

Cover Sheet Autism Programme Board Papers

Date of meeting

24 April 2013

Attachment number

APB (13)06

Title of paper

Draft Guide on Autism for Clinical Commissioning Groups from the Joint Commissioning Panel for Mental Health.

Summary

The paper allows Programme Board to see the draft of the Guide that will be issued by the Joint Commissioning Panel for Mental Health to CCGs. The process to publication will be outlined at the meeting.

Action required / recommendation

Comments from Programme Board members on the draft would be welcome at the meeting. Following the meeting, comments can be sent to Michael Swaffield by 1st May.

DRAFT

**A Practical Guide for Clinical Commissioning
Groups to Support Health Professionals
Implementing the Adult Autism Strategy
Statutory guidance and NICE Guidelines on
Diagnostic Services**

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Introduction

The Joint Commissioning Panel for Mental Health (JCP-MH) (www.jcpmh.info) is a collaboration co-chaired by the Royal College of General Practitioners and the Royal College of Psychiatrists, which brings together organisations and individuals with an interest in commissioning for mental health and learning disabilities. These include:

- Service users and carers
- Department of Health
- Association of Directors of Adult Social Services
- NHS Confederation
- National Autistic Society
- Mind
- Rethink Mental Illness
- National Survivor User Network
- National Involvement Partnership
- Royal College of Nursing
- British Psychological Society
- Representatives of NHS Trusts
- Mental Health Providers Forum
- New Savoy Partnership
- Representation from NHS and Specialised Commissioning
- Healthcare Financial Management Association.

The JCP-MH has two primary aims:

- to bring together service users, carers, clinicians, commissioners, managers and others to work towards values-based commissioning
- to integrate scientific evidence, patient and carer experience and viewpoints and innovative service evaluations in order to produce the best possible advice on commissioning the design and delivery of high quality mental health, learning disabilities and public mental health and wellbeing services.

The JCP-MH has published a series of short guides describing 'what good looks like' in various mental health service settings.

Companion guides and information on these issues are available at www.jcpmh.info

Who Is This Guide For?

This guide is about an important part of the Autism Act requirement for the commissioning of effective diagnostic services and post diagnostic support for people with autism, and so should be of value to:

- NHS England as it provides strategic overview for the NHS and holds CCGs to account for their local commissioning;
- CCGs in commissioning diagnostic services to identify people with autism spectrum conditions (ASC) and working with Local Authorities to provide post diagnostic support for people with and without learning disabilities;
- Health and Wellbeing Boards as they plan integrated services that meet the needs of the whole community including people with autism.

How Will This Guide Help You?

Many people with autism have often been invisible to everyday health services and health professionals. This practical guide is designed to support CCGs, with Local Authorities, to commission diagnostic and post diagnostic services in ways that achieve better health outcomes for adults with autism in the current financial climate.

Whilst Local Authorities will lead commissioning for a considerable proportion of services for people with autism, CCGs must take responsibility from PCTs for leading the commissioning of diagnostic and post diagnostic support services.

This guide aims to assist CCGs to:

- demonstrate that they use a range of collated evidence/information/data to ensure evidence based commissioning diagnostic services;
- inform the commissioning of a range of person centred and cost effective options for post diagnostic support based on the local profile and future needs of people with autism;
- include a needs assessment in the local JSNA and that corresponding plans are in place which reflect policy and best practice guidelines;
- have well functioning partnership agreements between health and social care organisations.

The guide draws on and refers to previously published guidance, including NICE guidelines.

It has been written by a group of autism experts, in consultation with service users and carers. The content is primarily evidence-based but ideas deemed to be best practice by expert consensus have also been included. By the end of this guide, CCGs should be more familiar with the concept of effective diagnostic services for people with autism and better equipped to commission this.

Policy Drivers For Change

When the *Autism Act* became law in 2009, for the first time it put a legal duty on health and social care agencies to provide services for this client group, and committing the Government to producing a national adult autism strategy for England.

Fulfilling & Rewarding Lives: The strategy for adults with autism in England was then published by the Department of Health in March 2010, setting out the Government's vision for service improvement.

This was followed up with *Implementing Fulfilling & Rewarding Lives* in December 2010, statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy, which made a set of mandatory recommendations regarding what action PCTs and Local Authorities should take to develop services for adults with ASC.

Statutory Guidance

The Statutory guidance placed a legal requirement on developing a range of local services to address the needs of adults with ASC. This is enforceable under Section 7 of the Local Authority Social Service Act (1970) and, as such, local authorities and NHS bodies must follow the Act and unless a good reason can be given, can be challenged through the courts. Local authorities, the NHS and other local partners have to work together to make sure that they are developing cost effective and appropriate services for adults with autism in their area.

The statutory guidance re-enforced the concept that each Local Authority area should have a lead professional to develop diagnostic and assessment services for adults in their area, and that the local Directors of Adult Social Services, supported by the NHS, are responsible for ensuring that the correct processes are in place locally for:

- conducting assessments of needs;
- prompt sharing of information between diagnostic services and services for adults diagnosed.

As such, the national adult autism strategy focuses on five things:

1. Making sure that more people understand about autism;
2. Making it easier for adults to get a diagnosis of autism;
3. Ensuring adults with autism can choose how they live, and get the help that they need to do this;
4. Helping adults with autism to find jobs;
5. Helping local councils and health services to write plans so that the adults with autism who live in their area get the help that they need.

Amongst other actions, the guidance clearly states that local authorities and the NHS should:

- Provide autism awareness training for all staff;
- Must provide specialist autism training for key staff e.g. GPs and community care assessors;
- Cannot refuse a community care assessment based solely on IQ;
- Must appoint an autism lead in their area;
- Have to develop a clear pathway to diagnosis and assessment;
- Need to commission services based on adequate population data.

In April 2011 the Government published a list of the 10 outcomes that should be achieved if the autism strategy and statutory guidance can be judged as a success. These are:

- Adults with autism achieve better health outcomes;
- Adults with autism are included and economically active;
- Adults with autism are living in accommodation that meets their needs;
- Adults with autism are benefiting from the personalisation agenda in health and social care, and can access personal budgets;

- Adults with autism are no longer managed inappropriately in the criminal justice system;
- Adults with autism, their families and carers are satisfied with local services;
- Adults with autism are involved in service planning;
- Local authorities and partners know how many adults with autism live in the area;
- A clear and trusted diagnostic pathway is available locally;
- Health and social care staff make reasonable adjustments to services to meet the needs of adults with autism.

These ambitious objectives will be best achieved through partnership working between local authorities, the NHS, the voluntary sector and people directly affected by autism. Local Overview and Scrutiny Committees are ideally placed to support this process.

NICE Guidelines

In June 2012 the National Institute for Health and Clinical Excellence (NICE) published a clinical guideline on Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. This followed the September 2011 publication of its clinical guideline on Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum.

NICE is also developing guidance on managing autism in children and young people which is due for publication in November 2013, which will include reference to the need for more attention to social communication interventions and whole family support plans.

A key factor in options for local commissioners to design the diagnostic pathway will be NICE guidance on who should make a diagnosis of autism. The level of autism predicted in the population suggests that a range of professionals need to be involved in diagnosis in order to achieve the rate of diagnosis suggested by the prevalence study. NICE's approach is to ensure that diagnosis is made by those with sufficient understanding/knowledge of autism through a multi-professional approach rather than restricting to any one clinical specialism.

NHS Commissioners should have, in line with the NICE clinical guideline for adults, been reviewing their diagnostic processes and services against this best practice and reducing the gap between likely prevalence and diagnosis rates. CCGs will need to carry on with this depending on what progress has been made locally, including the differentiating between the mechanisms to enable diagnoses for large numbers of people with ASC as opposed to more detailed assessment profiles of smaller numbers of people with ASC and additional complex support needs.

Social factors such as poverty, discrimination, unemployment, housing and social isolation adversely affect the health of people with autism. CCGs should demonstrate through local Joint Strategic Needs Assessments and Local Authority autism self assessments the need for autism services in their area and the priority they are giving to autism, and by doing so provide information for local service users and representative groups to identify any gaps.

The current financial climate has made effective commissioning even more important. The Quality, Innovation, Productivity and Prevention programme (QIPP)

requires NHS organisations to improve the quality of care they deliver while making efficiency savings that can be re-invested in the service to deliver year on year quality improvements. Examples of good practice that have either saved money, or have the potential to save money, are highlighted in the guidance.

Local Autism Partnership Boards

The adult NICE guidance also recommends that local autism multi-agency strategy groups should include representation from managers, commissioners and clinicians from adult services, including mental health, learning disability, primary healthcare, social carer, housing, educational and employment services, the criminal justice system and the third sector. There should also be meaningful representation from people with autism and their families, partners and carers.

Autism strategy groups should be responsible for developing, managing and evaluating local care pathways. The group should include a lead professional responsible for the local autism care pathway.

The aims of the strategy group should include:

- developing clear policy and protocols for the operation of the pathway;
- ensuring the provision of multi-agency training about signs and symptoms of autism, and training and support on the operation of the pathway;
- making sure the relevant professionals (health, social care, housing, educational and employment services and the third sector) are aware of the local autism pathway and how to access services;
- supporting the integrated delivery of services across all care settings;
- supporting the smooth transition to adult services for young people going through the pathway;
- auditing and reviewing the performance of the pathway.

NICE Quality Standards

NICE is due to publish adult and children's' quality standards later in 2013. The quality standard will be reflected in the new Commissioning Outcomes Framework which will inform payment mechanism and incentive schemes such as the Quality Outcomes Framework.

The quality standards will help to embed the needs of adults with autism into the health and social care system by helping:

- health and social care professionals to base decisions on the latest evidence and best practice;
- people with autism to understand what service they should expect from health and social care providers;
- service providers to assess and implement high standards of clinical performance and care;
- commissioners to purchase high quality and cost effective services.

Winterbourne View Hospital Review

The Department of Health Review: Transforming care: A national response to Winterbourne View Hospital was issued in December 2012. The report sets out the government's final response to the event at Winterbourne View hospital. It sets out a programme of action to transform services for people with learning disabilities or autism and mental health conditions or behaviours described as challenging.

The report contains many actions for health and care commissioners and others, including a strong presumption in favour of pooled budget arrangements, including also for people with autism but also have a co-morbidity of learning disability or challenging behaviour.

The subsequent Winterbourne Concordat Programme of Action confirms that *"Health and care commissioners will:*

- ✓ *by 1 June 2013, working together and with service providers, people who use services and families review the care of all people in learning disability or autism inpatient beds and agree a personal care plan for each individual, based on their and their families' needs and agreed outcomes;*
- ✓ *put these plans into action as soon as possible, so that all individuals receive personalised care and support in appropriate community settings no later than 1 June 2014;*
- ✓ *ensure that all individuals have the information, advice and advocacy support they need to understand and have the opportunity to express their views. This support will include self-advocacy and independent advocacy where appropriate for the person and their family."*

The Local Government Association (LGA) and the NHS England have established a two-year joint improvement programme to provide leadership and support to transform services locally. This programme is expected to mark a fundamental turning point in the culture and delivery of care that will deliver real, rapid and lasting change by listening to and meeting the needs of this very vulnerable group of people and their families.

This programme requires progress in ensuring access to effective autism diagnostic and post-diagnostic support for people with learning disabilities as well as those without learning disabilities. Too often challenging behaviours resulting in high cost out-of-area placements and admissions reflect misunderstanding the why people act as they do in response to ASC, as well as ineffective behaviour support plans and services. In line with the NICE Guidelines, specialist ASC multidisciplinary teams must be established in each locality to provide:

- Diagnosis and assessment
- Care and treatment
- Care coordination
- Advice and training (specifically to health and social care professionals)

From a commissioning point of view the important issue is to stop inappropriate spot-purchasing, especially in high-cost out-of-area and/or specialist units by more effective person-centred commissioning programmes that develop effective local practical support strategies.

This may also most likely include collaborative commissioning across several CCGs and Local Authorities with specimen contracts in place across larger locality footprints (equivalent to several CCGs or at the NHS England Local Area Team level) from which individual commissioners can draw down individual cost-per-case or cost/volume contracts with preferred framework providers.

These providers will therefore have been selected in line with being clear about the positive elements of the care they provide, what quality really looks like, and what outcomes everyone wants to see as the return on investment.

As such, this has often been referred to after the Winterbourne View and Francis Reports Inquiries as 'staff at the front-line in these sorts of establishments must have intelligent kindness imbued in their management' and their direct line managers having access to ongoing dynamically informed supervision and reflective learning opportunities.

Autism Spectrum Conditions

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.

It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways, commonly divided into three key areas:

- Difficulties with social interaction and relationships. This includes recognising and understanding other people's feelings and managing their own. Not understanding how to interact with other people can make it hard to form friendships.
- Difficulties with social communication. This includes using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice.
- Difficulties with flexible and abstract thinking or social imagination. This includes the ability to understand and predict other people's intentions and behaviour and to imagine situations outside of their own routine. This can be accompanied by a narrow repetitive range of activities.

Many people with autism may also experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours. As a result, people with autism often prefer to have fixed routines, special interests and can find change difficult to cope with.

Many people with autism may also have other co-existing conditions such as attention deficit hyperactivity disorder (ADHD), a learning disability or dyspraxia, and are more vulnerable to experiencing emotional and mental health problems.

Asperger syndrome (AS) is a form of autism and is mostly a 'hidden disability'. This means that you cannot tell that someone has the condition from their outward appearance. People with Asperger syndrome are often of average or above average intelligence. They typically have fewer problems with speaking than others on the autism spectrum, but they do still have significant difficulties with communication that can be masked by their ability to speak fluently. They are also often of average or above average intelligence.

ASC is now seen as the collective term for a range of autism conditions that are lifelong neuro-developmental disorders which are seen to profoundly affect how a person learns and makes sense of the world, processes information and relates to others. The result is that some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support.

People with ASC have reported that they need many of the same things that all people want and see as important. These include: a safe and happy home life, jobs, friends and partners, and money to access the same valued opportunities as anyone else. However, adults with autism are amongst the most socially excluded people in the country. This follows from too many people being undiagnosed and mainstream services lacking the necessary confidence, skills and experience to enable this.

How Common Is Autism?

Research indicates that approximately one in every hundred people is affected by ASC. It is estimated therefore that there are at least 623,000 people with ASC living in the UK (Office for National Statistics, 2011), many of whom will require access to mental health, learning disability and social care services at some point in their lives.

Estimates of the proportion of people with autism who also have a learning disability vary considerably, and it is not possible to give an accurate figure. Collecting together the existing research, NAS believes that it is likely that over 50% of those with autism have an IQ in the average to high range and do not have a learning disability.

A key issue is the gap in terms of estimated numbers of people with autism and capacity of the NHS to offer diagnosis. Around 50% of adults have autism but not a learning disability and most of these are at present unknown to the NHS or Local Authorities. Together with their families, they make up over one million people whose lives are touched by autism every single day. Yet, research has shown that all too often adults with autism are unable to access the support they need, which was why the Government took forward the Autism Act and the subsequent strategy and statutory guidance.

What Is The Impact Of Autism?

ASC does affect people in different ways and degrees, affecting people in many different ways and to varying degrees. The needs of this vulnerable group too often have not been adequately met by mainstream and specialist services, as they typically “fall between” of learning disability and mental health services, and are as a result frequently excluded from necessary health and social care provision.

This means that in particular adults with AS are very seldom even able to receive a diagnostic assessment, let alone access a range of timely preventative services. Consequently, they are often unable to get any help or support, except at times of crisis.

This represents very poor value for money in terms of commissioning: crisis intervention is expensive; is contrary to the intention of recent Government policy which highlights the need for preventative services; and results in adults with AS receiving typically poor-quality, and reactive interventions.

While these guidelines and all recent guidance refers to the whole autism spectrum, it should be noted that the main focus should be on the development of services for vulnerable adults with and without learning disabilities who are not able to access appropriately assessed support – particularly those who do not meet Social Care FACS eligibility criteria or placed in inappropriate care settings. These are the groups with the greatest unmet need, and where resources are most required.

Over 60% of adults with AS or high functioning autism who responded to an NAS survey in 2007 said that they have experienced difficulties in accessing services and 52% of these were told that they do not fit easily into mental health or learning disability services people with autism are dealt with on a case-by-case basis and dealt with inconsistently.

Also, as a consequence people are too often inappropriately placed in out of area settings. On average, out of area placements are considerably more costly.

Why Are Autism Diagnostic Services Important To Commissioners?

The failure to deliver services that meet the needs of adults with autism can not only have a devastating effect on the individual with autism, it also has a serious cost implication on a wider level.

Nationally, the estimated cost of autism is £28 billion per annum (£25.5 billion for adults, and £2.7 billion for children). This averages out at £500 each year for every man, woman and child in the country. It has been estimated that if we include the cumulative impact of service use, the need for accommodation assistance and low employment rates:

- Someone with high functioning autism or AS the lifetime cost is £3.1m;
- Someone with autism and a learning disability the cost was 50% higher at £4.6m.

This cost can be reduced by making sure autism diagnostic and post-diagnostic support services are accessible in a timely and appropriate way.

When the National Audit Office (NAO) investigated public spending into adults with autism; they found that failing to invest in autism provision is a huge false economy. They also found that if local services identified, through autism specialist teams, and supported just 4% of adults with high functioning autism and AS the outlay would become cost neutral over time.

The Autism Act Statutory Guidance supports local action that both supports individuals with autism and their families, as well as the wider community by requiring as a minimum in each local area:

- Better **local management and leadership**, with named lead clinicians and commissioners in each area.
- Access to a **local diagnostic and clinical pathway** - NICE guidelines recommends that in each local authority area a specialist community-based multidisciplinary team for adults with autism should be established. The membership should include a range of professionals including: clinical psychologists, social workers, psychiatrists, nurses and speech & language therapists;
- Planning to ensure smooth **transitions** from child to adult services;
- **Training** for frontline health and social care staff, both to raise awareness and to develop specialities among professional groups;

This action addresses the common demands noted by families that led to the Autism Act including: a clear pathway pre and post diagnosis; early practical support interventions; reduced waiting times; improved access to 'helpful' specialist advice; increased awareness of co-existing mental/physical health problems and the uniqueness of each individual's presentation through clear formulations and personal profiles; and, making sure actions are more collaborative with improved coordinated support during and after diagnosis by different professionals and services, such as skills teaching to reduce dependence; reasonable service accommodations by professionals, and services that are 'autism-friendly'.

What Are The Main Obstacles To Fulfilling The Autism Act Duties And What Are The Solutions?

Lack of Resources and Clarity in What is Required

Previously, the lack of guidance as to what services need to be developed may have meant that emerging CCGs were likely to be uncertain about what to commission. However, NICE guidelines now set out some very clear, unambiguous recommendations for the development of access to specialist ASC teams across the country.

The statutory guidance now also means that a lack of resources is not a valid reason for not being compliant with the Autism Act requirements.

Legislation means that commissioners have a legal duty to provide appropriate services for adults with ASC. As services are re-tendered for and re-commissioned, budgets can then be freed up to invest in developing new provision, and contracts with providers can place clearer responsibilities on them to work effectively with people with ASC.

The Autism Strategy notes that Local Authorities are responsible for ensuring that the diagnosis of autism will trigger a community care assessment and carers assessment, but that these assessments may also be triggered without a diagnosis. Further, the statutory guidance includes a commitment on the type of helpful information that should be provided to people with ASC and their families after a diagnosis. As such, CCGs and Local Authorities must collaborate through Health and Well Being Boards to ensure proper consideration of post-diagnostic support, with both these commissioning processes working in unison to avoid unnecessary frustration on the part of local people.

The Autism Act and associated guidance therefore also required the establishment of named local Autism Service Leads or Co-ordinators to translate local JSNA and Health and Well Being Strategy planning with respect to autism to be actioned.

Limited Local Needs Information

Lack of prevalence data on the numbers of people with ASC in local areas can make it difficult to commission services to meet local need. Efforts should be made to improve data gathering on numbers of people diagnosed with ASC. The local JSNA and Health and Well Being Strategies are one vehicle to achieve this, as is greater communication between child and adult services.

In the absence of good local data, local prevalence can be extrapolated from national epidemiological surveys which suggest the figure of 1% per local adult population.

While existing learning disability and mental health services should be re-developed to ensure compliance with the Autism Act agenda, a major focus will often be for new investment on the development of new services for adults with Asperger syndrome previously unsupported.

Problems in Transitions from Children to Adults Services

Child and adult providers tend to be very different in terms of what services they offer, and how they offer them. Transition between child and adult services can indeed be a complex yet important process for people with ASC. Implementing a few

simple recommendations can help with this, including: ensuring that planning data regarding numbers of young people aged 14 to 19 with autism is routinely passed on to adult services every year; each local area has a properly joined-up transition care pathway; and that services are required by commissioners to communicate with each other about this.

A key area is for services to ensure local pathways are easily understood and able to signpost families to support. Often, families of children with learning disabilities and ASC have clearer options to access specialist support than do families of children in mainstream education. As such “Approaching Adulthood” programmes being piloted in Greater Manchester can help. These offer information and support to families about a range of things from education, employment, welfare benefits, the Mental Capacity Act, FACS eligibility criteria, etc. These can be run jointly by professionals in adult and children’s services with an emphasis on empowering families, and can go hand-in-hand with existing transitions protocols.

The Department of Health is also working with the Department of Education to introduce from 2014 a new single assessment process and Education, Health and Care Plan to replace the current system of statements and learning difficulty assessments for children and young people with special educational needs; supported by joint commissioning between local partners (subject to parliamentary approval). The process will include young people up to the age of 25, to ensure they are supported in making the transition to adulthood.

Insufficient Access to Specialist Clinicians and Costly Specialist ASC Teams

It has too often been assumed that implementation of NICE guidance requires only specialist autism clinicians or teams to be able to diagnose ASC and/or provide effective support. However, it is the case that most senior specialist mental health and learning disability professionals are able to provide significant support in this regard (with the necessary easy access to specialist autism-skilled case supervision and consultation in line with effective CPD programmes)

As such, the distinction needs to be made in terms of locally agreed protocols for when particular individuals with ASC require stepping-up to specialist autism teams for more detailed assessments and interventions (that are additional to core mental health and learning disability competence).

Therefore, the commissioning of any new specialist services must address this workforce support agenda to enable an efficient and effective local system, which includes adequate specialist resources for consultation and liaison to mainstream services, thereby enhancing the ASC competence and capability of existing consultants and services.

What services are needed for people with autism in terms of diagnostic and post-diagnostic support services?

A diagnosis is the formal identification of autism, usually by a health professional. Most frequently they will be psychiatrists, clinical psychologists or speech therapists and, in the case of children, paediatricians.

Some people see a formal diagnosis as an unhelpful label; however for many a diagnosis is helpful for two reasons:

- It helps people with autism (and their families, friends, partners, carers, professionals, colleagues) to better understand their needs and why they experience certain difficulties as well as what they can do about them
- It allows people to easier access to services and support

Some people live with autism for their entire life without ever getting a formal diagnosis. Often this is simply because autism wasn't widely known or understood when they were growing up. For adults, a diagnosis of autism can help to explain why they have always found certain things difficult. For children, it can mean that the right support is put in place from an early age.

It can also prevent common misdiagnoses, such as schizophrenia or personality disorders, and inform appropriate support plans for people who have more than one condition such as autism, ADHD, epilepsy and sensory impairments.

The NICE Guidelines require comprehensive assessments should be:

- Undertaken by professionals who are trained and competent;
- Be team-based drawing on a range of professional expertise and relevant skill;
- Actively involve an informant, family member or other to use documentary evidence of early development and current/past behaviours.

Any complete autism diagnostic assessment must include:

- Detailed enquiry about parent and carer concerns, and if appropriate the person's perspective;
- A medical history including prenatal, perinatal and family history of past and current health conditions;
- The person's experiences of home life, education and social care;
- A developmental history focussing on developmental and behavioural features consistent with ICD-10 criteria (using a valid autism-specific information gathering tool such as DISCO);
- Assessment through interaction with and observation of the person of their social and communicative skills and behaviours – focusing on features consistent with ICD-10 criteria (again using a valid autism-specific information gathering tool such as ADOS);
- A physical examination according to clinical judgement and symptoms;
- A systematic assessment of co-existing conditions;
- Consideration of differential diagnosis;
- Communication of assessment findings, using accessible information;
- Any other assessments required to create a full profile of the individual's strengths, skills, impairments and support needs - that can be used to create a needs-based positive support and management plan that takes account of the context of the person's life.

As a result, each CCG area should have in place a clear pathway for diagnosis of autism, from initial referral through to assessment of needs, or enter into arrangements with other CCGs.

An important starting point will be to review the current pathway to diagnosis if this has not already been done. Where there is an effective pathway locally, which has the support of clinicians and adults with autism, their families and carers; this should form the foundation of any further changes. Information about the pathway should be made available in accessible formats to families and people with ASC. Routes into the pathway should be straightforward and understood by all.

Specialist teams should be multi-agency, and should ideally therefore be jointly funded from health and social care commissioning budgets. Experience suggests pooled budgets can result in teams with sufficient capacity to meet the demand.

The cost of developing a new service will be relatively small and research indicates that investment in this area is likely to result in significant savings to commissioning budgets across the care pathway (NAO, 2010).

In preparing a business case, it is often useful to quantify existing expenditure on ASC via: out-of-county referrals for diagnosis/treatment/accommodation, rates of crisis intervention, and frequency/duration of acute admission. The NAO report provides sound estimates of cost savings following investment in preventative services for adults with ASC.

What would good NHS diagnostic autism services look like?

An effective local comprehensive autism commissioning programme will include:

- a strong **integrated health and social care component that focuses on early identification and support of people with autism, and targets high-risk groups** such as people who are at risk of exclusion from local communities or services and/or presenting challenging behaviours or complex support needs with accompanying health conditions or risk factors.
- **assessment and early diagnosis services** for people with autism spectrum conditions. Autism is a neurodevelopmental condition which is diagnosed behaviourally. This includes advice and support during the assessment phase and after diagnosis to assist with action planning for the future. It should include a **treatment service in accordance with NICE recommendations**.
- **evidence-based early interventions targeting social and communication enhancement interventions** (such as PACT) and **working with whole families** with respect to emotional health and well-being to enhance through both statutory and third sector partners (such as the NAS).
- an **identified range of initial post diagnostic support options, including person-centred interventions, access to support groups and family support programmes** (given the risk of progression to more severe problems where Autism Spectrum Conditions cannot be accommodated in mainstream settings).
- **on-going local post-diagnostic support based in the community, especially for individuals with complex support needs**. These will incorporate evidence-based specialist health and social interventions for patients and carers, and will where appropriate include coordinated care for individuals either by a member of a community health care team or an identified person in a voluntary sector organisation (linking with the community health care team). This could include an autism advisor or a designated member of the health or social care team to act as a care manager if the person has more complex needs.
- **a range of mainstream community options and ‘reasonable adjustments’ in place to support access** may be required, including telecare, housing adaptations, carer support and access to day/education/work opportunities.
- **specialist mental health or learning disability care services for patients with autism who present with behaviours that challenge, patients whose ASCs are complicated by co-morbid functional mental health problems, and those with complex diagnoses**. These services will include a specialist service to manage patients with extremely challenging behaviours who need intensive support (including assessment and interventions to manage behaviours that place the individual or others at risk). This service will have a strong community focus, but will have access to a limited number of inpatient assessment and treatment beds for short periods of time (and include those detained under the Mental Health Act or the Deprivation of Liberty Safeguards). Special attention should be given to people living in supported or care homes.
- **effective involvement of people with ASC and their families in recruitment, training, running and monitoring of services** – as well as supporting peer mentorship and user-led initiatives such as self-help groups, employment schemes

CCGs will therefore need to build on existing arrangements or establish a local specialist multidisciplinary ASC team resource to provide the following:

- Help people with autism **access appropriate mainstream services**
- **Direct work with individuals and workforce support to agencies** across the care pathway (including health, social care and voluntary sector services) involved in providing mainstream services and support to people with autism
- Access to **local diagnostic assessment**;
- **Limited post-diagnostic support** for all assessed individuals (e.g. through structured support groups and individual de-briefing sessions)
- Comprehensive **post-diagnostic support** for small numbers of individuals with complex support needs that make accessing mainstream services difficult;
- **Liaison with everyday health and social care services** to help them make their services more accessible to people with autism, and work more effectively and efficiently with this client group;
- **Autism training** to frontline staff, including specialist training to identified groups (i.e. social workers, GPs, psychiatrists);
- Access to a range of low-cost, **preventative interventions for people with autism** to promote wellbeing, social inclusion, and minimise reliance upon other health and social care services;
- **Help for families and carers** of adults with ASC, to enable them to provide appropriate, sustainable support.

CCGs should ensure that there is both a **named lead clinician and commissioner for autism** in their area, with a clear brief and targets that they should report on to the CCG – including general objective setting, milestone identifying and monitoring. It is also important that the local Autism Partnership Board is meaningfully linked into the Health & Wellbeing Board, and that autism appears in the Health & Wellbeing Strategy.

CCGs should also request relevant child and adult service providers and commissioners to develop and publish a **“lifetime” care pathway for autism** (which for families helps to positively clarify responsibilities and local joint working arrangements), and focus particular attention on the needs of young people making the transition into adult services.

Examples Of Effective Autism Support Services (usually targeted at resolving gaps in provision for people with ASC without learning disabilities)

Example 1 (Based on arrangements in Bristol)

A small, multi-agency specialist ASC team led by a senior consultant level clinician, with two main areas of activity: **workforce support** and **direct work**;

- **Workforce support:** providing training, supervision and liaison for agencies across the care pathway - including health, social care and voluntary sector providers – to develop their competences in working effectively and efficiently with adults with ASC;
- **Direct work:** with adults with ASC who would not otherwise be able to access services, providing: diagnosis, post-diagnostic support, signposting, problem-solving, and a range of low-cost group interventions.

Staff mix per 500 000 total population:

- 2.0 wte clinical psychology
- 1.0 wte specialist nurse/team manager
- 1.0 wte social work
- 1.0 wte training/liaison worker
- 1.0 wte assistant psychologist
- 0.5 wte psychiatry
- 1.0 wte admin
- 0.2 wte speech & language therapy

Total cost: approx. £400k

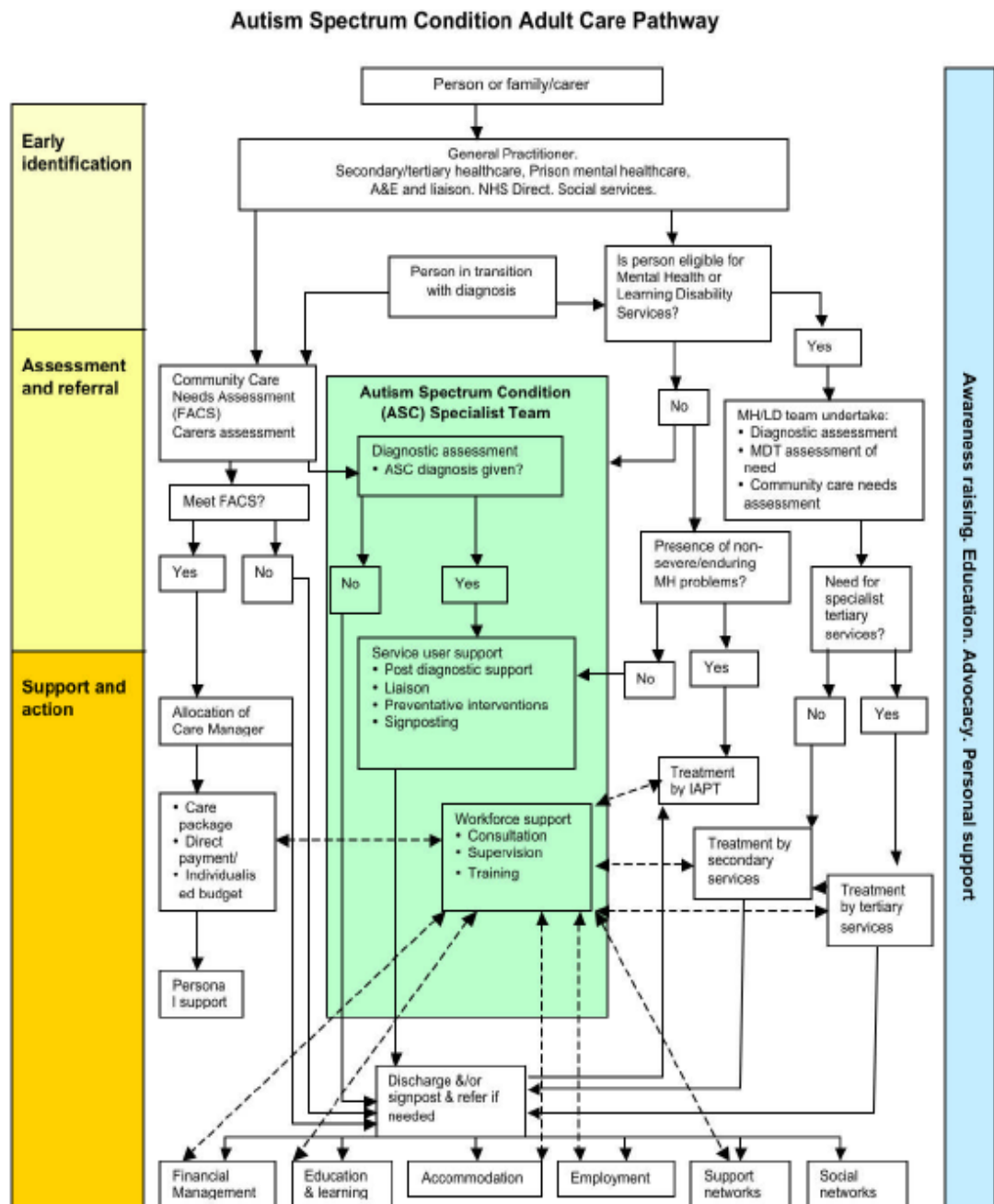
This model will deliver substantial cost savings to health and social care budgets primarily by:

- providing local diagnostic assessment, meaning that people no longer have to be funded to be assessed out-of-area;
- supporting local secondary mental health and learning disability professionals to diagnose and manage people with ASC on their caseloads effectively and efficiently;
- engaging in preventative treatment work with those at risk of losing their independence, minimising contact with mental health services, and in particular the current over-reliance on crisis intervention and/or acute admissions;
- joint-working with care managers to evaluate the quality and value-for-money offered by out-of-area providers, with a view to facilitating the return of people, as appropriate, to the local area.

This model is reliant on generic Adult Services teams in Local Authorities leading on the majority of Community Care Assessments and commissioning services using Personal Budgets. The Social Worker in the team acts as a resource to advise assessors on good autism practice in assessment and to offer a Social Care signposting and occasional short-term intervention to individuals who may not be FACS eligible.

It is not likely that this sole member will carry a full caseload of complex individuals as this will limit their responsiveness for Workforce Support and Direct Work.

Local Authorities will therefore need to ensure that they have adequate specialist practitioner roles within their Adult team structures to respond to the demand for experienced assessors of adults with autism. They will also need to ensure that a wide programme of autism-specific assessor training is made available to all staff so that assessments are tailored to acknowledge the needs of individuals across the whole spectrum both in CLDT's and mental health services.



Contact xxxxxxxxxxxxxx for further information

Example 2 (based on arrangements in Swindon)

An ASC specialist team will consist of:

- **Team management:** This will need to be from an experienced manager. This could be from a wide range of professional backgrounds but with knowledge of the full range of ASC conditions and the experience of managing multi-disciplinary teams. CQC Compliant;
- **Administrative Support:** This is essential for the running of a small but complex service. This role requires skills for direct engagement with people with ASC and coordinating support to an MDT;
- **Diagnosticians :** Potentially from a range of professional backgrounds, ideally striving for even balance of professional perspectives;
- **Wider Support Staff:** Potentially from a range of backgrounds (qualified/unqualified). This group may be part of the specialist team or may be linked and supported by the specialist team. The activities of these groups would be coordinated through the local Autism Partnership Board. Examples of support this group may be involved with providing could be:
 - Employment mediation
 - Transition support workers
 - Advocacy
 - Needs assessment
 - Carers assessment
 - Training
 - Support groups
 - Health care support workers

Requirements of Diagnosticians:

These include:

- Proven history of direct work at a senior level with people with a range of ASC presentations both LD and non LD and with experience in a range of mental health presentations;
- Professional Qualification which is recognised as a prerequisite of training on accredited diagnostic courses such as DISCO and ADOS-G;
- Demonstrable skills in autism diagnosis and recognised training in one or several diagnostic approaches outlined in NICE guidelines;
- PDP that demonstrates active development of skills and knowledge base, active interest in current best practice and current research and thinking, LD and Non LD;
- All diagnosticians should be able to demonstrate active joint working as part of a multidisciplinary team as part of their current practice.

Requirements of the team

The team must be multidisciplinary with no requirement for dominance from one particular profession as part of diagnosis or support. Individuals with ASC may require access on the diagnostic pathway to the following professions. These may be part of the specialist team or may be part of existing services:

- Speech and Language Therapy
- Psychology
- Nursing
- Psychiatry
- Social Work
- Occupational Therapy

Other team roles that may be within team

These are:

- **Support workers:** These are an essential part of a service that is going to support individuals during and post diagnosis. They need support from professionals on the team but may or may not be employed by the team;
- **Advocacy:** These provide essential support during and post diagnosis and may or may not be directly employed within the autism team. Accesses appropriate training and support including :
 - Supported employment/Job centre plus/voluntary agencies;
 - Carers association;
 - Local NAS/autism organisation- support groups. Autism alert cards, training;
 - Disability leisure services;
 - Local support for access to primary care/secondary care: health ambassadors, hospital complex care team;
 - Other relevant support groups: eating disorders, AA, gamblers anonymous etc.

Swindon Model (Population approx. 200,000)

Example based on arrangements in Swindon:

- Block contract of 24 (Non LD) cases per year, charged at set cost per case (non LD). See up to 30 per year with LD or borderline LD. In 2010 saw an additional (Non LD) cases at the request of Swindon PCT, as a pilot, who had been awaiting assessment;
- Team take lead role in developing autism economy to support people with ASC diagnosis;
- Team can be commissioned to provide training and provide regular awareness training free to carers and people with ASC, small charge to others;
- Increasing referral patterns (beyond 24 per year non LD) reported to commissioners;
- Different care pathways for LD and non LD but shared resources;
- Selection of clinicians for each client will vary depending on clinical need;
- Shared clinical supervision.

The team has a small amount of permanent funding with all clinicians working flexible additional hours according to needs and commissioning requirements. The figures below reflect resources shared for ASC between non LD and LD pathways:

- Admin: 0.2 wte

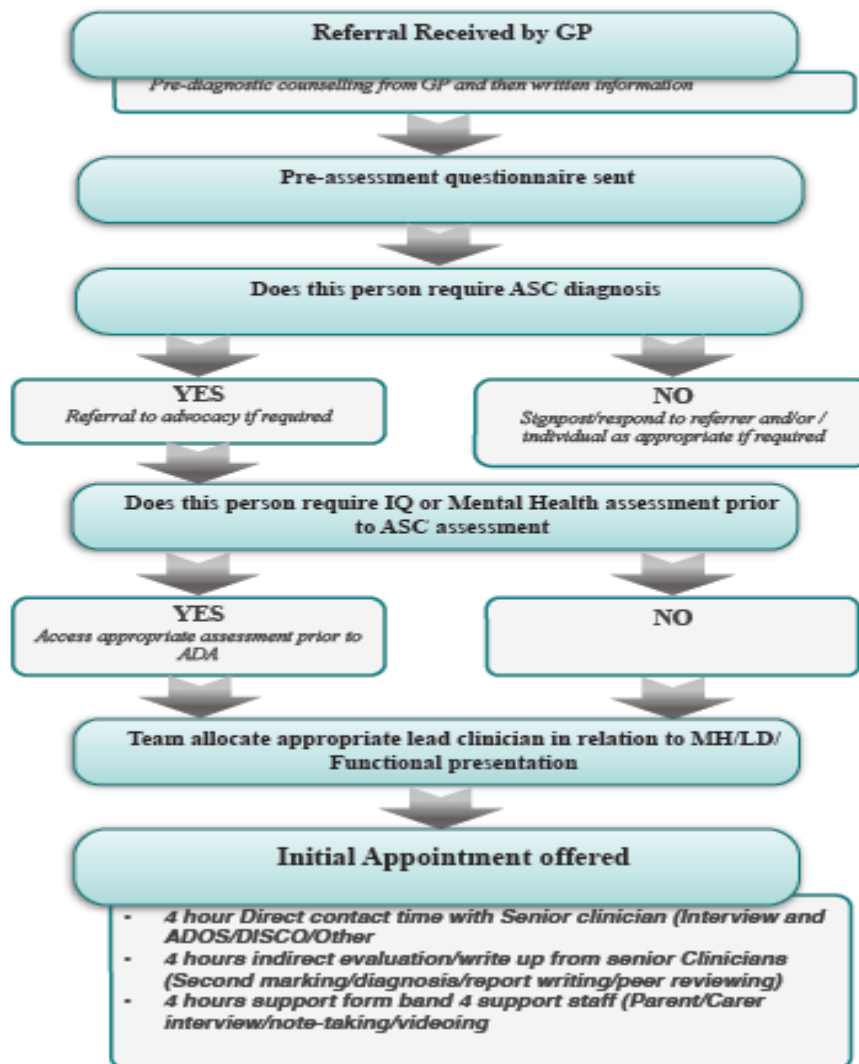
- Professional Lead/Team Manager: 0.4 wte
- Support Worker: 0.2 wte (primarily LD)
- SLT: 0.3 wte + additional contracted hours as required - currently approx. 0.6
- Psychology: 0.2 wte + additional contracted hours as required. Currently approx. 0.4
- Nursing: 0.1 wte + additional contracted hours as required
- OT available for sensory integration assessment on request.

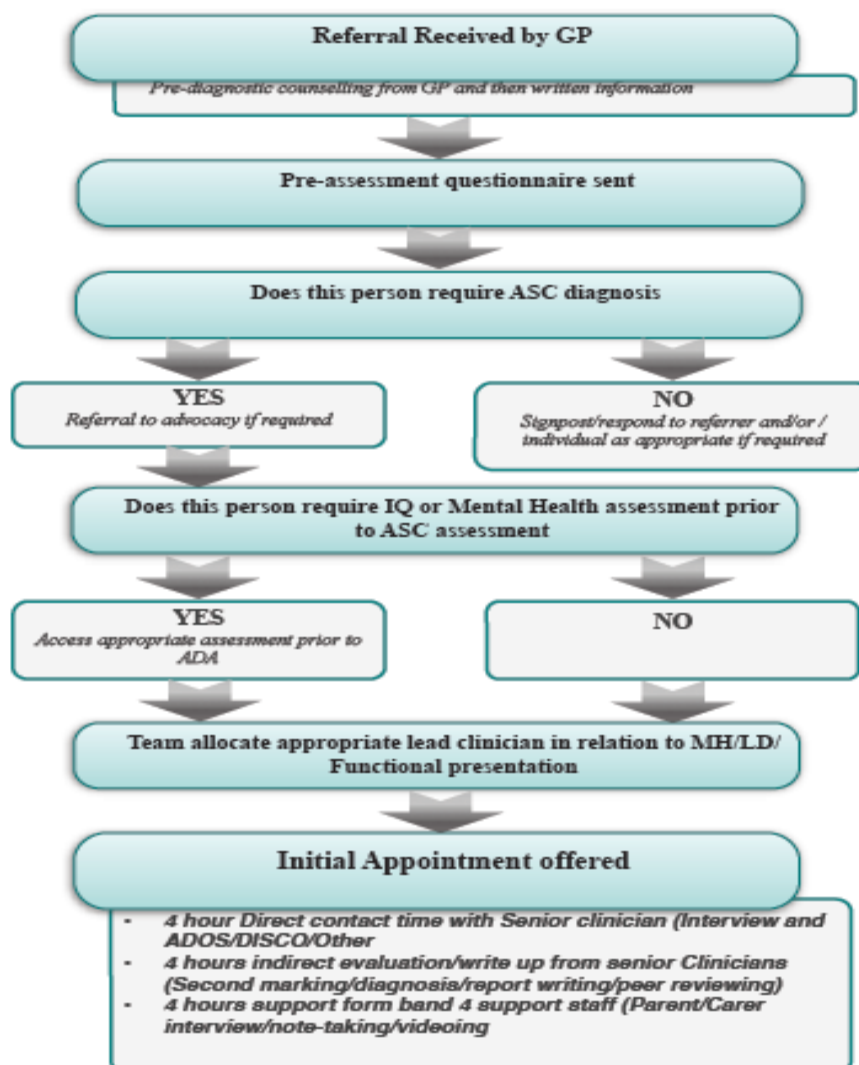
This mix is under constant review to decide if additional permanent resources can be provided. Psychiatry and Social Work referrals as appropriate to relevant local pathway (mental health, LD, Personality Disorder) with joint working from team member. Specialist social worker available to support local pathways.

Contact xxxxxxxxxxxx for further information.



Care Pathway for Adult Autism Diagnosis





Training Resources

AUTISM TRAINING & AWARENESS ONLINE TRAINING RESOURCES

The Department of Health has funded a series of on-line training resources and booklets to increase awareness and understanding of autism across all public services costing £500,000 in total following the publication of the Autism Strategy.

ROYAL COLLEGE OF NURSING

These links are available as free downloads for all healthcare professionals that may come into contact with people who have autism, highlighting key issues to consider.

<http://www.autism.org.uk/~media/NAS/Documents/Working-with/Autism-strategy/Royal-College-of-Nursing-How-to-support-people-with-autism-poster.ashx>

<http://mentalhealthpractice.rcnpublishing.co.uk/>

<http://mentalhealthpractice.rcnpublishing.co.uk/supplements/booklets-and-guides/autism/>

www.rcn.org.uk – this link provides a general link to RCN resources, which include links to professional forums for members and publications.

<http://nursingstandard.rcnpublishing.co.uk/supplements/autism-online-resource-centre> - RCN autism resource centre

ROYAL COLLEGE OF GENERAL PRACTITIONERS

The Autism in General Practice course enables GPs to improve the care they and their practice provide for patients with Autistic Spectrum Conditions (ASC). Using video clips of real patients and carers recounting their experiences, this course helps to understand the challenges that people with ASC face on a daily basis.

www.elearning.rcgp.org.uk
<http://elearning.rcgp.org.uk/course/view.php?id=78>

ROYAL COLLEGE OF PSYCHIATRISTS

The Royal College of Psychiatrists aims to engage in expanding knowledge about the psychiatry of learning disability and autism.

If you encounter any difficulties opening these links, please contact the Royal College of Psychiatrists on Tel: 020 7235 2351.

<http://www.rcpsych.ac.uk/>

SKILLS FOR HEALTH & SKILLS FOR CARE

Skills for Health and Skills for Care have developed a framework to guide the delivery of autism training for the mainstream health and social care workforces.

SKILLS FOR HEALTH

www.skillsforhealth.org.uk/service-area/autism/

SKILLS FOR CARE

http://www.skillsforcare.org.uk/developing_skills/autism/autism_skills_and_knowledge_list.aspx

SOCIAL CARE INSTITUTE FOR EXCELLENCE

This training package looks at the techniques and skills that care workers and social workers need to support people with autism and help them achieve their goals. The link will take users directly to the page with two Autism films on it.

<http://www.scie.org.uk/socialcaretv/topic.asp?t=workingwithpeoplewithautism>

SCIE have also produced a guide titled SCIE's Guide 43: Improving Access to Social Care for Adults with Autism. The link below provides access to the full guide, an at-a-glance summary of it, an easy-read of the summary, and the underpinning research from the University of Sussex:

<http://www.scie.org.uk/topic/careneeds/autism>

BRITISH PSYCHOLOGICAL SOCIETY

The Society has developed three e-learning modules on autism, which appeal to a range of learners by delivering knowledge and understanding from introductory to specialised levels. The e-learning modules are delivered via the BPS Learning Centre. The BPS have worked in partnership with psychologists with expertise in autism and an e-learning provider to produce and deliver these modules. Two modules are freely available to both members and non-members of the BPS and the third is aimed principally at psychologists and all professionals working in this field.

<http://www.bps.org.uk/events/e-learning/e-learning>

UNIVERSITY OF OXFORD

The Health talk online website lets you share in other people's experiences of health and illness. This information is based on qualitative research into patient experiences led by experts at the University of Oxford.

www.healthtalkonline.org/Autism/

NATIONAL AUTISTIC SOCIETY

The National Autistic Society website provides increased awareness and understanding of autism. It also details some of the examples of autism awareness training that currently exist.

<http://www.autism.org.uk/>

NICE

Clinical case scenarios to support the guidelines on recognition, referral, diagnosis and management of adults on the autism spectrum

<http://guidance.nice.org.uk/CG142>