

***AUTISTIC SPECTRUM DISORDERS NEEDS
ASSESSMENT REPORT (2001)***

**SCOTTISH EXECUTIVE REPORT ON
IMPLEMENTATION AND NEXT STEPS**

February 2006



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Introduction

In 2001, the then Public Health Institute of Scotland (PHIS, now NHS Health Scotland) was commissioned by Scottish Ministers to carry out a needs assessment of services for people with autism spectrum disorders (ASD) in Scotland. The report, published in February 2002, identified a patchwork of services and made 32 recommendations that set out what ideal services should look like. These were set out in the categories of standards and monitoring, matching resources to need, training, research, and diagnosis and assessment. This report describes some of the progress made in each of these categories, and suggests priorities for further action at national and local level.

Scottish Ministers accepted in principle the findings of the report and agreed that a programme of work was required to develop services for people with ASD, within the context of ongoing broader policy developments, to improve inter-agency working and service delivery. The Scottish Executive set up the national ASD Reference Group in June 2002, to agree priorities and identify action that would best support and encourage the development of good practice across a range of services.

The reference group was initially made up of members of the PHIS needs assessment group. From summer 2003, members worked in sub groups to focus on training, and assessment and diagnosis, with co-opted members with relevant knowledge and experience supporting that work. From March 2005, that work has been integrated into the work of the main reference group, which benefits from the support of the additional members. An Information sub group set up in 2004 continues to meet to support the development of the 2 Scottish Executive funded information projects¹.

¹ See Annex 2

Standards and monitoring

'A working party should be established by the Scottish Executive to develop global standards for lifelong services for those people with autistic spectrum disorders (ASD) that require it. It should also review current training provision in Scotland.

Thereafter the Scottish Health Advisory Service (SHAS), or an alternative body, should monitor these standards.

A request is made to the Scottish Intercollegiate Guidelines Network (SIGN) to develop guidelines for the evidence based approaches to the diagnosis and management of ASDs.

A conference is planned for 2002 and should be used to bring together interested parties to discuss the implication of this document.'

What has happened

The ASD Reference Group fulfils the role of the recommended working party. A list of the group members is in Annex 1.

There are a number of developments that monitor standards and which are relevant to people with ASD. These include NHS Quality Improvement Scotland learning disability quality indicators, national care standards, the SCLD database project, and education quality indicators. The inclusion of ASD in wider developments is indicative of a heightening awareness of the needs of this client group.

The Scottish Commission for the Regulation of Care registers and inspects all regulated care services, including support services, housing support services and care home provision to ensure they are meeting the national care standards.

Her Majesty's Inspectorate of Education (HMIE) is currently conducting a specific inspection of educational provision for children and young people with autism spectrum disorder across Scotland. The inspection began in April 2005 and is due to conclude at the end of March 2006. The inspection is following an integrated assessment approach using a multi-agency (education, health and social care) team and includes consideration of:

- how far pupils with ASD have access to a broad and relevant curriculum to ensure they are learning
- how far pupils with ASD are included and enabled to engage with more socially equipped peers
- how expertise is used in schools and why certain interventions are chosen

A report on the inspection is due in late summer 2006 and will highlight current good practice, identify any gaps in provision and make recommendations for the way forward.

Joint Inspections of learning disability services, for which a framework is presently being developed, will also include services for people with ASD. These joint inspections will bring together SWIA, NHS QIS, the Care Commission, HMIE and HMIC. The report of a pilot joint inspection taking place in Ayrshire, across 3 local authorities and an NHS board, is due in summer 2006.

NHS QIS conducted a programme of visits to NHS Boards from October 2004 onwards. Information from these visits is available in a national overview report published on 28th February 2006.

The SIGN Council agreed to the development of a guideline for children and young people up to age 18. The guidelines will cover diagnosis, assessment and clinical interventions and will take into account the views of parents and carers on diagnosis and assessment.

An autism conference was held in 2002. Since then, Ministers and officials have met and corresponded with the Cross Party Group on Autistic Spectrum Disorders to update on developments in relation to the PHIS Report. There have also been a number of other events relating to diagnosis, training and information, to highlight the need for action in line with the Needs Assessment Report.

What still needs to happen

In recognising that progress will take time, the reference group believes there is a need to develop an agreed care pathway, from childhood to adulthood. The Scottish Executive has funded specific

developments¹ in adult services in Greater Glasgow and Lothian, and a project developing services for young people on transition from children's to adult services in Highland. Evaluation of these projects will contribute to the development of an agreed care pathway and will also demonstrate good practice on which others can build.

The roll-out of Joint Inspections needs to ensure that the requirements of people with ASD are being addressed across all services.

The broad range of existing care standards and performance measures need to be looked at to identify what further work is needed and where the gaps are in relation to ASD.

¹ See Annex 2

Matching resources to need

'Development of services for people with ASD should be sought through local health and joint planning mechanisms. Plans for development should be based on audit of current service provision, expenditure and training and should cover all the relevant agencies. The Scottish Executive should ensure that the audit, planning and relevant action has taken place in each area. This should be built on the mapping exercise being carried out by the SSA and NAS in Scotland.

Resources for systematic development of services for those with ASD should await completion of this audit.

Each NHS board with its local authority partners should ensure that existing resources are reshaped to address the issues raised in this report.

Thereafter additional resources should be allocated according to identified gaps in local provision.'

What has happened

Audit of existing services

All local authorities and NHS Boards were asked to complete a survey of their existing services and training provision to assist service commissioners in future service planning and delivery at local level. This data was analysed by statisticians within the Analytical Services Division and was published on the Scottish Executive web-site. This and other information about related developments can be found at:

<http://www.scotland.gov.uk/Topics/Health/care/18950/15906>

The audit did not make a case for resources due to poor baseline information. Local agencies were asked to set out their plans for future services development in the 2004-07 Partnership in Practice Agreements (PiPs). The agreements outline a broad variety of plans and proposals for service development, ranging from appointing a development worker to audit ASD services, to converting areas within existing day services to accommodate the specific needs of people with ASD. Plans were outlined for children's services such as an outreach education service;

secondary school bases; an after school care service; school holiday play-schemes and specially trained support workers to deliver local family support and short-breaks for children on the autism spectrum.

Other local partnership plans included involving service users in delivering Aspergers and autism training; developing specialist care pathways for people with ASD and developing a short breaks/respice strategy.

Pilot Projects

The Scottish Executive has funded a number of pilot projects, endorsed by the National Reference Group, which have developed innovative adult services in Greater Glasgow and Lothian, a project developing services for young people on transition from children's to adult services in Highland, and an ASD Coordinator in the Borders.

ASD Database

A related activity to the audit is the setting up of a database of people with ASD – again to assist with planning for the future. This work is being taken forward through the eSAY project led by the Scottish Consortium for Learning Disability. The Scottish Executive awarded an additional £50,000 to the project, which will deliver a dataset of people with ASD for use primarily by local authorities and NHS Boards. Information about the database can be found on the Consortium website at www.sclld.co.uk.

What still needs to happen

The ASD Reference Group recognise the need to build on the learning from the pilot projects to inform service development elsewhere. There needs to be change on the ground for more people with ASD and their families. The reference Group will address this through the new subgroups focussing on Commissioning and Policy into Practice.

Local Authorities need to continue to develop ASD friendly services and incorporate ASD awareness and accessibility into mainstream services such as leisure and recreation. Similarly mainstream health service providers need to ensure they are meeting the range of health needs of people with ASD.

Individuals and organisations, both local and national, need to be encouraged to proactively use the National Autism Service Network to build, support and raise awareness of local networks.

Training

'A national audit of training should be included in the remit of the working party to be established to develop standards of services to assess training needs and gaps.

Local training audits should also take place in each NHS board area as part of the wider audit recommended with a view to addressing training needs and gaps.'

What has happened

The service audit did raise awareness of the need to plan locally to meet the needs of those on the spectrum.

Work on 2 new Professional Development Awards has been completed by the Scottish Social Services Council, who have worked closely with the training sub-group of the ASD Reference Group. Candidates can choose between a Certificate in Supporting Individuals with Autistic Spectrum Disorders (SCQF Level 7) or, a Certificate in Managing the Support of Individuals with Autistic Spectrum Disorders (SCQF Level 8), to equip themselves with transferable skills.

A major conference took place in June 2004 targeted at senior managers and educators to ensure that ASD training is provided in all practice contexts and at all levels.

The Executive funded NHS Education for Scotland to develop Continuing Professional Development training materials for GPs and primary care staff.

The National Centre for Autism studies and the National Autistic Society published a framework for autism training <http://www.strath.ac.uk/autism-ncas/pdf/TFP.pdf>.

What still needs to happen

Local Service providers need to support front line staff with appropriate ASD training. Service managers and commissioners also need to be trained to understand the needs of people with ASD when commissioning and delivering services.

Staff in primary care should access training in relation to autism spectrum disorders on the NHS Education Scotland website to ensure they are equipped to provide appropriate and effective care.

Information about existing training needs to be made widely available across all services. The ASD Reference group will develop a training leaflet to signpost professionals to relevant ASD training.

Research

'Research funding bodies should encourage further research into autistic spectrum disorders.'

'A working group should be convened to consider the practicalities of establishing a database of people with ASD in Scotland.'

What has happened

The Medical Research Council is focusing on research on bio-medical issues. The Chief Scientist Office within the Scottish Executive takes the lead in working in collaboration with the Medical Research Council on a number of ASD specific pieces of research. They are currently in the midst of discussions with several groups of scientists about autism research proposals.

Studies into ASD that the Chief Scientist Office has funded to date include:

- Study on potential for interventions using fatty acid supplements
- Pilot study of fMRI to image imitation in autism spectrum disorders
- Molecular analysis of breakpoint regions of a de novo reciprocal translocation associated with autism
- Prosodic skills in children with autism
- An HPLC and MS analysis of the urines of autistic and control children to investigate the validity or otherwise of dietary intervention as a treatment

The ASD Reference Group agreed to fund a retrospective study of a consecutive series of those who have been diagnosed at the Scottish Centre for Autism. This study aimed to capture the developmental history and symptoms of 300 children to better understand the variability within a group of children who receive a diagnosis and the boundary with those children who do not. The study also aims to identify variables which may predict the need for a diagnostic review in a small minority of cases. A report on the study will be available in summer 2006.

The Scottish Executive held a conference in November 2005 to focus on developments and research in relation to Health and Autism. The aim of the conference was to disseminate research findings to health and social care professionals so that they could consider and apply these in their own localities where they thought it appropriate to do so.

The conference programme included psycho-social interventions and the development of cognitive behaviour therapy; dietary interventions; pharmacological treatments; genetic counselling; improved assessment and diagnosis and the individualised treatment of medical disorders often associated with autism. A full conference report will be disseminated widely, to continue the dialogue about health needs in Autism in Scotland and to focus on contributing to a broader perspective on how we deliver interventions.

The establishment of a database of people with ASD in Scotland is being taken forward under the eSay project. Further details are in the Matching resources to need section of this report.

What still needs to happen

A number of recent reports, including *Mapping autism research* and the 2001 Medical Research Council Review, identify some areas of weakness in autism research that require expansion and development in terms of topic of study, enhancing multidisciplinary collaboration and translating research findings into practice. The draft SIGN guideline issued for consultation last year also identified areas where research is under-developed.

A UK wide Autism Research Co-ordination Group (ARCG) has been established by the Department for Education and Skills, to provide a framework to enable greater co-ordination of autism research activity in the UK, which should lead to more informed policy development in areas affecting people with autism. It has a number of aims, including a particular focus in autism research funding on identified gaps such as biomedical research and research on interventions (especially in adults). The Scottish Executive ASD reference group is represented on the ARCG.

In addition, the Scottish Autism Research Group provides a platform for sharing research-in-progress. It is an interdisciplinary

group of academic researchers, postgraduate students and practitioners involved in research into autistic spectrum disorders. The Group provides networking opportunities and promotes a coherent programme of scientific research in autism.

At local and national level, policy development and service commissioning needs to be informed by research. Research funding should be directed to areas where there are clear gaps in evidence to inform policy development.

Diagnosis and assessment

'Primary care professionals should consider including assessments of the triad of impairments as a standard part of all routine surveillance for infants within primary care.'

In order to limit waiting times and improve services for assessment and diagnosis of children and adults, resources are required to train and employ more specialist professionals in all agencies.'

What has happened

The SIGN Guideline development will cover surveillance and should consider the evidence base for routine screening.

The diagnosis sub-group of the ASD Reference Group held a clinicians conference in March 2004, to discuss ways of improving assessment and diagnosis. One proposal was for publication of a diagnosis service quality statement aimed at improving the consistency of diagnosis. This quality standard for ASD diagnostic services issued in 2005 offers people with ASD and family carers a clear indication of what can be expected from a diagnostic service and provides a checklist for multi-disciplinary teams providing the service. Responses to a Scottish Executive consultation unanimously supported the adoption of the quality service standard statement (Annex 4) nationally and at local level. It is intended to complement the SIGN guideline currently being developed. We are now looking at how implementation will be measured through the work of NHS Quality Improvement Scotland.

Delegates from the clinician conference are also now able to participate in an e-network, sharing information and discussing issues relating to diagnosis across Scotland.

The diagnosis sub-group agreed to a number of projects to pilot training in diagnostic tools. The aim of the training is to reduce waiting times for diagnosis for families where an individual may have an ASD. The projects are examining the impact of training more professionals at tiers 2 and 3 to undertake diagnosis within multi-disciplinary teams. There are four pilot projects.

- A project in Argyll and Clyde, covering rural and urban areas, to improve confidence of professionals at tier 2 in taking the

history of children and young people with suspected ASD and to provide confidence in giving feedback.

- An adult diagnostic services pilot, which aims to increase confidence in tier 2 and will involve the use of the diagnostic instrument ADI-R.
- A school based pilot in Fife based on an observation schedule, which aims to reduce the volume and time delay for referral.
- Training on the diagnostic and assessment tool, DISCO.

A Directory of individuals and teams undertaking assessment and diagnosis of ASD in Scotland has been developed as part of the Autism Argyll/Autism Information Scotland Project. It has been developed by NHS Education Scotland (NES) to link various professionals involved in the assessment and diagnosis of ASD and to inform primary care health professionals across Scotland where individuals can be referred for a diagnosis of ASD.

The Directory will be distributed to all GP's in Scotland in Spring 2006 and an edited version will be available from the National Service Network website, which is currently being developed.

What still needs to happen

Action on workforce planning and tackling waiting times locally and nationally needs to include the need for specialist services for people with ASD.

An evaluation of the training diagnostic pilots will be conducted. This will be useful for local agencies' to inform decisions about training for tier 2 and 3 professionals which will help to reduce waiting times for individuals with ASD to receive a diagnosis and assessment.

Other developments to assist multi-agency working

ASD Service Network

The National Service Network is being taken forward by the National Centre for Autism Studies, part of the University of Strathclyde. The network will include an internet presence for information provision; a structure for sharing advice and receiving emotional support; an annual conference; and a hub for direction to services for people affected by ASD.

The network will serve as a means of information-sharing and a central point to co-ordinate social and professional activities. The National Service Network is working closely with NAS, to form links with their Public Autism Resource and Information Service (PARIS) www.info.autism.org.uk.

Information pack for users, carers and professionals

Autism Argyll, a charitable organisation, has produced information packs for families and for professionals, that are given out when someone is diagnosed with ASD. Through NHS Education for Scotland, the resource is being developed to be available online in acute, primary or local authority services. A booklet for parents and carers will be available in hard copy to those involved in diagnosis for distribution to parent/carers at time of diagnosis.

The Executive is also funding the National Autistic Society to develop a complementary information resource for distribution through educational settings when a child is believed to have ASD. The Information sub group is supporting these developments.

Next Steps

As identified in the previous sections the ASD Reference Group have priorities for further action towards implementing recommendations from the PHIS report. They recognise that the key to real change is dependent on service delivery and have formed two groups to focus on policy into practice and commissioning. Evaluation of the numerous pilot projects endorsed by the reference group will contribute to the development of an agreed care pathway and will also demonstrate good practice on which others can build.

The reference group intend to look at what support can be given to a short breaks and respite project. They will also consider a proposal to enhance the capacity of advocacy services to ensure there is suitable provision of advocacy for people with ASD.

The key role local authorities and health boards have, in continuing to develop ASD friendly services and ensuring mainstream services are suitable for people with ASD, must also be recognised. This is dependent on service managers and commissioners being suitably trained to understand the needs of people with ASD when commissioning and delivering services.

Annex 1

ASD Reference Group Members

Anne Aberdein	Fife Council
Ken Aitken	Action Against Autism
Clare Brogan	Glasgow Caledonian University
Carolyn Brown	Fife Council
John Cameron	Glasgow Autism Resource Centre
Joanna Daly	National Autistic Society
Paul Dickinson	New Craigs Hospital, Inverness
Aline-Wendy Dunlop	National Centre for Autism Studies, University of Strathclyde
Carol Evans	National Autistic Society
Bette Francis	Scottish Executive
Jane Hook	Representing service users and carers
Wendy Johnston	SSSC
Alison Leask	Autism Information Scotland
Stella MacDonald	Representing service users and carers
Tommy MacKay	National Centre for Autism Studies, University of Strathclyde
Jean MacLellan	Scottish Executive
Iain McClure	SIGN
Robert McKay	National Autistic Society
Val Murray	Scottish Centre for Autism, Yorkhill Hospital
Jane Neil-McLachlan	Lothian Primary Care Trust
Jenny Pickthall	Scottish Executive
Shona Pittilo	Scottish Executive, Education Department
Val Sellars	Scottish Centre for Autism, Yorkhill Hospital
Isobel Sutherland	Scottish Society for Autism
Charlene Tait	National Centre for Autism Studies, University of Strathclyde
Polly Wright	ADSW

Projects and where to get further information

Pilot services for adults with ASD and Asperger's and their families

Two projects, one Glasgow based and one Edinburgh-based provide a one-stop shop for adults with ASD, including those with Asperger's syndrome, and for family members.

The services aim to address their health needs in a wider sense, preventing unnecessary admission to very specialist settings. Those who use the service also benefit from the knowledge and skills of staff beyond the health sector.

The projects include:

- Health maintenance and health improvement
- Social skills training
- Parent and carer self-help groups
- Employment advice and coaching

Boards and local authorities have worked collaboratively and involved the Scottish Society for Autism and National Autistic Society in project design and development.

Contact details for further information about the one stop shops:

John Cameron
Glasgow Autism Resource Centre
The Quadrangle
59 Ruchill Street
Maryhill
Glasgow, G20 9PX
Tel: (0141) 201 6247

Don Mackenzie
Number 6: One Stop Shop
6 Melville Crescent
Edinburgh
EH3 7JA
Tel: (0131) 240 2370

Project	Contact details for further information
Highland Service Review and Development Project: Adults with ASD and Transition to Adulthood	Simon Webster Tel: 01463 703436 Email: simon.webster@highland.gov.uk
Borders ASD Coordinator	Kirsten Haughey Tel: 01835 825080 Email: khaughey@scotborders.gsx.gov.uk
Two new professional development awards (SCQF Level 7 and Level 8)	Eleanor Ramsay at Care Scotland, Tel: 0141 242 2337 E-mail: Eleanor.ramsay@sqa.org.uk
National Training Framework	Dr Tommy MacKay Email: Tommy@ardoch.fsnet.co.uk
Learning Resource for Primary care professionals	Jane Cantrell Email: jane.cantrell@nes.scot.nhs.uk
Autism Information Scotland <ul style="list-style-type: none"> • Directory of ASD diagnosis and assessment in Scotland. • Parent/Carer booklet 	Alison Leask Email: alison.leask1@btinternet.com
National Autistic Society Post Diagnostic Information Pack	Nicola Gray Email : nicola.gray@nas.org.uk
The Scottish Autism Service Network	Dawn Larman (Autism Network Service Manager) Tel: 0141 950 3072 Email: scottishautismnetwork@strath.ac.uk

Annex 3

QUALITY DIAGNOSTIC SERVICE STANDARD FOR CHILDREN AND ADULTS WITH AUTISTIC SPECTRUM DISORDERS

A quality service should:-

1. Take place within the context of a multi-disciplinary AND multi-agency service involving professionals with ASD training.
2. Understand that diagnosis ought to be a process which supports the development and progress of an individual.
3. Be aware of the need to involve both the person with ASD, and parent/carer/partner/independent advocate if applicable, in the assessment and explanations.
4. Recognise and acknowledge cultural differences of all individuals and families.
5. Dedicate sufficient time for assessment in keeping with consensus timeframes.
6. Allow individuals of all ages access to a service appropriate to their needs in their locality.
7. Make a diagnosis if appropriate regardless of whether there are statutory services available.
8. Use internationally recognised diagnostic criteria and specify which criteria have been used.
9. Make a full diagnostic assessment including developmental history. In adults the developmental history is not always available but every effort should be made to ascertain it.
10. Use information drawn from observation, standardised interview and clinical experience in a variety of contexts such as home, school, workplace and the community.
11. Identify psychological, physical, social and other needs of the individual as well as making practical suggestions

through joint planning of health, education, social work and the voluntary sector, to ameliorate any particular difficulties the individual is facing.

12. Produce a document to state diagnosis, which criteria and tools were used to assess, and describe any co-morbid conditions.
13. Give clear sensitive verbal explanations of the syndrome and provide quality written information.
14. Refer on for any medical or other assessment as appropriate or relevant genetic counselling.
15. Offer a follow-up appointment, preferably face to face, for the individual to ask further questions.
16. Offer clear explanations if a diagnosis of autism is not made (and any differential diagnosis) and offer second opinion as appropriate.
17. Provide information about post diagnostic services such as support groups.



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