

PUSH FOR ACTION

**Implementing the adult
autism strategy:**
a guide for local authorities
and local health bodies

The Autism Act 2009 was a landmark piece of legislation. It was the first ever disability-specific law in the UK and it led to the publication of two key documents: *Fulfilling and Rewarding Lives: the strategy for adults with autism in England* and *Implementing Fulfilling and Rewarding Lives: statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy*.¹

The aim of the strategy is to revolutionise the way services are delivered to adults with autism² and to make sure they can live full and prosperous lives. The statutory guidance backs this up by placing legal duties on local authorities and NHS bodies to improve services.

Since the publication of the strategy and statutory guidance, some authorities have taken great strides in improving planning, services and outcomes for people with autism. Most, however, still have a long way to go.

To inform the Government's 2013 review of the strategy, The National Autistic Society (NAS) undertook research looking at progress made so far. This included an assessment of the key barriers and enablers to implementation at a local level.

The professionals that we spoke to told us that they wanted clearer guidance on how to implement the strategy and improved sharing of good practice.

The short guides in this pack aim to act as a quick reference for local authorities and the NHS, setting out the basics of what they must do to implement the different aspects of the strategy and statutory guidance, as well as what they need to do next, once they have the basics in place. We also include examples of good work already taking place, showing how a few straightforward, practical measures can have a positive effect on the lives of adults with autism.

Further examples of good practice can be found at www.autism.org.uk/autismstrategy

The South West Autism Strategy Network Group has developed a benchmarking toolkit with local areas. This toolkit enables local areas to recognise best practice and to benchmark their progress against outcomes independently, with the aim of assisting the development of detailed action plans.

For more information, visit www.autism.org.uk/strategy/benchmarkingtool



¹These documents were published by the Department of Health in 2010.

²The term autism is used throughout this document to refer to all conditions on the autism spectrum, including Asperger syndrome.

Getting the right services and support in place

What does the strategy and statutory guidance say?

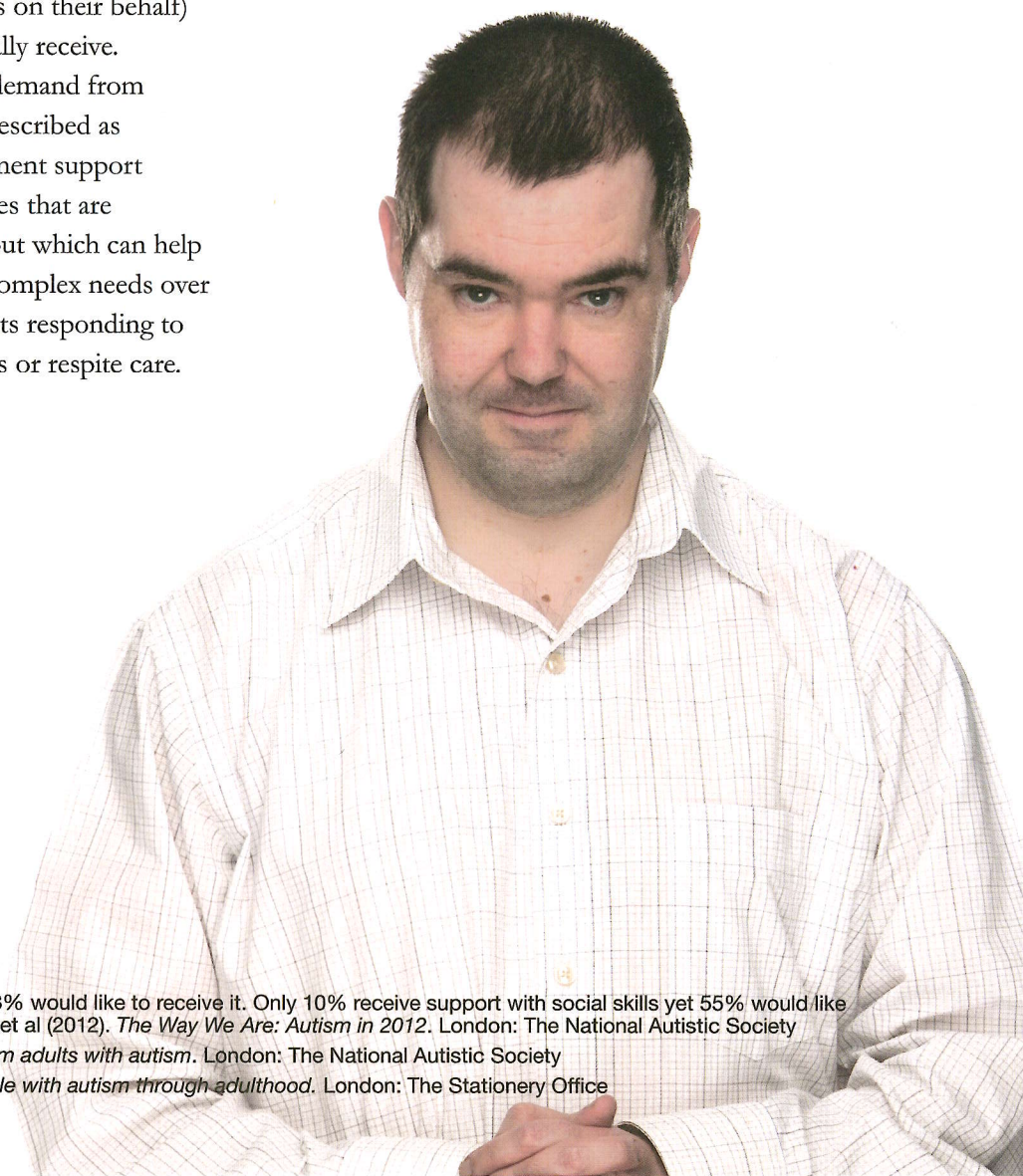
Adults with autism routinely struggle to access the help they need. The Autism Act 2009 was passed because Parliament recognised that this was unacceptable and needed to change.

Both the strategy and statutory guidance place particular emphasis on the importance of consulting locally and carrying out local needs assessments, on which the planning and commissioning of services should be based. Both, however, also discuss the different types of services that are helpful across the board: services such as help with how to travel and advocacy, for example.

Our research identified that there are significant and persistent gaps between the types of support that adults with autism (or their parents and carers on their behalf) say that they need, and what they actually receive. Our survey data demonstrates a clear demand from adults with autism for what could be described as 'preventative services' such as employment support or help with social skills – those services that are low-level and less intensive in nature, but which can help to prevent the development of more complex needs over time.¹ In addition, nearly half of parents responding to our survey called for more short breaks or respite care.

Failure to provide adequate services can have costly consequences for individuals and the state. It can mean individuals fall into crisis situations, requiring expensive mental health services or residential care. A third of adults with autism responding to The National Autistic Society's *I Exist* survey said that they had developed serious mental health problems due to a lack of support.² The 2009 National Audit Office (NAO) report explains *"Beside the negative impact of such crises on a person's life, acute services are also expensive, with inpatient mental health care costing between £200 and £300 per day."*³

As a result of this, the NAO report found that if local services identified and supported just 4% of adults with high-functioning autism and Asperger syndrome, the outlay would become cost neutral over time. If they did the same for just 8% it could save £67 million each year.⁴



¹Only 10% receive employment support yet 53% would like to receive it. Only 10% receive support with social skills yet 55% would like to receive it. All figures here are from Bancroft et al (2012). *The Way We Are: Autism in 2012*. London: The National Autistic Society

²Rosenblatt, M (2008). *I Exist: the message from adults with autism*. London: The National Autistic Society

³National Audit Office (2009). *Supporting people with autism through adulthood*. London: The Stationery Office

⁴Ibid.

Good practice

Case study: Kirklees

In Kirklees, 'prevention' has been supported by the council on a long term basis. The viability of this approach has been strengthened by evidence on social return, including a report from the New Economics Foundation that evaluates the cost-effectiveness of establishing community groups.⁵ The council supports over 220 community projects that are available to people with a wide range of social care needs. Described as "Community Partnerships", these projects create a network that is in touch with some 9,000 people a week.

This long term investment gives people who are not eligible for Fair Access to Care Services (FACS) access to some community support.

Kirklees use the 'Outcomes Star' to measure progress – a tool that commissioners are using more and more to assess the outcomes of the services they are commissioning, and as a means of assessing if their money is being well spent. There is evidence that referral rates for social care are reducing over time in Kirklees.

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This sheet is part of the Push for Action guide for local authorities. For more resources, visit www.autism.org.uk/push

⁵Trudi Wright, JIP Project Manager, Kirklees Council and Jonathan Schifferes, nef Consulting (2012). *Growing social capital: A social return on investment analysis of the impact of voluntary and community sector activities funded by grant aid*

Case study: Lewisham

In 2012, Lewisham Council and NHS Lewisham PCT commissioned Burgess Autistic Trust (BAT) to set up an 'information, advice and support service' for adults with autism and their families. To be eligible for the service you must a) live in the Lewisham borough or be registered with a Lewisham GP and b) not be eligible for FACS.

Funding for the service is for three years. It allows for a service manager, a full-time practitioner, a part-time practitioner, a librarian, a visual support and communication worker, rented premises and office supplies that are autism-friendly and accessible, and advertising and marketing.

BAT has been planning and implementing the Lewisham service over the last few months, forming relationships and links with other local organisations and statutory services, identifying key issues and difficulties experienced by those living with autism, conducting initial assessments of service users, and advertising the service. They have so far received over 60 referrals from service users requiring services.

The service is awaiting the opening of new premises. Once open it will deliver support to adults with autism and their families, depending on the individual's needs and preferences, including peer support interest groups, training workshops (including understanding your diagnosis, travel training and healthy lifestyles), employment support, 1:1 sessions, visual and communication support, and parent and partner support groups.

The Lewisham support service works closely with the Lewisham ASD Assessment Clinic. Patients diagnosed at the clinic will be referred to the support service for post-diagnostic and continuing practical support.

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Diagnosis and the care pathway

What does the strategy and statutory guidance say?

The strategy is clear that by 2013 there should be a 'pathway' to diagnosis in place in every local area. This means a process that starts with the possible identification of autism and leads to referral for a diagnosis.

Crucially, however, this process shouldn't stop here. It should go on to provide individuals with support and advice to meet their needs. The statutory guidance says that a diagnosis of autism should act as a trigger for a community care assessment for the individual and a carer's assessment for the individual's family or carers.

To oversee this whole process, the guidance says that local areas should appoint a professional who is responsible for developing diagnostic and assessment services for adults with autism in their area.

In addition, as a result of the strategy, in 2012 the National Institute for Health and Clinical Excellence (NICE) developed clinical guidelines on establishing a pathway to diagnosis and providing appropriate care and services for adults with autism.¹ These guidelines call for the creation of autism-specific multidisciplinary teams. NICE guidelines are considered to be best practice and the NHS in particular is expected to follow them.

Putting this into practice:

STAGE 1

- no community care assessments should be refused on the basis of IQ
- a clear pathway to diagnosis and assessment should be put in place
- diagnosticians should inform the local authority of diagnosis and inform individuals of their right to a community care assessment (and their carers to a carer's assessment)
- community care assessments should be carried out by a trained assessor
- people should be given information on autism and local support when diagnosed and post-diagnostic support offered
- people with autism should be given access to personal budgets and direct payments.

STAGE 2

- diagnostic pathways should be compared against best practice and NICE model pathways
- NICE recommendations should be implemented in full and all professionals in the area should be made aware of the diagnostic and assessment pathway.

STAGE 3

- a local service should be developed that goes beyond diagnosis
- an ongoing programme of staff training for all health and social care staff should be put in place to ensure all staff can recognise signs of autism and refer people to the diagnostic pathway and support that meets their needs
- local authorities should contact individuals to inform them of their right to an assessment, as standard.



¹NICE (2012). *Autism: recognition, referral, diagnosis and management of adults on the autism spectrum*

Good practice

Case study: Bristol Autism Spectrum Service (BASS)

The Bristol Autism Spectrum Service (BASS) is a small multidisciplinary team jointly commissioned between health and social care.

Crucially, the aim of BASS is not to directly provide all services for all people with autism – this would be unsustainable and would locate all the expertise in a small part of the care pathway. Instead, a key role of the team is to liaise with mainstream services to help them work better with people with autism, as well as directly offering diagnostic and preventative services to people with autism who otherwise would not be picked up.

If an individual is eligible for mental health or learning disability services, it is the responsibility of these services to diagnose and support the individual, although BASS will support them to do this, where necessary. They do this via a supervision clinic, an ongoing programme of training and awareness-raising, a consultation and liaison service, and partnership working with relevant stakeholders. For people who are not able to access existing provision due to the absence of significant psychiatric co-morbidity and/or learning disability, BASS works directly with them.

BASS offer a diagnostic service, accessible from primary care, and a comprehensive package of post-diagnostic support for people with autism and their families or carers. The team also offer an assessment of need across health, social care, housing, employment and education, and signposting to agencies who can help with this, as well as a range of preventative interventions to help avoid unnecessary contact with mental health services, and to promote social inclusion and independence, such as social skills training.

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Case study: SEQOL in Swindon

SEQOL, a social enterprise that provides a range of health and social care services to adults in Swindon, has developed a multidisciplinary model for the diagnosis and care assessment of people who didn't 'fit' the existing learning disability or mental health pathways.

Following diagnosis, individuals are offered two follow up meetings: a first meeting which is an opportunity for people to absorb the news, then a subsequent, longer meeting to discuss and assess needs. Needs assessments usually involve two clinicians, usually a psychologist and a speech and language therapist.

Following the needs assessment, individuals are signposted either to a community care assessment or to an information and advice centre.

One advantage of this flexibility is that it provides a pathway for those who are not eligible for local authority funded community care services but who might still have presenting care needs. The individual is able to consider the support that they might access, including support that they might pay for.

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Planning and leadership

What does the strategy and statutory guidance say?

Few local authorities and health bodies collect information on the needs of their local population of adults with autism. The structure of local service provision has meant adults with autism have been denied access to services.

Improved local planning, therefore, is an important part of the adult autism strategy. This is backed by the statutory guidance, which is clear that an annually reviewed local commissioning plan is essential, and that local authorities should appoint a joint commissioner/senior manager to oversee the development of these plans. The strategy also recommends establishing a local autism partnership board that brings together local stakeholders, to support the work of this local commissioner.

The statutory guidance says that commissioning plans should be based on the best available information about local needs. It will typically be necessary to gather information about the number of adults known to have autism in the area, the support people need to live independently and the age profile of adults with autism in the area, including those approaching 65 or above working age, as well as the number of children approaching adulthood, in order to predict how need and numbers will change over time. As an important first step to ensuring that they are aware of local need, local authorities and the NHS should also make sure that autism is included in their local Joint Strategic Needs Assessment (JSNA).

Putting this into practice:

STAGE 1

- an autism lead should be appointed to oversee implementation of the strategy and the production of a commissioning plan
- accurate data should be collected about the local population of adults with autism and their needs
- the views of people with autism and their parents and carers should be taken into account in the development of local plans
- an in-depth chapter on the needs of people with autism, including those who are undiagnosed, should be included in the JSNA
- an autism partnership board should be created, bringing together relevant commissioners, organisations, service providers and people affected by autism (including people with autism themselves).

STAGE 2

- the data and information set out on page 25 of the statutory guidance should be collected
- local specialist services should be developed alongside opening up mainstream services
- the autism partnership board should have strong links with wider governance structures, particularly health and wellbeing boards.

STAGE 3

- services should be commissioned based on a preventative, supportive approach
- the local commissioning plan should be reviewed annually and its impact monitored.



Good practice

Case study: Hertfordshire

In 2006 Hertfordshire appointed a project lead for autism and particularly Asperger syndrome, because it was recognised that this group was not having its needs met. It now has plans to set up an Asperger team, alongside the learning disability and mental health teams.

The transition team set up by the local authority was immediately overwhelmed by demand for their services, demonstrating that a small team would not be able to directly handle all the required case management. They realised that the best way to utilise this team would be to support other teams to meet people's needs instead.

Having learnt from this experience, the Hertfordshire Asperger team will not aim to handle all caseloads, but will work closely with providers and agencies, as well as the learning disability and mental health teams, to ensure that they are equipped to support people with autism in the area.

The team will be funded by joint commissioning and will span the local authority and health trust. In Hertfordshire there are strong joint commissioning arrangements. The local authority autism lead sits on the management board of the health trust, and her equivalent within the trust sits on the management board of the local authority, so that there is close liaison and awareness. This helps to ensure joined-up thinking and working.

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Case study: Derbyshire

Derbyshire decided that, especially during a time of great change within health and social care, they needed to keep the profile of autism high.

To ensure autism remains high on the agenda, the local autism lead submits reports on progress to the local Adult Care Board and the Joint Commissioning Board. These boards, along with the Clinical Commissioning Group (CCG) boards, decide on topics to be included on the Health and Wellbeing Board's agenda.

The autism lead recognised that Health and Wellbeing Boards have a huge remit, and it is important to get them thinking about autism. As a result, the Joint Strategic priority to implement the autism strategy has been endorsed by the Health and Wellbeing Board in Derbyshire and they can, therefore, request updates at any time.

The autism lead's progress reports to date have highlighted the local authority's responsibilities and how they are working to meet them. There is an ongoing expectation that the lead will continue to update on progress.

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What does the strategy and statutory guidance say?

Improved training allows frontline staff to identify, support and respond effectively to adults with autism. As such, it is one of the most important aspects of the strategy and statutory guidance.

The statutory guidance explicitly says that local authorities and NHS bodies should seek to make autism awareness training available to **all** staff working in health and social care. The guidance is also clear that key staff should develop specialist knowledge of autism, particularly GPs and those who carry out community care assessments.

Ensuring this training is of sufficient quality is crucial. One project, developed in conjunction with the NAS and Skills for Health and Skills for Care, provides a training framework that details the types of information needed for good training.¹

The strategy is also clear that it is good practice to involve adults with autism, their families and their carers in planning or commissioning training, where possible.² Adults with autism could, for example, comment on or contribute to training materials, talk to staff about autism, or provide the training.

Training should be of high quality and be ongoing. One training course will not make a professional an expert on autism. People must change and improve what they do because of the training they receive and only when people start doing so will services for adults with autism improve.

Putting this into practice:

STAGE 1

- › staff should be able to identify signs of autism and know how to make reasonable adjustments
- › specialist autism training should be developed and provided for key staff such as GPs and community care assessors
- › autism awareness training should be included in standard equality and diversity training for all staff.

STAGE 2

- › the local authority should join up with other public sector organisations to share resources and budgets
- › the local autism lead, people with autism and parents and carers should be involved in commissioning training.

STAGE 3

- › training should meet the Skills for Health/ Care framework
- › an ongoing programme of staff training for all health and social care staff should be put in place to ensure all staff can recognise signs of autism and refer people to the diagnostic pathway and support that meets their needs
- › in-depth training should be given to all public sector staff, including the police, fire service, nurses, doctors and office-based staff who make decisions related to people with autism.

¹Skills for Care, Skills for Health and The National Autistic Society (2011). *Autism skills and knowledge list, for workers in generic social care and health services*

²The National Autistic Society is working on a new project called Ask Autism to produce e-learning modules, training and consultancy opportunities which are developed and delivered by people on the autism spectrum.

Good practice

Case study: Surrey's Autism Champions

Surrey's autism lead has set up autism training as part of the Adult Social Care Commissioning team. The aim is to develop local expertise, train people to deliver training to their colleagues, and improve practice in supporting people with autism.

Any service supporting people with autism in the county was invited to nominate a staff member as their 'Autism Champion'. These Autism Champions received autism training based on The National Autistic Society's SPELL framework to be cascaded down to colleagues. Each Champion is given a mentor who supports them with their ongoing learning, and who they can contact for advice and guidance. Within this model, staff are expected to incorporate the training into their everyday working practices, with the goal of making reasonable adjustments throughout local services as well as in their direct work with people with autism.

The training scheme brings together staff from health, social care, education, voluntary and private sector services. Autism Champions include staff employed as support workers in residential, day and supported living services, job coaches in supported employment, college and university staff and care managers.

The Autism Champions scheme is a cost-effective way of disseminating learning amongst a range of staff. The aim was initially to have 50 Autism Champions in place across the county. This has been exceeded: following six rounds of training, there are currently 74 Champions in place.

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Case study: Redbridge

After the publication of the autism strategy, Redbridge's Learning and Development Coordinator conducted an analysis of current autism training provision in Redbridge and neighbouring boroughs. Feedback from three parent and carer focus groups, local authority and Jobcentre Plus staff, the Met police and local voluntary organisations, identified a need for both general awareness training and more specialist training provision for priority groups.

As Redbridge's Learning and Development Coordinator has personal experience of autism and their in-house learning disability trainer is an experienced autism diagnostician, it was decided that they had capacity to provide training courses in-house.

In 2012-13 Redbridge offered a series of day and half-day courses on autism, addressing issues such as stress management and behavioural difficulties. Courses were attended by Jobcentre Plus staff, GPs and representatives of the Met police, amongst others, and many requested further training.

Attendees have been recorded at each session to ensure that training is reaching priority groups and feedback from the sessions has been used to amend and improve training. An extended programme is planned for next year.

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For details of autism training provided by the NAS, please email training@nas.org.uk

This sheet is part of the Push for Action guide for local authorities. For more resources, visit www.autism.org.uk/push

What does the strategy and statutory guidance say?

Transition to adulthood can be particularly difficult for young people with autism. This is why the adult autism strategy and statutory guidance place so much emphasis on improving transition.

Planning needs to start early. Transition planning must start in Year 9 (age 13-14) for young people with statements of special educational needs, and multi-agency involvement is important for all young people with special educational needs. Too often this does not happen. Other services, particularly adult social care, need to routinely get involved in the process. Many areas also need to get better at involving young people and their families or carers in the planning process. Reforms to the SEN system will introduce Education, Health and Care Plans (EHCPs) to replace statements. EHCPs, which go up to the age of 25, make multi-agency working even more essential for young people with SEN moving into adulthood.

As well as planning for individuals, local areas should plan to meet the needs of young people coming up through the education system, and commission services well in advance. Directors of adult social services should be working closely with directors of children's services to make this happen. Data from schools and individual plans can also help to inform this planning.

Finally, a key problem that the NAS identified in our *You Need To Know* campaign is with transition from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS).¹ To help improve this, the statutory guidance says that NHS bodies and NHS Foundation Trusts should ensure that protocols are in place in every local area for the transition of children with autism in receipt of CAMHS. Where individuals do not fulfil referral criteria for adult mental health teams, it would be good practice for local authorities and NHS bodies to signpost on to other sources of support and information available locally and nationally.

Putting this into practice:

STAGE 1

- > assessment of needs should be arranged for those with statements going into further or higher education
- > adult social care and other relevant agencies should be involved in Year 9 transition planning for young people with statements
- > young people, parents and carers should be involved in transition planning, focusing on what outcomes they want to achieve
- > young people, parents and carers should be involved in designing the implementation of the new SEN system locally, including the development of the 'local offer'.

STAGE 2

- > CAMHS transition protocols should be put in place, as set out in the statutory guidance
- > data from the schools census and individual plans should be used to inform the planning and commissioning process.

STAGE 3

- > transition planning should start in Year 9 for all young people with autism
- > the transition process should be monitored to ensure that it is working effectively
- > learning from the transitions monitoring should be used to inform future planning and commissioning.



¹ Madders, Tom (2010). *You Need to Know*. London: The National Autistic Society

Good practice

Case study: The National Autistic Society

The National Autistic Society (NAS) has taken a leadership role in areas close to their schools to bring together local stakeholders and to encourage collaborative working to improve transition to adulthood.

NAS schools have brought together local colleges, specialist providers of supported employment, other schools and local authorities, to develop their transitions practice for young people with autism. The groups work together to identify ways to increase the range of opportunities that young people have in the local area, in order to ensure effective preparation for adulthood, and to identify the best possible phased transition arrangements in the area.

Some of the groups are developing support mechanisms and information to improve access to work experience and supported employment. Some are focusing on developing social enterprise models to increase the range of life and work experience opportunities available. The groups are also considering the best ways to support families through the transition from school and further education into adult life.

This project was set up with funding in October 2012 and officially comes to an end in July 2013. The collaborative working arrangements will, however, continue to influence how local schools, colleges, key agencies and organisations seek to support local authorities in their work to support young people with autism to have a successful transition into adult life.

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Case study: The Greater Manchester Autism Consortium

The Greater Manchester Autism Consortium is a partnership between the ten local authorities in Greater Manchester and The National Autistic Society (NAS). The consortium carries out joint work on a variety of issues. One area of work is their transition project.

At the request of the Department of Health, the consortium undertook research into what was happening for people with autism in transition from childhood to adulthood in Greater Manchester. The findings were published in the *Greater Manchester Consortium Transition Report* in June 2012.² The report made three key recommendations:

1. Better access to information for parents
2. Better information about what adulthood means for young people
3. Better understanding of needs from services within the community

The Consortium funds and steers the Family Services Development Project (FSDP) which is managed by the NAS. The FSDP was tasked to action the report's recommendations. So far the FSDP have developed and delivered a two-day workshop for parents covering issues such as working with services and transition to college and university. The FSDP have also developed a project in Wigan, which delivers awareness raising to agencies such as job centres and housing services and runs one stop shops with other local non autism-specific agencies. The FSDP also plan to work on a course or workbook on transition for people with autism.

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For more resources, visit www.autism.org.uk/push

²Saeki, M. and Waters, D. (2012). *Greater Manchester Consortium Transition Report*

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We are the leading UK charity for people with autism (including Asperger syndrome) and their families. With the help of our members, supporters and volunteers we provide information, support and pioneering services, and campaign for a better world for people with autism.

Around 700,000 people in the UK have autism. Together with their families they make up over 2.5 million people whose lives are touched by autism every single day. Despite this, autism is still relatively unknown and misunderstood. This means that many people don't get the level of help, support and understanding they need. Together, we are going to change this.

From good times to challenging times, The National Autistic Society is there at every stage, to help transform the lives of everyone living with autism.

We are proud of the difference we make.

We rely on donations to enable us to fund campaigns, such as this one, to bring about positive change.

**Adults with autism are still waiting for the everyday support they need.
It's time to turn the Autism Act into action.**

Join our campaign today at autism.org.uk/push



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