

Supporting adults with autism

A good practice guide for NHS and local authorities



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Foreword

I am delighted to support the development of this good practice guidance, which will be a vital step in making a real difference to people with autistic spectrum conditions (ASC), their families and carers.

We know that families, adults with ASC and their carers have to face many difficulties and barriers in their everyday lives trying to access services and support. People with ASC are often overlooked or ignored by services; professionals and society can misunderstand their condition. The Department of Health (DH) recognises these issues and as a direct result of this launched a consultation on the first ever Adult National Autism Strategy in April 2009 (Department of Health (2009). *A better future: a consultation on a future strategy for adults with autistic spectrum conditions*).

We know that many people with ASC are undiagnosed, misunderstood and looking for support. People with ASC and their families and carers are a hidden minority, some actually 'falling through' local services and failing to receive any service, or getting an inappropriate one. We know that people with Asperger syndrome have a particular difficulty in accessing services.

I have in my role as Specialist Autism Advisor with the DH heard of far too many examples where adults with ASC cannot get the right support services, they are advised that they do not 'fit' into any service area, they are not recognised as individuals requiring personalised support.

I am very pleased to support The National Autistic Society with its publication - it is a step nearer to better quality and accessible services.

Elaine Hill

Specialist Autism Advisor, Department of Health

Introduction

This good practice guide for local authorities and NHS authorities and trusts is part of The National Autistic Society's (NAS) *I Exist* campaign, which aims to transform the lives of adults with autism.

Local authorities¹ can encounter challenges when developing and providing services for adults with autism². The NAS is often approached by local authorities that are seeking advice about how to improve their services. In this good practice guide, we talk about how different local authorities are working to identify and meet the needs of adults with autism.

The guide has four themes:

- **count me in** – examples of local authorities collecting and analysing data on the numbers of adults with autism in their area
- **understand my needs** – local authorities that are actively seeking to assess the needs of adults with autism, particularly those outside current eligibility criteria, and authorities that are working with other agencies, such as health
- **meet my needs** – examples of specific services that reach vulnerable and isolated people with autism, including preventative services
- **lead the way** – strong leadership at local level.

These four themes – count me in, understand my needs, meet my needs, lead the way – can help authorities to better understand and support adults with autism.

The examples we give in this guide demonstrate some of the ways in which authorities can overcome the challenges of identifying and meeting the needs of adults with autism. There is no one-size-fits-all approach and this guide is by no means exhaustive. Adults with autism have very different, and individual, needs. Every local authority has different people to serve – and so can adopt or create their own way of identifying people's needs and developing services for them.



¹We include NHS authorities and trusts in the term 'local authorities'.

²In this publication, we use the term autism to refer to all diagnoses on the autism spectrum (including Asperger syndrome and high-functioning autism). However, we sometimes refer to high-functioning autism or Asperger syndrome alone, where authorities are specifically working with these groups of people.



Count me in

Our *I Exist* campaign aims to transform the lives of adults with autism. To inform the campaign, we carried out a survey of people with autism, their parents and carers, and local authorities and health services.

Our survey found that 86% of local authorities believed that, if they had better data and information about adults with autism in their area, it would help with long-term planning. The lack of comprehensive data makes it extremely difficult to plan and deliver the services that are needed. Local authorities are now turning their attention to the systems that need to be in place to accurately record the number of adults with autism in their area. Some are including the needs of adults with autism in their commissioning strategies and Joint Strategic Needs Assessments (JSNA).

Recent information from the Commission for Social Care Inspection (now the Care Quality Commission) on self-assessment notes that several authorities used national prevalence rates to estimate the number of adults in their area. Meanwhile, others were gathering information from a range of sources, including transition services, mental health services, vulnerable adult services, third sector organisations and independent service providers, among others. This reflects an attempt to gather comprehensive data about adults with autism including those who may not be receiving services, but who do need support.

Here is how some local authorities are gathering and analysing information about the numbers of adults with autism in their area.

Lewisham

Local and national campaigning, along with the authority's adult social care modernisation programme, are the reasons behind Lewisham conducting a detailed needs analysis for people with autism – with a focus on those with high-

functioning autism and Asperger syndrome who may fall between learning disability and mental health services. Lewisham collected two types of data: quantitative and qualitative.

To collect quantitative data, Lewisham asked its statutory and voluntary partners about the numbers of adults with autism that they know of, and compared this to the total number of people in the UK who are thought to have autism. This helped to establish a more reliable figure of the number of people with autism locally, as well as the potential future number of adults with high-functioning autism.

As well as looking at the numbers of people with autism, Lewisham profiled the gender, age and ethnicity of those identified: 58% were of non-white ethnic origin, most were male between the ages of 25-35.

Lewisham combined this with its qualitative data, which was the result of interviews where local people were encouraged to speak freely on a range of topics. The interviews identified people's main needs as they saw them: practical life skills, social and emotional skills, education and employment, housing, and support for family and carers.

Face-to-face interviews with learning disability services, mental health teams and the voluntary sector also revealed the need for better access to diagnosis, information and social care assessments.

Lewisham now had a clearer idea of who might need which services in the years ahead.

Lewisham's final report will be made public in 2009. The report will feed into the JSNA, the development of transition services, and other commissioning strategies.

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Cumbria

In 2006 Cumbria County Council conducted a mapping exercise, after two of its autistic spectrum development groups (ASDGs) raised concerns about the increasing numbers of people being diagnosed with autism in the county. How would these people's needs be assessed and planned for?

The mapping exercise identified a 43% increase in the number of adults with autism recorded in Cumbria, compared with an exercise carried out in 2003. The authority recognised that this figure probably didn't fully capture people with Asperger syndrome and high-functioning autism, who can find it harder to get a diagnosis.

Since the mapping exercise, Cumbria has developed a new electronic social care record system which includes people who have a diagnosis of autism. This should mean that the authority knows more about the numbers of people with autism accessing social care services – negating the need to carry out more mapping exercises. However, there is a recognition that many people with autism will not be getting social care support and as yet, Cumbria does not have a system for recording this population.

In 2007 Cumbria produced a report called *Are we ready?* This report followed a review that looked at gaps in service provision to adults with autism, and where things could be improved. The council's first recommendation was an acknowledgement of the growing numbers of people in Cumbria with autism:

“Appropriate services need to be developed to be able to cope with the demand of this increase...all policies and procedures are inclusive to people with ASD [autism spectrum disorder].”

Following the mapping exercise and the review, in 2008 Cumbria asked adults with autism and Asperger syndrome, their families and professionals, to rate services for **all** people with autism based on guidance documents, and to say what the authority was doing well. It also asked people to identify priorities for service development.



In 2009 Cumbria will publish an adult autism strategy for consultation. Key issues are likely to include social support, diagnosis, and transition. The local authority is leading on the adult autism strategy but health services are also involved and it is hoped the final strategy will be a joint one.

Royal Borough of Windsor and Maidenhead

The Royal Borough of Windsor and Maidenhead (RBWM) commissioned Berkshire Autistic Society to work on a data collection and needs analysis project. An Asperger specialist post was created to do this, and a comprehensive report written and recommendations made. As a result RBWM has established an adult ASD team. The team monitors existing services for people with autism, works with the transition team, and develops new services.

RBWM is one of a small number of local authorities that has detailed data on adults with autism in their area. They are also in the minority of local authorities who are following Government guidance by having a named individual or team with responsibility for autism. Other local authorities have referred to RBWM as being an example of good practice in this area.

Surrey

Surrey's County Autism Project is led by the County Autism Group, which has representatives from children's and adult services, children's and adult health services, Connexions, specialist schools, the NAS, and parent/carer representatives. The project is working to make services for people with autism in Surrey more responsive and effective. It has set up a network of autism champions across the county, and created a strategy that will underpin future service development.

To inform the strategy, a mapping exercise was carried out to find the number of young people and adults with autism in Surrey. This found a significant increase in the numbers of people with autism in the county. Nonetheless, a large number of people will not have been identified. It is hoped that the Surrey Adults Linked Disability Registers will provide additional information about adults with autism, including those who do not receive services, in the future.

There is also information about the numbers of children and young people with autism in Surrey. This information has been used to create a commissioning strategy: specialist supported living services for young people who are making the transition to adulthood will be commissioned each year from 2008-2016. In the first year, Surrey commissioned services for 16 young people, and these have been well received.

Surrey's County Autism Project, which has also overseen development of new training programmes for council and primary care trust (PCT) staff, has been recognised as a good practice example in the Department of Health's *Better services for people with an autistic spectrum disorder* document.



Understand my needs

Adults with autism have very different, and individual, needs and a range of services are required to meet these needs. This means local authorities, health authorities and the voluntary sector need to work with people with autism and their families to understand people's needs and look for innovative and practical ways of supporting them.

Autism is a developmental disability and many adults with autism do **not** have an accompanying learning disability or mental health problem. Yet services are often provided by learning disability and mental health teams. This means many adults with autism – those with high-functioning autism and Asperger syndrome in particular – do not receive any services at all. They fall through the gaps in service structure.

Here we give examples of local authorities who are assessing the needs of adults with autism, particularly those outside eligibility criteria. Some authorities are working with health and other agencies, combining resources and expertise, to do this.

Leicestershire and Rutland

In Leicestershire and Rutland there is an Asperger planning group: a multi-agency forum that includes people affected by autism, Leicestershire Partnership Trust, Leicestershire County Council, Leicester City Council, the primary care trust, learning disability services, and child and adolescent services. The group reports to the local implementation team for mental health and has links with other services.

The group focuses on making sure that people with high-functioning autism and Asperger syndrome have fair access to assessment and services. Regular meetings take place where the group talks about issues such as diagnosis, education, carers' needs, transition, Fair Access to Care, and service commissioning. Other professionals are invited to the meetings to contribute expertise in specific areas. Action is then taken as a result of the meetings.

The Asperger planning group has mapped services for adults with autism for each of the three local authorities, to identify what services are being provided and commissioned for people with autism. At the moment, the planning group is examining databases of people with learning disabilities and mental health to identify people with autism.


Members of the group have established a clear pathway protocol and responsibility for community care assessments and care packages. The group has also developed a training strategy. It wants to deliver ten training sessions including a one-day Asperger awareness training session, and a more in-depth one-day session that will look at interventions. The target audience is professionals, including health staff and psychologists.

Wokingham

In early 2006 Wokingham Learning Disability Partnership Board's autism sub-group identified that many adults with autism could not access the services that they need locally. It was felt that too often, arrangements were being made for care and support out of area (often some distance away and at considerable expense); at other times local arrangements were inadequate or inappropriate.

The autism sub-group secured funding for a 30-month project to identify people's needs. Wokingham and District Mencap were commissioned by Wokingham Learning Disabilities Services to manage the project and write an autism strategy for the borough. It was hoped that the results of this work would include:

- better outcomes for adults with autism (primarily more independent lives, better access to services and greater social inclusion)
- more local provision and greater expertise amongst service providers
- better transition planning
- fewer preventable out-of-area placements
- better value for money.



A final report was produced in March 2009. It found there was a widespread lack of understanding of autism. Less able people generally had their needs met – particularly when they had additional learning disabilities – but those with high-functioning autism or Asperger syndrome were ill-served.

The report also found that, for adults with autism, reasonably simple, preventative services could save money; that the numbers of adults needing services are likely to double; that there is inadequate local housing provision; non-existent adult education opportunities; and gaps in social care, health and support services. Key recommendations include:

- › establish an autism team
- › expand preventative services
- › run an autism training programme
- › improve housing provision and accommodation
- › improve education facilities
- › improve employment support and health services
- › improve partnership working with the voluntary sector.

The report and its findings are subject to consultation and review and an implementation strategy will follow.

As the project was commissioned by Learning Disabilities Services, the focus has been on those with autism and a learning disability who meet eligibility criteria only. It has been agreed, however, that research into a wider group (ie all adults with autism, including those without a learning disability and/or who do not meet eligibility criteria) will be important.

Dudley

Dudley Metropolitan Borough Council has developed a three-year strategy (2007-2010) for services for adults with high-functioning autism and Asperger syndrome. The strategy looks at existing services, gaps in services, and how provision can be improved.

Dudley acknowledges that good local services only exist where agencies work well together, and alongside people with autism and their families. It wants to stop over-reliance on single service providers and sending people to out-of-area

services. It also proposes to commission specific services from independent providers to help meet individual need.

The strategy identifies that it is important for people to understand **how** they can access services, and proposes to make this clearer.

Dudley also wants to improve support for people with autism who are leaving school. This support might include independent living skills, travel training and preparation for employment, as well as the development of an advocacy service for people with autism. Preferably, a specialist worker will join an existing advocacy organisation to work with people with autism.

Autism awareness training for local agencies and key professionals also features in Dudley's strategy.

The strategy suggests seeking funding for a neuro-psychiatrist for one or two sessions a month, who can assess and diagnose people. The viability of a specialist diagnosis service could also be considered. It concludes that there is evidence to support the development of a specialist team of professionals who can identify the complex and diverse needs of people with high-functioning autism and Asperger syndrome.

Greater Manchester Consortium

The Greater Manchester Autism Consortium is England's best example of joint regional working. It has been formed by the ten local authorities in Greater Manchester, who work together to understand the needs of local people with autism. The consortium funds and steers the NAS Family Services Development Project, which supports the development of local services for people with autism and offers help and information.

There are autism services development groups (ASDGs) in each of the ten local areas, made up of people affected by autism and staff from social services, health and education. The ASDGs are all part of the consortium, and their Chairs are members of the consortium's steering group. The ASDGs help authorities to work together and to develop and improve services in the region. Current plans and developments include:

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- a North West-wide proposal and business case on adult diagnosis prepared by Manchester and the NAS to be presented shortly to the North West Strategic Health Authority
- Stockport's development of a new Asperger syndrome service
- developing and delivering training programmes for police volunteers
- developing and delivering training for social workers who carry out assessments of need
- developing training around sexuality and relationships
- work on sibling workshops and groups by Rochdale and Bury
- five of the local authorities run youth groups for children and young people with autism
- most of the local authorities are doing work on care pathways for children who are sent for diagnosis, and support after diagnosis
- the local NAS resource centre and the Family Services Development Project are developing 'one-stop shops' for adults with autism
- Manchester is developing a series of person-centred planning workshops for parents of children and young people with autism
- the NAS regional team and the Family Services Development Project are organising a forum for criminal justice professionals to discuss training needs and possible areas of work together.

Nottinghamshire

Nottinghamshire County Council, working with Nottinghamshire primary care trust, produced an adult social care and health commissioning strategy in 2007. This incorporated the county's first strategy for people with Asperger syndrome. The strategy examined the current policy context, the number of adults with Asperger syndrome, and current service provision. It also discussed future commissioning plans.

Nottinghamshire will now:

- establish a multi-disciplinary, multi-agency team to provide specialist assessment, care management and short-term interventions
- determine the level of demand for services from adults with autism
- develop a range of housing and support options
- provide community care services to an extra 20 people a year for the next three years
- provide guidance for staff about how services can overlap, and how they can work together.

Somerset

In Somerset, the Asperger Syndrome Consultancy Service was set up in January 2005. The service was created after social workers and learning disability specialists noticed a high volume of referrals of adults with autism during liaison work between mental health and learning disability services.

The service, which consists of a team leader, a specialist social worker for learning disability, a specialist occupational therapist and a nurse – with input from a clinical psychologist – is part of Somerset Partnership, a mental health and social care trust. It has a close relationship with carers, learning disability services and voluntary organisations through an autism interest group that meets quarterly.

People can now get a diagnosis locally, and support after diagnosis. Referrals come from an identified care co-ordinator and the team is piloting a diagnostic pathway.

Carers, people who use services and professionals working with people with Asperger syndrome can access advice, consultancy, support and training.

The Asperger Syndrome Consultancy Service has also devised basic awareness training, which is followed up by enhanced training for 'link workers'. The plan is to have a link worker in every mental health team, who will look after a maximum of three to four cases and act as a source of knowledge and support. Link workers will receive further training and expert supervision from the consultancy service.

Since the Asperger Syndrome Consultancy Service was set up, Somerset has seen significant improvements in the way people with Asperger syndrome and their carers are supported. People can now get a diagnosis in-county and be referred to other services that can help them. Carers, people with autism and professionals can also access advice, consultancy, support and training. Somerset is now being contacted by other authorities who want to learn from its experience.

Kent

In mid 2008, Kent County Council (KCC) formed a select committee to investigate a wide range of issues concerning autism in adults. In particular, the committee considered the extent to which services met the needs and expectations of adults with autism in Kent, and ways in which services could be made more effective.

The committee also looked at the prevalence of autism in Kent; existing and emerging national and local policies and strategies on autism; how much partnership working happened between different agencies in Kent; and ways of funding services.

The following recommendations were included in the committee's final report.

- › Through the Joint Strategic Needs Assessment establish the most effective way of investigating the numbers of adults with autism in need of support and not currently receiving services, and the levels of service satisfaction of those adults with autism living at home and currently receiving support.
- › Encourage the inclusion of autism-related services, in the form of 'care pathways', among the services provided by multi-disciplinary mental health teams in the county. Explore the possibility of setting up, in partnership with the NHS, a specialist autism service in Kent.
- › Make sure that advocacy services with autism-specific knowledge are offered to all people with autism who need them. Contribute to the funding of a befriending scheme, using trained volunteers, which may be run in collaboration with the NAS.

- › Aim to achieve greater access to person-centred planning for, and a greater usage of Direct Payments by, people with autism.
- › Set out how Kent's learning disability and mental health teams can work together to provide a more inclusive and responsive service to people with autism.
- › Ensure well co-ordinated, seamless transition into adulthood, involving person-centred planning and support.
- › Review the availability of specialist psychology, psychiatry and speech therapy services to people with autism.
- › Support a campaign to raise awareness in the community about autism and urge other agencies, including the NHS, the criminal justice system, the police and the housing, employment and education services, to raise awareness among their staff.
- › Review recruitment practices and selection criteria so that they support the employment of more people with autism in the authority; explore how further education colleges in Kent could maximise the employment opportunities of people with autism in the county.
- › Carry out an audit of the housing options available to people with autism; take particular account of the needs of people with autism when deciding housing options; and consider allocating some PFI housing options to people with autism.
- › Carry out a county-wide audit to gauge the need for respite from people with autism and their families.

The select committee reported to the KCC Cabinet in March 2009, then to the county council in April 2009. The report's recommendations were endorsed by both, and a group has now been set up to implement the report.

Meet my needs



A person-centred approach is vital to meeting the needs of adults with autism, but the lack of personalised, autism-specific services leaves many people isolated and vulnerable.


The NAS *I Exist* survey identified that the main sources of support people with autism wanted were social skills training, social groups and befriending: simple, cost-effective and 'low level' services which can make a big difference to the lives of adults with autism. Preventative services like social skills training can help stop the needs of people with autism escalating to a point where more serious intervention, or expensive crisis support, is needed.

Here are examples of local authorities and health trusts commissioning autism-specific, preventative services that reach vulnerable and isolated people.

Kingston

In 2007, the Royal Borough of Kingston-upon-Thames developed an Asperger syndrome service to help adults with Asperger syndrome who had previously received a service either from the community mental health team or the community learning disability team.

Because of changes in the eligibility criteria in Kingston under the Fair Access to Care scheme, only people with critical or substantial need receive support from community care services. Therefore, the Asperger syndrome service operates as a specialist service which works to meet the needs of adults with Asperger syndrome, including those who do not meet the eligibility criteria for community care services: a vital and important service.



The service works closely with the community learning disability team and the community mental health team, as well as with Kingston Workstart, the local employment service for disabled people. The service offers:

- two work-related training programmes
- one-to-one appointments
- a carers' support group
- a monthly social group that gives people with Asperger syndrome the chance to meet each other and take part in social activities
- training to develop skills and confidence
- a drop-in facility and social activities.

The overall aim of the Asperger syndrome service is to help adults with Asperger syndrome to live more independently.

Liverpool

The Liverpool Asperger Team is funded by Mersey Care NHS Trust. A team of professionals provide a specialist service for people with Asperger syndrome, helping people with the social and communication barriers that they may face in everyday life. The service's person-centred approach means that each person receives a service geared to their individual needs.

The Liverpool Asperger Team has eight core members and a range of other professionals who provide further support and advice to adults who use the service.

Adults can access social and healthcare support within the 'managed care pathway'. This is a network of services that work together to help people with Asperger syndrome. The Liverpool Asperger Team takes a co-ordinating role and may work with schools and colleges, with mental health services or other local services. In particular, there are strong links with local provider agencies, adult mental health services and Network Employment.

Through the network, the team offers assessment and diagnosis of Asperger syndrome, possibly coupled with other interventions. For some people, a diagnosis of Asperger syndrome may be all that they need to help make sense

of their experiences. Others may need help adjusting to the diagnosis, dealing with other social or mental health difficulties or learning to fit in to a 'neurotypical' world.

The team also offers training and advice to other agencies, including Asperger awareness training to professionals who work with adults with the condition.

More than 400 people have been referred for assessment, diagnosis and intervention and many other local authorities are interested in the model the Liverpool Asperger Team provides - a specialist service that really does meet the needs of local adults with Asperger syndrome.

Gloucestershire

The Gloucestershire Autism Centre was officially opened in 2008 and is jointly funded for two years by Gloucestershire County Council and the NAS. The centre is a place for people with Asperger syndrome to meet. It also provides information and advice, and acts as a base for awareness-raising and establishing links between services.

The centre is the result of multi-agency work involving parents and carers, people with autism, the county council and the NAS. Following a conference where parents and professionals spoke about the problems for adults with autism and their families – including the lack of knowledge of services available, and people 'falling through' gaps in services – an ASD partnership board was set up. Its aims are to:

- organise a local training programme – basic awareness training has been completed for professionals such as housing officers and job centre staff, second level training for social workers is currently being developed
- explore existing commissioning arrangements and develop a commissioning process. A joint commissioner has now been identified to set up autism-specific services
- develop a web page for the centre on the NAS website, which carries information about local agencies and organisations

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- › build a group of high-level autism champions, define their role and equip them with a suitable 'toolkit'. These champions will be both at a decision-making level and at practitioner level
- › once an autism-specific service has been established, develop clear guidance and protocol
- › ask people whether their needs are being met in the way they want.

Nottinghamshire

Nottinghamshire Healthcare NHS Trust, the mental health and learning disability service provider for Nottinghamshire, has established a new service for adults who have – or suspect they may have – Asperger syndrome. The new service was launched in April 2009.

The service includes professionals from the fields of clinical psychology, psychiatry, speech and language therapy, occupational therapy, and social work, as well as a number of support workers.

The Nottinghamshire adult social care and health department has already established a team to provide social care support for adults over the age of 18 who have – or suspect they have – Asperger syndrome and do not have a learning disability.

This team can carry out a diagnosis, and will then help people with Asperger syndrome and their carers to decide which support they need, and to access this support. Often, people will want information and support following a diagnosis; support with maintaining their home; help at college or in employment; support accessing social and community activities; and support accessing other care services, such as mental health care.

Nottinghamshire Healthcare NHS Trust is currently recruiting a complementary clinical team; this team will work alongside the county adult social care team.

Medway

The social exclusion task force at the Cabinet Office is funding 12 pilot schemes that will address the needs of adults who are facing exclusion. The Medway project is one of these pilots. It runs from 2007-2010 and is delivered by the charity MCCH.

Medway wants to improve the ability of adults with learning disabilities, autism or mental health problems to access housing, social and health care, learning, employment, leisure and financial services. It will look at people who experience chronic exclusion, as well as those with a history of 'bouncing in and out' of services. A special focus will be on adults with autism and Asperger syndrome, often undiagnosed, neglected, and ineligible for services, or referred by default to learning disability or mental health teams.

The pilot aims to engage the people who use services, the people who provide them, and the people who commission them. The ultimate aim is to make services easier to access – and to stay in – by offering individual support, person-centred plans, mentoring and advocacy, and access to individual budgets and self-determined services. Medway will share what works well and use it as a model for future service development.

The pilot has already supported people with travel training, accessing education and voluntary work and opportunities to socialise with other service users.

Training will be offered to professionals. At the moment, a training package is being put together for Rochester Young Offenders Institute to make officers more aware of adults with autism and those with other particular needs. There is discussion with Mid Kent College about setting up a buddying service, which can help people with autism to succeed in further education. As well as this, local artists have started working with adults with autism to help increase people's confidence.



Northamptonshire

In Northamptonshire the emphasis is on identifying people with autism who are making the move into adulthood, and on support after diagnosis. Transition support is normally offered to young people during their last year in school.

Northamptonshire has a health-funded transition and liaison team that provides a diagnosis service and short-term post-diagnosis support to adults with Asperger syndrome over the age of 18, with no upper age limit.

Support services are available to adults who already have a diagnosis and who are experiencing difficulties. These services might include: learning about new ways to cope with difficulties; issues with friendship and relationships; helping the person and their family to understand their needs; and helping the person to access college or employment. People are referred by their GP, a health professional or a care manager.

Local authority commissioners have also been working closely with the NAS to find out how many people have to go out of county to get support.

Newham

Newham adult services, in partnership with East London NHS Foundation Trust, has a project to co-ordinate services for adults with Asperger syndrome or high-functioning autism. This is called the Asperger Service, and it has an open referral system.

The Asperger Service provides a diagnosis service; and care co-ordination for people with a diagnosis, which includes help accessing social and leisure activities, employment and education, housing, benefits advice, mental health services, and other services. There is also a monthly social group, and staff can support adults to attend other groups.

Carers can get support too, for example by going to the monthly carers group. The Asperger Service also offers training and outreach support to other services working with people with Asperger syndrome or high-functioning autism.

There is ongoing work to develop local, specialist services for adults with autism, as well as improving access to general community services.

Because of Newham's success, the neighbouring boroughs of Tower Hamlets, Hackney and the City of London are planning to develop similar projects.

Lead the way

Local leadership is essential if the complex needs of adults with autism are to be met. Statutory guidance from the Department of Health in England makes it clear that the Director of Adult Social Services and/or Director of Public Health should make sure that the needs of all client groups are assessed. In the NAS / *Exist* survey, of the 89% of local authorities who had appointed a Director of Adult Social Services, only 39% had appointed a lead team or person to assess and meet the needs of adults with autism.

Here are some examples of how local authorities are championing the needs of adults with autism in their area.

Oldham

Oldham uses several approaches to meet the needs of adults with autism locally. There is high-level commitment to autism in the authority. Oldham's Executive Director of People, Communities and Society chaired the Greater Manchester Autism Consortium; and its Service Director for Adult Social Care has now taken on this role.

Oldham's Way Forward Group is made up of teams that develop and maintain services for children and adults with autism. This group has been instrumental in helping to bring about a range of initiatives to support people with autism, including a development and implementation manager who is a central point of contact in the authority, and a vulnerable adults service that works with people who are eligible for support following a FACS assessment, but who do not fit the remit of other teams. A significant number of the people it supports have Asperger syndrome or high-functioning autism.

All Oldham's learning disability, supported tenancy, day and respite services are autism accredited.

There has been investment in training, which starts with basic awareness sessions and progresses to very specialised training.

This training is given to professionals who provide direct support and carry out assessments of need, but also to others who may come into contact with people with autism including the police, housing providers, and probation services.

Meanwhile, Oldham children's services has allocated significant resources to identifying gaps in extended school provision for children in its autism resource bases. This has led to investment in training for leisure and youth providers.

At the moment, Oldham is piloting a course on stress and anxiety for people with autism.

Oldham has also invested in preventative services for adults with autism, such as social groups. These low-cost services give people the social support they need, but develop confidence and can help people to, for example, access employment.

Transition is another area that Oldham is paying attention to. The authority is developing a 'transition house' so that people can start to be brought back from out-of-area placements. A pilot transition project, 'Get a life', is partly focused on autism and Asperger syndrome and is looking at making sure that good transition and person-centred plans are in place. The pilot should be completed and a system in place by March 2011.

More generally the authority has run national conferences sharing good practice and is contributing to the Department of Health's national autism strategy.

Buckinghamshire and Oxfordshire

For the last two years, Oxfordshire and Buckinghamshire Mental Health NHS Foundation Trust has been focusing on identifying the needs of adults with high-functioning autism and Asperger syndrome. This work is in conjunction with Buckinghamshire County Council and Ridgeway NHS Partnership Trust, the providers for learning disability services in Oxfordshire and Buckinghamshire.

In 2002, the NAS published *Taking responsibility: good practice guidelines for services – adults with Asperger syndrome*, funded by the Department of Health. The *Taking responsibility* proposals were discussed at length in Thames Valley's local specialised commissioning group (LSCG) and a Thames Valley-wide conference on the subject was held in September 2006. After this, an initial mapping exercise of the local population with Asperger syndrome took place.

Buckinghamshire and Oxfordshire then set up a local steering group to see how progress could be made locally. The steering group, which includes senior local authority staff, as well as service users and carers, has designated a group of volunteer frontline staff as 'team champions'. These champions have received general autism awareness training, along with specialist training for senior medical and psychology staff.

Buckinghamshire and Oxfordshire's mapping exercise found that a number of people with high-functioning autism and Asperger syndrome were known to learning disability or mental health services but not receiving appropriate treatment or support. More people were identified as they came through transition.

The exercise highlighted the financial cost of the services these people were receiving. Could expenditure be pooled to provide a specialist service which better meets people's needs? Over 600 people were identified who would benefit from such a service: 30 were in high-cost, out-of-authority placements, and 79 were receiving community support from mental health or learning disability services. The project steering group is looking at the feasibility of developing a specialist service for assessment, diagnosis and support.

Durham

Durham's ASD care co-ordinator addresses the needs of people with high-functioning autism and Asperger syndrome who fall between mental health and learning disability services. The co-ordinator takes on specific, often complex, casework. They receive referrals from all agencies and feed into the autism spectrum disorder group (ASDG) for Durham, part of the North East Autism Consortium.

The co-ordinator works closely with mental health services to develop packages of care, and with the commissioning department to plan independent living packages for young people with autism and complex needs. A 'virtual team' made up of the primary care trust's commissioning manager and consultant psychiatrist supports the co-ordinator.

Durham's focus is on making sure that people who may fall between learning disability and mental health service remits receive the support they need to live as independently as possible. The co-ordinator has identified the need for new services, such as an autism care pathway team, and an outreach or family intervention worker.

Royal Borough of Windsor and Maidenhead

The Director of Adult Social Services has taken the lead on development of services for adults with autism in the Royal Borough of Windsor and Maidenhead (RBWM), one of a small number of authorities that have followed Government guidance in doing so. This leadership has had a significant and positive impact on services for adults with autism in the borough.

Following data collection and analysis of people's needs, the borough established an adult ASD team. This is a specialist service for adults with autism who otherwise have not been able to receive a service at all, or were perhaps supported by teams such as mental health or learning disability. The adult ASD team supports people in the community: it runs drop-ins, social groups, groups on health and well-being; and raises awareness and provides training on autism in the borough.

The team also monitors the local autism population by working with the transition team; looks at existing services for people with autism; and develops new services. There is also an adult ASD steering group: the NAS is a member, along with statutory and voluntary sector representatives and carers.

Wales: a strategic vision

In 2008 the Welsh Assembly Government launched the *Autistic spectrum disorder (ASD) strategic action plan for Wales*. This plan aims to help the estimated 100,000 people who are directly or indirectly affected by autism in Wales, making improvements to health, social care and education services for children and adults. The ASD action plan has five key areas.

- **Mapping prevalence, needs and services:** commissioners and service providers are to set up systems to identify and record people with autism and estimate current and future demand. A local autism champion, or lead, will work with stakeholders to deliver the action plan at a local level. Funding of £1.8million has been identified for the first year's mapping activities and an implementation manager appointed.
- **Commissioning services:** all Children and Young People's Plans, and local Health, Social Care and Well-Being Strategies are to include an overview of the arrangements for commissioning services for children and adults with autism. Authorities must say how they will make use of powers to pool resources when commissioning services.
- **Transition:** clear transition arrangements between children's and adult services are to be in place and there will be guidance for schools and local authorities on transition planning. £1.5m has been set aside over three years (starting in 2008-09) for more transition workers.
- **Services for adults:** a group has been established to identify the issues adults face when trying to access services, and how these can be tackled. It will investigate, evaluate and report on effective examples of services and support.

- **Raising awareness and providing information and training:** commissioners and service providers are to provide training for all professionals who come into contact with people with autism.

Before the ASD action plan was published, several local authorities in Wales already had multi-disciplinary working groups for autism. Monmouthshire, Powys, Rhondda Cynon Taf, Ceredigion and Conwy are just a few examples.

Ceredigion

In 2002, Ceredigion set up a group made up of adults with autism, parents, representatives from the local authority and health trust, and the charity Autism Cymru.

In 2004, a local authority development officer for adults with autism was appointed. The development officer champions the needs of adults with autism in Ceredigion, and instigated plans to create a team of autism practitioners in the area. Double the number of adults now receive support, there is more training for service providers, more autism information available, and moves to create a county-wide autism training scheme, Ceredigion Autism Training Scheme (CATS).

Ceredigion also developed a local planning strategy for adults with autism. This work was undertaken by Ceredigion in its role as the autism lead for the three counties project (Pembrokeshire, Carmarthenshire and Ceredigion) which started in 2002. The strategy included the creation of a small, specialist group of frontline staff with knowledge of autism. It drew up protocols for joint working, monitoring the quality of services, transition planning and ways to recognise the needs of local adults with autism.

Scotland: policy and practice



Policy and practice guidance for commissioners

In 2000, *The same as you?*, a review of services for people with learning disabilities, was the first policy document to address the needs of people with autism in Scotland. For the purposes of the review, 'learning disability' was deemed to include people with autism.

In 2001, the Public Health Institute of Scotland (PHIS) published the *Autistic spectrum disorders needs assessment report*, which set out priorities for service planning and

delivery. The Scottish Government then set up a national ASD reference group to inform a programme of work encouraging the development of good practice. Progress with the PHIS recommendations was reported in a 2006 Scottish Executive report.

In 2008, the Scottish Government published *Policy and practice guidance for commissioners of health and social care services for people on the autism spectrum* to inform the development of health and social care services for people with autism in Scotland. This guidance says local authorities and health boards should work in partnership to:

- be clear what outcomes are to be delivered for people with autism
- keep a record of people with autism in each local area. An audit of people's needs should be carried out to identify service gaps; this can build on a 2003 audit of services for people with autism
- make sure that diagnosis and assessments are carried out by specially trained and qualified workers who understand the needs of people with autism
- make sure that services meet the needs of people with autism
- involve people with autism in service planning
- offer information in accessible formats. Information about accessing services should be widely available and accessible
- give autism awareness training to staff. Training should be accredited
- appoint an autism co-ordinator to take responsibility for service implementation, monitoring, quality assurance and reporting.

National Learning Disability and Autistic Spectrum Disorder data standards

The National Learning Disability and Autistic Spectrum Disorder data standards were released in February 2007. These standards are used for recording information about services for people with learning disabilities and/or autism as part of health and social care assessments. The data will



be used to create a national database and from there, local databases. It will make sure that there is consistent recording and measuring of data and provide an accurate picture of what is happening in each local authority area, allowing comparisons to be made.

Glasgow

The Joint Community Care Committee of Glasgow City Council/Greater Glasgow Health Board established an autism task force in 2003 to make a difference for people in Glasgow living with autism. Following the publication of its report in 2004, the task force became a working group which would oversee the implementation of the report's recommendations.

In 2004 the Scottish Executive made available £250,000 per year for three years, to pilot a one-stop shop for people with autism in Greater Glasgow. Around the same time Glasgow City Council, through Glasgow Learning Disability

Partnership, made available a recurring resource of £189,900 to set up an autism development team.

Later that year the Autism Resource Centre (ARC) opened. The ARC became the focal point for the development of autism-friendly services in the area. It works with other services and people affected by autism to develop best practice, and design, deliver and evaluate new services.

The ARC is a partnership between Glasgow City Council, NHS Greater Glasgow, NAS Scotland, the Scottish Society for Autism, and Strathclyde Autistic Society. The ARC currently receives recurrent funding from Glasgow City Council and NHS Greater Glasgow (both through Glasgow Learning Disability Partnership), and some one-off monies through 'hosted' posts from NHS Greater Glasgow. This aspect is currently funded by the Mental Health Partnership.

The ARC's services include:

- **information base** – advice and information for people affected by autism, including the services available to them; a library of books, articles and service information; computer access; access to specialist support and advice
- **training** – the ARC works to improve understanding of autism among professionals, especially in the field of social care and health. It offers a range of training from one-day autism awareness training to high-level diagnostic training. Training is currently free and available on an outreach basis
- **adult autism service** – diagnosis and assessment (via weekly clinics); individual and group interventions; drop-in facility; user-led interest groups
- **development team** – planning for autism services; partnership working with mainstream services and care groups; ensuring standards of service delivery for all people with autism; helping Greater Glasgow Health Board and Glasgow City Council make sure that they meet national standards.

Some recent and current developments include:

- development of post-diagnosis courses for people with autism, including a course for young people called 'Me, myself and ASD'
- 350 autism alert cards issued to date in partnership with Strathclyde Police
- a DVD for all Strathclyde Police staff
- a screening project on 80 prisoners, with an autism prevalence rate of 7.5% in mainstream prison and 14.5% in a high dependency unit being identified
- a housing needs assessment for families which has identified a need for larger style accommodation and secure garden areas
- good practice guidance for housing staff who work with people with autism and their families.

Aberdeenshire

Aberdeenshire Council runs an autism strategic outcomes group, chaired by a social work manager, with involvement from all of the main autism-specific third sector organisations, a sub-group for people with high-functioning autism, and representation from the four autism organisations operating in the area.

In 2007 Aberdeenshire established an autism base at the Harlaw Centre in Inverurie for adults. The aim of this service is to help adults with autism to become more independent. The staff are trained to develop person-centred, daily schedules for people who use the service. They work with the Scottish Society for Autism to assess people's individual needs.

Together with the NAS, staff are exploring the potential of a pilot project which would help people with Asperger syndrome to gain the skills needed to access employment, college or university.

Aberdeenshire is also developing an information base at the Harlaw Centre which can be used by people with autism, their families and carers, and the general public.

Highlands

In the Highland Council and NHS Highland area, a two-year project ran from May 2005 to May 2007. The project reviewed services for adults with autism, identified the highest-priority needs of service users and carers, and made recommendations to chief officers in community care about how services should be developed. This project included a focus on the transition from childhood to adulthood, and was funded by the Scottish Executive. The project recommended:

- the development of specialist autism services
- consistent care and treatment for adults with autism
- the development of preventative services
- avoidance of lifelong, out-of-area placements
- improved detection and diagnosis and development of an autism mental health service.

Supporting adults with autism

There are plans to recruit autism-specific social work practitioners. Social work services have been including autism awareness sessions in their induction programme for social work teams.

Moray

Aspire (Autism Spectrum Project Intervention Review Evaluation) is a team of health and social work professionals who have expertise in autism and were brought together as an assessment and advisory service for the Moray Council area.

Key workers carry out initial assessments of need for people with autism. When the assessment is complete the Aspire team meets the person concerned to talk about the results. If a diagnosis is agreed the team will recommend ways to address the particular difficulties that person may face. If someone has a learning disability, their support needs will be reviewed by members of the community learning disability team. If the person does not have a learning disability, a community care officer will support them.

The Aspire Employment Project was developed to help people with high-functioning autism and Asperger syndrome access employment. The project provides a 12-week training course, SUSS (Support and Understanding of Social Skills). The course looks at any difficulties people may have with social skills and addresses these. SUSS encourages course participants to become more self-aware, more confident and, ultimately, helps them get into employment.

Renfrewshire

The Flexi-Care Project is a social work service for people with a learning disability and/or autism living in Renfrewshire. The project, set up by Renfrewshire Council, is establishing a network of trained volunteers and sessional workers who can offer personalised support to people with autism in their local community. The project:

- › promotes the inclusion of people with autism in community life
- › provides support to families caring for a son or daughter with autism by offering a flexible range of services
- › helps people with autism to access social and leisure activities
- › raises awareness of autism
- › provides ongoing support and training to volunteers.

Services provided by the Flexi-Care Project include befriending schemes and activity groups. The befriending scheme matches people with autism to volunteers or sessional workers who share similar interests, giving them the opportunity to get out and about in the community. Flexi-Care also runs several social activity groups, which are open to adults with autism or a learning disability, and autism-specific groups, including a creative arts group for adults.

The manager of the Flexi-Care Project has responsibility for the development of autism services in Renfrewshire.



Conclusion

There are many ways of identifying and addressing the needs of adults with autism. Local authorities and NHS authorities and trusts have much to learn from each other about the benefits of using these different approaches. There is also a lot to learn from local people affected by autism.

What is important to remember, no matter what approach is used, is that there are four main steps to supporting adults with autism:

- › count me in – effective data collection
- › understand my needs – ask people what their needs are

- › meet my needs – offer flexible and autism-specific services
- › lead the way – strong leadership at a local level.

We hope that this snapshot of local authorities' good practice will encourage you to work together to transform the lives of adults with autism where you live.

The National Autistic Society is here to help local authorities and NHS authorities and trusts who would like more information or support to meet the needs of adults with autism. You will find contact details for NAS teams in your area on page 24.



References, further reading and contacts

National Autistic Society reports

Rosenblatt, M. (2008). *I Exist: the message from adults with autism in England*. The National Autistic Society

Daly, J. (2008). *I Exist: the message from adults with autism in Scotland*. The National Autistic Society Scotland

Withers, L. (2008). *I Exist: the message from adults with autism in Wales*. The National Autistic Society Cymru

Stewart, S. (2008). *I Exist: the message from adults with autism in Northern Ireland*. The National Autistic Society Northern Ireland

Powell, A. (2002). *Taking responsibility: good practice guidelines for services - adults with Asperger syndrome*. The National Autistic Society

National reports

Department of Health (2006). *Better services for people with an autistic spectrum disorder*.

Welsh Assembly Government (2008). *Autistic spectrum disorder (ASD) strategic action plan for Wales*.

Scottish Executive (2000). *The same as you? A review of services for people with learning disabilities*.

Public Health Institute of Scotland (2001). *Autistic spectrum disorders needs assessment report*.

Scottish Government (2008). *Policy and practice guidance for commissioners of health and social care services for people on the autism spectrum*.

Scottish Consortium for Learning Disability (2007). *National learning disability and autistic spectrum disorder dataset (version 4.1)*

Local authority reports

Cumbria County Council (2007). *Are we ready? A scrutiny review of the services provided to adults with autistic spectrum disorders in Cumbria*.

Dudley Metropolitan Borough Council (2007). *A three year strategy for services for able adults with autism aged 16 and over in Dudley 2007-2010*.

Kent County Council (2009). *Autistic spectrum disorder select committee report*.

London Borough of Lewisham (Community Services Directorate) (2009). *Autism needs analysis: the needs of adults with autistic spectrum disorders (particularly Asperger syndrome)*.

Nottinghamshire County Council (Adult Social Care and Health) (2007). *Commissioning strategy 2007-2009 (chapter 6) Commissioning strategy for people with Aspergers disorder*.

Contacts

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Local authorities and NHS authorities and trusts can encounter challenges when developing and providing services for adults with autism. In this good practice guide, we talk about how different NHS and local authorities are working to identify and meet the needs of adults with autism.

The National Autistic Society is the UK's leading charity for people affected by autism.

Over half a million people in the UK have autism. Together with their families they make up over two million people whose lives are touched by autism every single day.

Despite this, autism is still relatively unknown and misunderstood. Which means that many of these two million people get nothing like the level of help, support and understanding they need.

Together, we are going to change this.

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