: none"> • Employment • Housing |

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| | <ul style="list-style-type: none">• Legal• Social Services• Benefits etc <p>They also send contact details for support around mental health issues.</p> |
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The information provided in this response is accurate as of 25th June 2012

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