

Asperger Service Norfolk: Annual Report 2011

The Asperger Service Norfolk was set up following the passing of The Autism Act 2009. It also responded to local pressures from stakeholders including parents, carers, the registered charity Asperger East Anglia and local MPs.

Fulfilling and Rewarding Lives

Following The Autism Act 2009 a strategy on services for adults with autism, *Fulfilling and Rewarding Lives*, was published in March 2010. The government's vision for service delivery was set out in this strategy: *'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.'*

Shortly after, statutory guidance for local authorities and local health bodies entitled *Implementing "Fulfilling and rewarding lives"* was published by the Secretary of State for Health on 17 December, 2010. The guidance states that adults with autism should be able to enjoy an improved quality of life, increased personal autonomy and greater inclusion in every aspect of society.

The strategy focuses on five core areas of activity:

- Increasing awareness and understanding of autism among frontline professionals
- Developing a clear, consistent pathway for diagnosis followed by the offer of a personalised needs assessment
- Improving access to the services and support which adults with autism need to live independently within the community
- Helping adults with autism into work
- Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.

Asperger Service Norfolk

Asperger Service Norfolk has structured the service such that delivery is consistent with the above guidance. We either meet or have clear plans to meet the recommendations made as part of the statutory guidance.

The service is advised by a steering group which includes a range of stakeholders: Health Commissioners (NHS Norfolk and Great Yarmouth and Waveney); representatives from the joint Learning Disability Service; a representative from Norfolk and Waveney Mental Health; members of Adult Services Asperger East Anglia; a member of Autism Anglia MP's; Parents, Carers and a link with people who have Asperger syndrome.

The service started with a three month trial in January 2010. Successful performance was followed by recruitment to two substantive professional posts (a psychologist and a social worker). In addition a service level agreement between Norfolk County Council and Asperger East Anglia for support workers and a carer support post was signed.

The partners in the service are the Norfolk County Council Adult Social Care; NHS Norfolk; Great Yarmouth and Waveney NHS Trust; and Asperger East Anglia. The service Lead is Dr Penny Morgan, Norfolk Learning Disability Service, Norfolk Community Health and Care NHS Trust.

Current service

The service is based in Norwich and covers the county of Norfolk. Recent statistics indicate a population of approx 2500 to 2900 people with Asperger syndrome in Norfolk.

Details relating to referral, diagnosis and case load can be seen at Appendix 1.

Asperger East Anglia provide a gateway and administration service. An open referral policy is operated, with referrals from GPs, Mental Health Link workers, Learning Disability Team staff, social workers and people with AS themselves. As noted

above, pathways have been developed for diagnosis, as well as treatment and life planning. Initial screening is undertaken by the team support workers via interview and screening tests. Outcomes are negotiated with the client, and following discussion with the team's psychologist and social worker pathways are agreed.

Following diagnosis (or on referral if previously diagnosed) the client and team member work together to prepare a plan that can be used as the basis for future work. This plan may be used to form the basis for a personal budget request; or it may indicate specific therapeutic intervention. The client is encouraged to formulate realistic and achievable goals and the team then work jointly with the client to secure appropriate employment, education, or support from other agencies.

Post diagnosis we offer information and support workshops for clients and (separately) for parents and carers. The service makes a positive contribution to individual's lives by providing timely support and a skilled and knowledgeable team of workers who are able to understand the specific problems faced by people with AS, HFA and the systems surrounding them.

Clients requiring specialist forensic or benefits advocacy are supported and signposted to other appropriate services. Meanwhile the team provide support, information, and advocacy to client's parents, carers and other medical or social services professionals who are living or working with them.

The team provide individual advice and support for parents, carers and partners of adults with Asperger syndrome, by means of telephone, text, e-mail, as well as home or office visits and attendance with carers at meetings, Tribunals, Court, prison and police stations. Informal workshops and Information days are an opportunity to provide information and share concerns.

Raising Awareness

At present, Asperger East Anglia (AEA) are continuing to provide awareness training to a range of organisations. ASN recognises the value of this training and seeks to build on the frameworks created.

Asperger Service Norfolk offer consultation and advice to other agencies and professionals who may be working with individuals with AS or HFA. Asperger Service Norfolk staff members are also encouraged to participate in specialist education and training. Opportunities for sharing new developments, learning experiences and research findings, are scheduled into regular team meetings. Asperger Service Norfolk have planned a rolling programme of presentations to external services and agencies, including GPs, Mental Health teams and Children's Services to raise awareness of our team, the services provided and referral process. Where transition to adult Asperger services is appropriate, the team will work closely with referring agencies and professionals involved to facilitate a smooth transition.

Pathway for Assessment

“Fulfilling and rewarding lives” states that:

- On receiving a diagnosis of an autistic spectrum condition, adults should be able to access a community care assessment and carers, a carers assessment.
- Services should put in place a clear route through which a person can receive a diagnosis and get a community care assessment.

Asperger Service Norfolk offer diagnostic assessment and have developed a pathway with a clear route through which individuals can receive a diagnosis. The pathway also identifies points at which community care and carers' assessments may be triggered. These may be conducted in-house, or by the referring agency. When being given a positive diagnosis, individuals are advised that they may request a community care assessment and that their carers also have the right to an assessment of their needs.

The guidance also states that relevant local organisations such as social care teams understand the pathway to diagnosis. Asperger Service Norfolk are undertaking a programme of presentations to local services informing them of the referral process for diagnostic assessment and the services and support that the team can offer.

The strategy document recommends that relevant information be provided to individuals receiving a diagnosis of an autistic spectrum condition, and their families or carers, to help them understand the condition and access local support.

At the point of diagnosis, individuals are given relevant information about Asperger Syndrome or Higher Functioning Autism as well as details of support and services that the team can provide. Asperger Service Norfolk (ASN) are offering specific post diagnosis sessions across the county for both individuals and their families or carers. These sessions include information about Asperger Syndrome and Higher Functioning Autism as well as addressing psychological responses to receiving a diagnosis. At these sessions staff describe the services and support that the team can provide as well as offering opportunities to ask questions. Where appropriate, additional post-diagnostic support is provided to individuals and families or carers.

Improving access to services and support

The team support individuals, and families, to access appropriate community services and support. This may be through advocacy or liaising with other agencies, such as housing, benefits or health. Support and advice may also be provided to services and external agencies to assist them to make appropriate adjustments to better meet the needs of individuals with Asperger Syndrome. Where eligible needs are identified under the Community Care Act, Asperger Service Norfolk will work alongside existing agencies to ensure that these are met in a way that best meets the needs of the person with Asperger Syndrome. Adults with Asperger Syndrome, or their carers, can visit or contact the team to access advice and support with some of the day-to-day issues that can present a challenge for someone with an autistic spectrum condition. This might include dealing with budgeting, official letters, housing, communicating with health professionals etc.

Helping adults with autism into work

The team work with individuals with Asperger Syndrome to help them identify their strengths, weaknesses and personal preference to put together a Life Plan. This may include plans to maintain or start a job. Team members have skills and experience to support those in work to maintain their roles and can also work with

employers if called upon to do so. Adults with Asperger Syndrome can be supported to find work or training and can also receive help negotiating the complexities of the benefits system.

Planning and developing services

Asperger Service Norfolk endeavour to keep key stakeholders and commissioners informed of the development of the service and progress of the work undertaken. This includes formal reports and audit information as well as feedback through steering group and other relevant meetings such as the County Council's Health Overview and Scrutiny Committee.

Best practice shows that where outcomes for adults with an autistic spectrum condition have improved this has been as a result of the '*development of local teams dedicated to supporting adults with autism, from diagnosis through to health management and help with day-to-day living*'. These approaches have proved to be cost-effective because they '*provide the integrated support needed to help adults with autism be economically included and reduce the likelihood of them falling into crisis – requiring costly and complex mental health interventions or coming into contact with the criminal justice system*'. (Fulfilling and rewarding lives) Asperger Service Norfolk are aware of the risk that individuals with Asperger syndrome can 'fall through the gap' between learning disability and mental health teams and work closely with these services to ensure that appropriate support is provided. This work is undertaken in partnership with Asperger East Anglia as well as working alongside individuals, families, other services and agencies.

Case Studies

Below are some anonymised examples of the teams work.

Case 1 'D'

D is a young man aged 21 and was referred to Asperger Service Norfolk by his leaving care team. D has been looked after by social services since he was 8 years old and had some very challenging behaviour and would occasionally have violent

outbursts at times of stress and frustration. Although D had been living independently he continued to have problems with maintaining his independence and reported mental health problems (anxiety and depression). He was clinically obese. The leaving care team were particularly concerned about the risk of an outburst of frustration leading to D losing his tenancy, or even contact with the police. Recognising that D may have some underlying problems aside from his mental health his social worker asked Asperger Service to assess D for Aspergers syndrome. This resulted in a positive diagnosis for Aspergers syndrome and borderline learning disability. As part of his assessment for Aspergers, D was also seen by a social worker who was able to identify eligible needs for social services and make the appropriate referral for services. D was offered a commissioned package of care via the Learning Disability services and ASN worked with D to help him understand his condition and begin to manage his anger more appropriately. D has developed his life plan and feels much more confident about his future.

Case 2 R

R is a 45 year old male who has had lifelong problems with his mental health and been treated by his GP for depression and anxiety with medication and referred for therapy. R's response to both of these approaches had not made much improvement to his emotional wellbeing which has been exacerbated by long term unemployment issues. Despite efforts from his GP to help R with his difficulties R continued to have problems with his depression and anxiety and would regularly report his emotional distress to his GP. R was eventually referred to Asperger service and seen by a support worker and social worker from the team; this initial meeting resulted in a positive screening for Aspergers syndrome which was discussed with R. R agreed to be put forward for diagnosis and expressed a great deal of relief that there may be some reason for the various difficulties he had experienced all of his life. He has engaged well with the support offered as he feels that the staff have some understanding of his long standing difficulties. The ASN team have been advocating on his behalf whilst R is waiting to for his diagnostic assessment.

Case 3: A

A is a 59 year old mother of a son who has been diagnosed with AS for 5 years, but has had long term difficulties. She is in reasonable physical health, but sees her GP regularly about anxiety and high blood pressure. Her husband has been recently diagnosed with cancer. A lives in his own flat, but is highly dependant on his elderly parents for help with finance and keeping his flat well organised and clean (environmental health have been involved). A has a habit of arriving at his parents' house at odd times of the day, expecting immediate help, which they find very stressful. Now, with the extra demands of hospital visits for a course of treatment, A's mother has felt close to despair. ASN supported the parents to put boundaries around A's visits home and helped them to accept that if they were not at the house when A arrived, A would cope with this, either waiting or calling back later. A's mother reports that both herself and her husband feel tremendously relieved and their relationship with their son has improved as a result.

Case 4: K

K is a young woman who has a long history of contact with services, firstly as a looked after child and later with Learning Disabilities services and children's services when she became a parent. K presented with various difficulties and would sometimes become involved with the police because of violent incidents (as victim and perpetrator). K had multiple and complex difficulties with housing, health and an outstanding charge of affray but was often chaotic and difficult to engage. K reached crisis point and was at risk of a custodial prison sentence and losing her local authority accommodation. The ASN social worker was able to engage with AS through understanding her needs as an AS sufferer and support K through the criminal justice system by ensuring she understood what was required of her and reminding her of the various appointments with Probation and the courts she needed to attend. K was eventually given a community sentence following input from ASN and placed on emergency re-housing register following direct intervention by ASN with Norwich City Council. K has been offered more suitable and appropriate housing allowing her to feel more secure and settled and the threatened custodial sentence has been avoided.

Case 5: W

W has a special interest in all things concerning the growing, production and use of tea. He has visited tea plantations in the Far East and reads widely on the subject. After dropping out of college because of bullying, W was drifting with no particular goals in life. His mental health was deteriorating. W contacted ASN whilst seeking work and, given his specialist skills and knowledge, a placement was arranged and supported at a shop specialising in tea sales. W was able to use his accumulated knowledge fully as part of this work; the other staff gained some knowledge of AS via the ASN support staff. W was well thought of during his placement and offered part time paid work at the shop. W has a clear purpose in life and is growing in confidence as a result.

Things people have said about the service:

'That's a relief, now I can have some sort of closure' – 23 year old woman, following feedback of a positive diagnosis of AS

'Relieved....it explains so much that happened in the past' -post diagnosis comment from 50 year old man

'I'd missed out so much....if it had only been picked up sooner...' – post diagnosis comment from 45 year old woman

'You are my guardian angel'- parent of person with AS

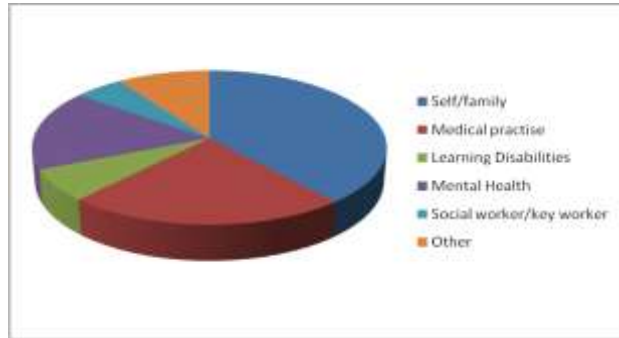
'At last I understand why I've always felt so different' – person with AS following post diagnosis workshop

'I think I can cope with my life now' – person with AS on completion of 8 therapeutic sessions.

Asperger Service Norfolk Client stats as at 15-4-11

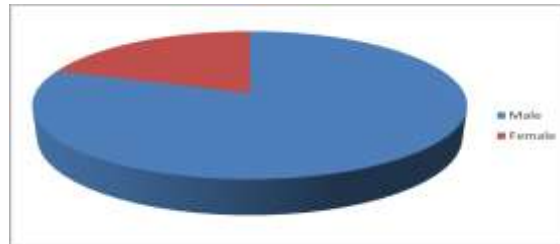
Asperger Service Norfolk Referrals - Referred by

Self/family	69
Medical practise	41
Learning Disabilities	12
Mental Health	30
Social worker/key worker	9
Other	17



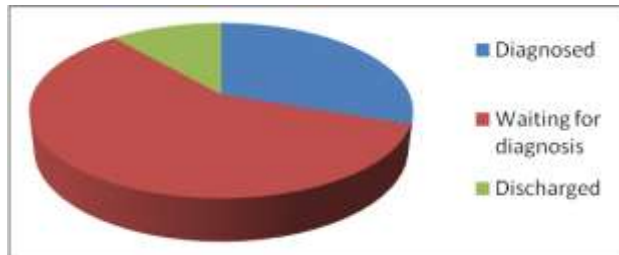
Asperger Service Norfolk Referrals - Gender

Male	146
Female	36



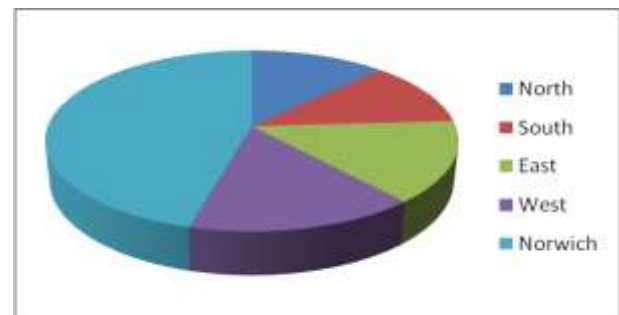
Asperger Service Norfolk Referrals - Diagnosed

Diagnosed	54
Waiting for diagnosis	104
Discharged	20



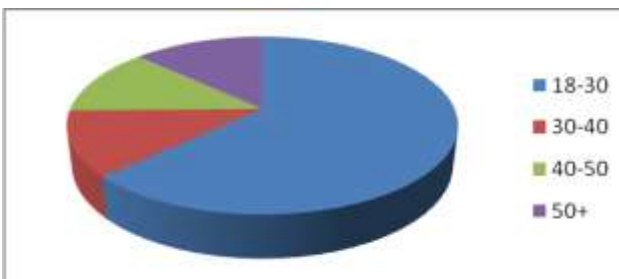
Asperger Service Norfolk Referrals - County location

North	22
South	21
East	26
West	28
Norwich	82



Asperger Service Norfolk Referrals - Age

18-30	112
30-40	21
40-50	22
50+	23



Asperger Service Norfolk Referrals -support requested. (More than 100% as some have more than area of support)

Financial/benefits	30
Housing	18
Life skills/social skills	63
Work/Seeking work	31
Other	12
None requested	26

