

Anyton Council



Market Position Statement for people with
High Functioning Autism (HFA)
and Asperger's Syndrome (AS)

Example MPS



The Anyton Pledge

Therefore, by December 2013 we will have...

- Had individual discussions with all the major care and support providers in our area about our future strategic direction based on this document. We will have met with any other provider who requests an interview and held a number of open forums to which all local businesses will be invited.
- Met with senior managers from a range of local public services (e.g. library, college, GPs) to help support them to make such services are more accessible to people with HFA/AS.
- Developed a system for collecting information about people with HFA/AS, to enable better analysis about needs and service uptake
- Conducted a market review of the priorities for people with HFA/AS and their families. This will include children, young people and adults.
- Worked with the new Anyton clinical commissioning group (CCG) to issue a statement about future joint commissioning of support services.
- Examined the feasibility of extending some of the current transitions and employment services provided by LD services to those with HFA/AS.

A sense of direction

Anyton Council wishes to stimulate a diverse market for care and support offering people a real choice of provision. This may come from existing providers of care and support, other local businesses, those who do not currently work in the authority or from new business start-ups.

To achieve this aim the authority recognises that it needs to know how best it can influence and support the local market to achieve better outcomes and value. We see our Market Position Statement (MPS) as an important part of that process, initiating a new dialogue with providers and businesses in our area, where:

- We more than meet the government's requirements.
- Market information can be pooled and shared,
- The Council is transparent about the way it intends to strategically commission and influence services in the future and how it wishes to extend choice to care and support consumers.
- Services can be developed that people with an HFA/AS and their families need and want.

The Anyton Market Position Statement

This Market Position Statement (MPS) is designed to contain information and analysis of benefit to providers of support services and other businesses in the local authority of Anyton.

It is intended to help identify what the future demand for care and support for people with HFA/AS might look like and to act as a starting point for discussions between the local authority and those who provide services.

It contains information concerning:

- What Anyton looks like in terms of current and future demography and service provision?
- The Council's intentions as a facilitator of support for people with HFA/AS
- The Council's vision for how businesses might respond to the changing needs for care and support in the future.

The Autism Act and the Equality Act.....

.....require that the needs of adults with autism be taken account of by all services including universal community and health services and other businesses.

The White Paper 'Caring for our future'

.....sets out the vision for a reformed care and support system:

- “The government supports the diverse range of care providers that currently offer care and support, including user and carer led organisations, small and micro enterprises and social enterprises.
- To strengthen this diversity, the Government will introduce a duty upon local authorities to promote diversity and quality in the provision of services.

Key Messages in this MPS

The number of children and young people with a diagnosis of autism moving to adult services is expected to grow by 59% between 2011 and 2015. In 2011 there were 170 children aged 11-15 with a diagnosis of autism.

People with HFA/AS stated that their biggest priority is to have access to services which enable them to be independent and help them to develop self-management strategies.

The Autism Act (2009) and the Equality Act (2010) require that the needs of adults with autism be taken account of by all services including universal community and health services.

There is a need to improve the access for adults with autism to the services and support they need to live independently. This is particularly true for people with HFA or Asperger’s Syndrome given that so many of them are not eligible for funding from the local authority.

There is a need to provide a better range of housing options to meet the needs of people with HFA/AS.

There is a need for advocacy and brokerage to enable adults with HFA/AS to take advantage of self-directed support and the potential choices this opens up.

Better education, training and specialist employment support is required to help adults with HFA/AS into work and meaningful daytime activities.

The Local Authority has to make a 20% cut to the social care budget over the next 12 months. There are no extra monies currently available to develop services.

The Local Authority is keen to work in partnership with all stakeholders to support the facilitation of the market with the aim of finding creative, innovative and cost-effective ways to meet the needs of people with HFA/AS. Developing the market requires all stakeholders to actively engage and take responsibility.

Key National Priorities

The National Strategy for Adults with Autism sets out 5 key objectives:

- Increasing awareness and understanding of autism.
- Developing a clear and consistent pathway for diagnosis of autism.
- Improving access for adults with autism to the services and support they need to live independently within the community.
- Enabling local partners to develop relevant services for adults with autism to meet identified needs and priorities.
- Helping adults with autism into work.

In June 2012 NICE set out detailed guidelines for the recognition, referral diagnosis and management of adults on the autistic spectrum¹. This guidance recommends that each area should establish a specialist community-based multidisciplinary team for adults with autism to have a key role in the delivery and coordination of:

- **Specialist diagnostic and assessment services.**
- **Specialist care and interventions.**
- **Advice and training to other health and social care professionals on the diagnosis, assessment, care and interventions for adults with autism (as not all may be in the care of a specialist team).**
- **Support in accessing, and maintaining contact with, housing, educational and employment services.**
- **Support to families, partners and carers where appropriate.**
- **Care and interventions for adults with autism living in specialist residential accommodation.**
- **Training, support and consultation for staff who care for adults with autism in residential and community settings.**

Demanding Times

1% of adults (and children) have autism resulting in an estimate of 1831 adults 18-64 in Anyton in 2012. Of these 50% have LD and 50% have HFA (IQ of 70 or above).

For the Anyton population - As at April 2010, the Pupil Level Annual School Census 2010 (PLASC) shows that out of the entire school population in Anyton there were 443 (0.9%) pupils aged 0-19, identified as autistic via a Statement of Special Educational Needs or School Action Plus. This figure is clearly similar to the 1% prevalence rate identified in adults.

The number of children and young people with a diagnosis of autism moving to adult services is expected to grow by 59% between 2011 and 2015. In 2011 there were 170 children aged 11-15 with a diagnosis of autism.

There is also a marked increase (40 %) in the number of older adults aged 55 - 64. This is in line with growth in the population aged 65 and over. Assuming a 1% prevalence rate, the numbers aged 65 and over predicted to have autism would rise from 388 in 2011 to 538 in 2030.

Based on an estimated prevalence of HFA (ASC and IQ \geq 70) of 50% of all adults 18-64 with autism, and the reported rate of 30% experiencing a mental health problem, we might expect at least 275 adults with an ASC in Anyton to have a co-occurring mental health problem such as depression or anxiety.

From all the national and local information it is clear that the local HFA population will have a range of needs split into 3 broad groups:

HIGH NEEDS	Services Required
Severe and enduring mental health problem, risk of suicide, offenders, severe autistic traits, challenging behaviour, physical disability or frailty	Secondary and tertiary mental health services, Forensic MH services, Adult Care Management Services
LOW NEEDS	
Isolated lifestyle and few or no friends, unable to cook, shop, travel independently, budget or maintain personal hygiene, difficulty dealing with bureaucracy, completing forms, claiming benefits. Difficulty finding and keeping a job, dependent on family.	Diagnostic assessment, post diagnostic support and information social skills training, practical support with everyday tasks, access to mainstream services, Cognitive Behavioural Therapy, social clubs.
NO CURRENT NEED	
No problems with daily living tasks, living independently or in a stable relationship, in Employment	No services required



What do people with HFA / AS and their carers say?

The Autism Steering Group organised a number of consultations that were jointly facilitated with the National Autistic Society (NAS). These included focus groups, interviews and questionnaires.

People with autism

Social Inclusion: People find it difficult to communicate in a way that others understand. This leaves people feeling isolated and alone. People express a genuine desire to make friends with others who understand autism and/or are on the autism spectrum themselves. A desire to make contact with people who share common interests and to build genuine friendships with people who can act as a support network. People feel they need support to do this.

Access to services: People report feelings of frustration and anxiety related to feeling confused / getting into troublesome situations but not knowing why or what rules they have broken. In many cases these feelings are linked to a lack of awareness and understanding about autism by staff working in community services. This often makes generic services inaccessible. Many services are also inaccessible because the physical environment is too noisy, lights are too bright etc.

Training, Employment and Education: People report a desire to gain qualifications and skills and ultimately to get a job. People also report a number of difficulties such as not performing well in interviews due to issues with communication. Once in a job people often face discrimination and bullying due to their difficulties around social communication. People report a need for better understanding of autism by employers and job centre staff. They also report a need for more opportunities to engage in voluntary work, supported employment and access to job coaches.

Family carers

Social Inclusion: Parents worry about their adult children being isolated and alone with no friends, social interactions or relationships. People expressed anxiety about the lack of understanding from society and the vulnerability of their adult children caused by their lack of ability to communicate with others in the 'acceptable' way. Family carers want appropriate advocates to be available for their adult children.

Access to Services: Family carers report a lack of understanding about autism from community services. This leaves their adult children unable to access the same services as other people their own age resulting in isolation and an inability to get their health, further education or social needs met. This means that their adult children rely heavily on them to interpret and advocate. Family carers want their adult children to have access to services that provide them with guidance, advice and support that enables them to access generic community services to get their needs met.

Training, employment and education: People report that many employers are unwilling to make reasonable adjustments. This leaves adults on the spectrum under enormous pressure to 'fit in' at work. More often than not the stress becomes too much and people on the spectrum lose their jobs. This often results in their adult children becoming increasingly depressed and anxious.

Key Messages from People with HFA and AS.....

- Our biggest priority is to have access to services which enable us to be independent and help us to develop self-management strategies.
- We want this to be followed by low-level continued support to maintain well-being.
- We want access to support that helps us to gain life skills such as managing our finances, moving into employment, developing friendships, relationships and social networks, cooking, shopping, etc.
- We need to access to support intermittently without lengthy waiting lists. This is the only way to help prevent situations escalating to crisis situations.

What do we currently know about who is accessing services?

- The Anyton council database indicates that 73 adults with autism were known to the local authority and receiving services. A further 22 had not received services in the current year but were on the database. Of this total of 95, 19 were those with HFA. 11 of whom were receiving services.
- The adult mental health team have records indicating that they are currently providing services to 43 adults with HFA.
- Of the 43, 17(40%) have a single, primary diagnosis of AS. The other 26 (60%) have a range of secondary diagnoses including paranoid schizophrenia with the remainder a mix of anxiety, personality, behavioural and psychotic disorders.
- The total number of adults with HFA, known to either the council or the mental health team, is 62 out of a predicted 915 living in Enfield. This represents a “discovery” rate of 7%.

The LA’s picture of the current state of supply

The consultation with carers or other stakeholders has revealed that the issue is a lack of services rather than dissatisfaction with those that are provided for those with HFA. Indeed there are very few specific services for people with autism and particularly for people with HFA or Asperger’s Syndrome.

A continuing theme throughout the conversations with providers and people with HFA / AS has been that responding to the health and social care needs of adults with HFA often falls between Learning Disability and Mental Health services.

The Mental Health team are not currently commissioned to provide treatment for adults with neuro-developmental disorders including ADHD or Autistic Spectrum Disorders where there is no associated mental health diagnosis.

The current main services provided within the Private and Voluntary sector which focus wholly or to a significant extent on those with HFA include:

- Specialist employment services .
- 5 providers deliver day opportunities, outreach, supported living and floating support.
- 1 provider delivers residential services.

Diagnosis and Assessment of Needs

Currently Anyton does not have a formal diagnostic service. GPs can send a referral to Anyton’s Health Commissioners who decide whether a specialist diagnosis will be paid for.

People with HFA do not have a clear route to a FAC assessment. There are no specialist services providing assessments of their care needs. The Primary Mental Health Care Team will only undertake an assessment where someone also appears to have a mental health need.

Supported Employment

There is one voluntary provider that delivers supported employment services specifically for people with HFA / AS.

A work psychologist attached to Anyton Job Centre is available to advise staff and employers and potentially the unemployed person about addressing barriers and how to support someone with HFA. The work psychologist has been involved with 5 or 6 people with HFA over the last few years. The number of people with HFA that there are likely to be in Anyton compared with the low number in terms of caseload mentioned above, would suggest that access to supported employment (and other employment based help) is difficult.

Case Study

John is 27 years old and lives in his own flat on the edge of town. John has HFA and experienced a series of crises and breakdowns in his late teens and early twenties. John and his family feel that this was due to a lack of appropriate support after leaving school.

John left school with 2 A-levels. He gained a place at college to study graphic design. John found college very stressful. The environment and people were unfamiliar which increased his levels of anxiety. As his anxiety increased he began to display aggression towards staff and other students. After 6 months John was excluded.

Unable to find another suitable and local college course John tried, unsuccessfully, to get a job. This meant he spent the next 5 years living in the family home becoming increasingly isolated and depressed.

John's parents tried, unsuccessfully, to access support for his depression and anxiety. By the time John was 25 years old he had attempted suicide three times. John also became increasingly aggressive to his Mother. Eventually the extent of the injuries she sustained resulted in John being arrested and consequently sectioned under the mental health act.

When John's parents refused to allow him to return to the family home the hospital social worker intervened and found him a place in sheltered housing. After 3 months John was again arrested and subsequently admitted to hospital, this time for hurting another resident.

John was discharged after 2 months. This time he went to live in his own flat rented from a private landlord. He was also in receipt of 2 hours support per day from an organisation with experience of supporting people with ASC. They have supported John to access college, increase his daily living skills and mend his relationship with his parents.

Supported Further and Higher Education

There is one provider who works with the local colleges to provide bespoke, alternatives to supported education to people who have not managed to cope with support in mainstream environments.

Advocacy

As people with HFA have difficulties in communication and in articulating their needs, access to advocacy services is essential. Currently only generic advocacy services are available within Anyton.

Housing

Based on national studies, it is thought that at least 40% of people with HFA are living with their parents. When linked with the findings that 60% of parents, carers or siblings do not consider the person with HFA they are caring for could live independently, this indicates a need for future supported housing. It has not been possible to get accurate figures for the number of people in supported housing in Anyton as someone with HFA is not a specific category or priority for eligibility when assessing housing need.

However there are a number of organisations within Anyton which offer floating support to those living independently or support within supported living schemes.

Social Integration

There is no club or group within Anyton specifically for people with HFA / AS.

Mental Health Intervention

Access to psychological therapies, in particular Cognitive Behaviour Therapy, has been shown to be affective. Currently there appears to be no defined access for appropriately adapted psychological therapies in Anyton.

Family/Carer Support

Anyton Carers Centre offers support and advice to unpaid family carers in Anyton. It offers social activities, advice and information and a counselling service. It is currently exploring the possibility of setting up a carers group for carers of people with HFA / AS.

Universal Public Services

Many of these services have not yet made reasonable adjustments to increase the accessibility for people with ASC.



The current costs and level of resourcing

There is no comprehensive local data on the current health and social care costs of services for those with HFA/AS. It has been possible to obtain some information about the cost of the social care provision to the 43 people with HFA receiving a service from the Mental Health Team within the block contract. The costs range from £182 per week to 24-hour support packages costing £1216 per week. According to the information provided the current total cost per year is £171,288 for the social care element of their support.

It has also not been possible to cost the services provided by Anyton Council to the 76 adults with autism (including those with LD), including the cost of direct payments or individual budgets.

We do know that 30% of people with HFA are likely to have MH problems. In Anyton this would equal 275 people. According to NICE (2011)¹ 0.06% of people in the general population with a mental health problem will access acute inpatient care. The NAO (2009) report identifies that if you are on the autistic spectrum you are twice as likely to access acute inpatient treatment resulting in a prevalence rate of 0.12%. In Anyton this equates to 33 people.

Based on the NAO (2009) report and taking inflation into account a conservative estimate of the cost of providing such treatment is £87,998 per person per year, a cost totalling £2.9 million per year. A cost set to rise given that the numbers of people with autism are also set to rise.

It must also be remembered that the only figures mentioned here are those related to acute inpatient care. However, as stated in the NAO report and the NICE (2011) report, the cost of acute inpatient care is actually less than the other inevitable costs that are incurred as a result of a mental health problem.

It is worth noting here that time and time again the research states that access to specialist autism services reduces the risk of mental health problems and hence is a cost-effective investment in the long-term.

Future levels of resourcing

The Local Authority must make a 20% cut to the social care budget in the next 12 months.

There are no new monies available for developing services for people with HFA/AS.

The Local Authority and its Health Partners have agreed a small budget (70K) to create a diagnostic service.

Service gaps.....

- The good language skills of those with HFA masked their difficulties. This resulted in many people with HFA being assessed as not eligible for FACs.
- Minimal formal diagnosis (and difficulty in getting a diagnosis) prevented access to some additional support services.
- College Courses or skills development courses specifically for those with HFA.
- An Asperger Group for service users – the one running in Barnet was too far.
- More knowledge about the needs of those with HFA so that a Centre could engage them more.
- Practical support and training for areas such as cooking, cleaning, paying bills and managing money have been shown as a high need for this group. This is probably currently largely provided by families at the moment.

Key Market Facilitation Priorities

The following are services that the LA will work with providers, service users and other stakeholders to create in the market but are not services the LA currently has any budget to commission:

- Support planning and brokerage services for adults with HFA / AS. Make this available to those who are not eligible for social care funding.
- Support to both obtain and maintain accommodation within social housing and the private sector.
- Advocacy services with specialist skills for supporting people with HFA / AS.
- Social skills training to help navigate social systems and address social difficulties
- Personal skills training e.g. transport training, personal hygiene, cooking and budgeting etc.
- Support to obtain and maintain a job.
- Support to help undertake mainstream further / higher education.
- Support and better information for carers and family members.

Key Commissioning Intentions

The following are activities that Anyton Council and their Health Partners will engage in over the next five years. They are also activities that the LA has resources for:

Develop with partners, a sustainable, ongoing, strategic workforce development strategy for training and raising awareness across the workforces of health, social care, the Council, VCS, the criminal justice system and beyond.

Create a tailored SAT that provides the following services:

- Diagnosis
- Community care assessments
- Carer's assessments
- Care management co-ordination
- Information, advice and signposting to other services

Increase access to personal budgets and direct payments for those people eligible for social care funding.

Address the current gap in access to appropriate psychological therapies such as CBT (Cognitive Behavioural Therapy) for adults with HFA.

Improve systems for collecting information about people with HFA, to include ethnicity, age, gender to enable better analysis about needs and service uptake

Work with local partners to push for the development of reasonable adjustments to existing services across the full range of public and community services. This includes the better use of IAPT's adapted for the needs of people with HFA.

Identify and promote reasonable adjustments that a range of mainstream services and employers could make to improve the employment outcomes of adults with autism.

Examine the feasibility of extending some of the current transitions and employment services provided by LD services to those with HFA.

Address the barriers resulting in the likely lower diagnosis and take-up of services from minority ethnic communities, women and other disadvantaged communities.

Ensure the Autism Steering Group maintains a robust strategic vision and remains committed to delivering the Market Position Statement.

Key Contacts and opportunities for networking.....

National Autistic Society, Anyton Branch
Address: 106 Highstreet, Anyton, AN1 3BD
Email: info@nas.org
Phone: 01603 632205

Community Leisure Centre
Address: 10 Burford Road, Anyton AN1 2JJ
Email: info@nexus.co.uk
Phone: 01603 635509

Anyton College
Address: Tisley Place, Anyton, AN3 6NM
Email: admin@anytoncollege.ac.uk
Phone: 01603 673945

Horizon Supported Employment
Address: Civic Offices, Main Square, Anyton
Email: enquires@horizon.org
Phone: 01608 652799

Community Volunteer Bureau
Address: 27 Broad Street, Anyton, AN2 8PB
Email: info@cbvanyton.co.uk
Phone: 01603 677432

Business Support Office
Address: Anyton Council, Civic Offices,
Main Square, Anyton
Email: business@anyton.gov.uk
Phone: 01603 687439

Key business development opportunities

Community activities

People with HFA/AS sometimes find socialising difficult and there are limited opportunities to engage in community activities in an HFA/AS sensitive way. People with HFA/AS would like businesses to deliver a wider range of activities in Anyton, and have the right support to access them.

Social and life skills training

People with HFA/AS have unique difficulties with many social and life skills such as cooking, managing budgets, maintaining friendships, arranging a trip, catching a bus etc. People with HFA/AS would like to access training and support that will help them to develop these skills and hence increase their independence.

Building friendships and relationships. People with HFA/AS would like to have the same opportunity to make friends, socialise, and have relationships as other people. There are opportunities for businesses to develop befriending and other friendship schemes in Anyton which will enable individuals to have company rather than paid support.

Personal support

Some people with HFA/AS may wish to have personal support to enable them to gain more independence. There is currently a limited number of Personal Assistants with specialist knowledge.

Employment, education, voluntary work and training

You may want to consider providing support and opportunities for people with HFA/AS to engage in employment, education, volunteering and training. People with HFA/AS would like more providers to support them into employment (paid and voluntary), work placements, education and training. There are opportunities to establish social enterprises, co-operatives, and skills exchanges.

Advocacy, support planning and brokerage

You may wish to offer services to help people set up and maintain their support plan or provide different types of advocacy support.

Back office services

People that choose to have a personal budget or are funding their own support may wish to employ a personal assistant to help them manage their support package and finances. This means they may need help with recruiting, employing and training people as personal assistants, or help with job descriptions, payroll and criminal record bureau checks.

Specialist Services

There are a limited number of specialist services for people with an HFA/AS. Including appropriate housing and therapeutic services e.g. counselling. There are opportunities to work in partnership to develop such services.

Support and Information Services for Families & Carers

Families and Carers want better support and information services. You may want to develop services that provide accessible information, signposting and support for parents, siblings and other informal carers.

Anyton needs you

For further discussion you and your organisation can book a personal appointment to discuss how we can work with you. As a matter of urgency we particularly wish to meet with:

- Businesses who are interested in developing appropriate housing for people with HFA/AS.
- Specialist HFA/AS providers who wish to diversify their care offer.
- Home care providers who feel they could take on a wider range of services.
- Community organisations that wish to extend their work in supporting people with HFA/AS.

For all businesses we would like to welcome you to our HFA/AS business opportunities open day on 1 April 2014 or arrange an appointment:

- **Write to the Strategic Social Care Commissioning Team, Anyton Council, The Town Hall, Midshire Street, Anyton, A13 5BB.**
- **Phone 01443 34 34 35**
- **Email any of the following commissioning staff**

rahat.sami@anyton.gov.uk

peter.wilby@anyton.gov.uk

amy.wilson1@anyton.gov.uk

How will the Local Authority help to facilitate the market and support the development of the key Market Facilitation Priorities identified above?

The Local Authority will develop and deliver a range of training opportunities for all local businesses. Topics will include:

- Autism awareness
- How to make universal services more accessible to people with HFA/AS
- Developing micro or social enterprises

The Local Authority will be appointing a Commissioning Officer dedicated to supporting the development of micro or social enterprises.

The Local Authority will be working in partnership with the local branch of the National Autistic Society to create an online information hub. The information hub will aim to put people with ASC and local businesses who can support their needs in contact with each other. It will also provide opportunities for people with HFA/AS to meet and for families to access peer support.

The local authority, their health partners and Anyton University will be working in partnership to undertake further research into specialist housing for people with HFA/AS. Specifically this will focus on ascertaining what a good model for specialist housing should look like.

Finally, the local authority will run regular events to provide local businesses with the opportunity to network and discuss with people with HFA/AS and their families how to improve services.